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**Policy learning and innovation in local regimes of home-based
care for the elderly:
Germany, Scotland and Switzerland.**

ANNEXES

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The national system of home based long-term care for the aged (HBLTC) in Germany

1. General structures of HBLTC system for the aged¹

After a short overview on the general structure of HBLTC in Germany in this chapter we will first give an historical overview on the institutional development of the HBLTC since World War II (1.a), analyse the horizontal and vertical repartition of responsibilities and tasks (1.b) as well as (1.c) the structure and development of financing and spending of HBLTC in Germany.

1.a. Historical development

After World War II, caring for elderly citizens in need of help and assistance remained a family¹ and charitable issue in the (West) German system of welfare corporatism. With the establishment of the law of social security (1961), following the idea of *Fürsorge*, municipalities were obliged to provide help and assistance for senior citizens, but without clear prescriptions what exactly ought to be provided. Care work at home was mainly done by near relatives and complemented by residential care in institutions that were provided by non-for-profit providers of the big, publicly supported welfare associations (Evers 1998, 2-3; Hammerschmidt 2010, 20), which were characteristic of the German system of welfare corporatism. From the late 1970ies on, this infrastructure was complemented by so-called “social care centres” (*Sozialstationen*) that provided medical as well as social care and home help. Their establishment had been promoted and financially supported at the municipality level throughout the country (Evers 1998). Those social care centres received public subsidies and – as the institutional nursing care homes – were mainly provided by the big welfare associations; only a minority of centres was run by the municipalities themselves (ibid.). During the 1980ies also some private suppliers, associations and registered cooperatives could establish because of the even greater demand for home based services; but public and non-for-profit-providers were privileged by the law (ibid.). The costs for care services had to be paid privately. In case that neither the care receiving person nor the near relatives could afford this, means tested social assistance could be applied for from the municipalities. Thus, to be in need of care at that time was not yet recognized as a general life risk that should be included in the German system of social security.

But during the 1970ies and 1980ies this gap in the social system as well as the psycho-socially and financially stressed situation of persons in need of care and their relatives was pointed out by several reports and increasingly became a matter of public discussion (Evers 1998, 3; Alber and Schölkopf 1999, 137). The problem was set on the political agenda. Problem perception focused on two points: One was the rising costs of social assistance that municipalities had to pay especially for people in institutional forms of living. The other was the fact that requiring care so regularly lead to the need to claim social assistance – which ideally had been thought for as only a subsidiary means and was seen as harming dignity (Pabst 2002, 129; Roth and Rothgang 2002, 46).

As a reaction to this debates, the law on national health reform (*Gesundheitsreformgesetz*) (1989) – the so-called „little long-term care insurance“ – for the first time provided limited benefits (home and short-time care) in cases of severe need of long-term care (Gerlinger and Röber 2009, 18).² Yet, the idea of introducing care as a further social risk in the German system of social security remained

¹ Pfau-Effinger et al. claim that West-German society traditionally had been a ‚home care society‘, in which child care and care for the elderly by relatives in private households were held in high regard (2008, 90). One could argue if there really had been a high *esteem* for this kind of informal work or rather high *expectations* that care were a private task. At least, to increase the social recognition of care work in (West-)Germany seem to have been part of the intention of the introduction of the long-term care insurance and is a still lasting task.

² With the introduction with the long-term care insurance those services had been eliminated again (Gerlinger and Röber 2009, 22-23).

a highly controversial issue. In the context of the financial consequences of German unification there followed several years of further political bargaining that were characterized by sharply conflicting interests (Alber and Schölkopf 1999, 134-145), especially on the applicable mode of financing: funded vs. pay-as-you-go (Campbell 2002, 175).

At last, the insurance model in its pay-as-you-go-version was accepted, and 1994 the long-term care insurance law was adopted. It introduced the provision of institutional and home based long-term care as the fifth pillar of the German social insurance system.³ Aims of the new institution were to reduce the municipalities' expenditures for social assistance, to lower the number of persons requiring care that were dependent on social assistance, to establish as well as to expand a mixed private market of social care, especially in the outpatient sector, and to improve the conditions for informal care.⁴ To achieve those aims, the law regulated a statutory pay-as-you-go based long-term care insurance that provided cash benefits as well as benefits in kind in the in- and outpatient care sector for either professionally or informally provided social care.⁵ Eligibility was based on a considerable high degree of care needs, applying a body-oriented concept of need of care (see below).⁶ In the construction of this insurance the German health insurance principle of commodity coverage was dropped in favour of only partial coverage. That was achieved by introducing a relatively high threshold of need of care that was required to establish eligibility. Additionally, three levels of need of care were defined and benefits capped. The principle of equal payment⁷ of contributions by employers and employees – a core concept of the German variety of social insurance – had been de facto rejected.⁸ Being insured either in the social long-term care insurance or the simultaneously introduced private long-term care insurance was defined to be mandatory (§§ 20 - 27 SGB XI).

Based on the experiences with the implementation of the system in the following years there were carried out several adaptations. These did not change the described overall logic of the insurance principle, but more explicitly regulated certain areas: Quality issues were addressed by the quality assurance law that came into force in 2002. It obliged care providers to establish measures of internal quality management and demanded the development of procedures to assess the appropriate staff ratio (Gerlinger and Röber 2009, 101). As existing benefits did not cover special psychosocial needs of persons with psychiatric diagnoses or dementia, the complementary law on caring service (*Pflegeleistungsergänzungsgesetz*) (2002) provided further services (to the amount of 460 Euro per year). Entitled were only persons who also were entitled to general long-term care insurance-benefits; additionally they had to be assessed to have a considerable need of general supervision and care.^{9 10} The care-development-law (*Pflegeweiterentwicklungsgesetz*) (2008, parts later), which in the run-up had also been debated highly controversial, pursued several goals: to strengthen the prin-

³ Until then, the German system of social security, characterized by Esping Andersen as a Bismarckian type of welfare system (1990), consisted of statutory health, accident, unemployment and pensions insurance.

⁴ This aims were not completely achieved: While the reduction of the municipalities' expenditures was achieved and especially the professional and private care market grew enormous, the lowering of the number of care requiring persons dependent on social assistance stayed under the expectations (Cuellar and Wiener 2000, 12; Roth and Rothgang 2002, 48-57; 69-71).

⁵ The law was implemented in three steps to create the financial bases: Contributions had to be paid from the beginning of 1995, outpatient care benefits could be received since April 1995, and inpatient care from July 1996 on (Gerlinger and Röber 2009, 19).

⁶ § 2 para 1 states that benefits shall help to live an as independent and self-determined life as possible that corresponds to human dignity. The long-term care insurance law describes an holistic and activating care as principle of performance (§ 28 para 4 SGB XI, « ganzheitliche, aktivierende Pflege als Grundsatz der Leistungserbringung ») (Kohl-Schabram 2007, 76). In consequence, measures to guarantee this performance may not be reimbursed as extra-services.

⁷ Above a certain income limit contributions are not calculated as percentage of the income but stay fixed. In 2010, the contribution assessment ceiling for health- and long-term care insurance was at 3,750 Euro incomes per month.

⁸ The compromise was that the employees' side had to renounce their right to one statutory holiday.

⁹ Benefits were not paid before April 2002.

¹⁰ With the Statutory Health Insurance Competition Fostering Law (*Gesetzliche Krankenversicherung – Wettbewerbsstärkungsgesetz – GKV-WStG*) (2007) provisions of the long-term care insurance-funds (SGB XI) might be integrated in contracts on integrated care that ground in the health insurance system (SGB V), whereas provisions of social work still are not included (Dieterich and Kümpers 2009, 120).

principle of outpatient before inpatient care,¹¹ to enhance quality and quality transparency of services, to enhance counselling on and coordination of care (case and care management), to support voluntary engagement in low threshold services, to supply higher and more diverse benefits for persons with dementia and to strengthen the principle “cure before care.

1.b. Horizontal and vertical repartition of responsibilities and tasks

In Germany, the horizontal and vertical repartition of responsibilities and tasks regarding home based long-term care follows the principles of subsidiarity and partial coverage of needs, federalism and provider competition.

Long-term care of the population is stated in the long-term care insurance-law as a task of the whole society (§ 8 para 1 SGB XI). Long-term care insurance is not meant to cover all needs of care¹² but shall support home care and the willingness (and ability) of relatives and neighbours to care (*Pflegebereitschaft*) (§ 3 SGB XI). This founds its complementary character of partial coverage. Therefore it provides paid professional services, payments for self obtained services or a combination of both.

Under the heading of “common responsibility” (*Gemeinsame Verantwortung*) states, municipalities, service providers and long-term care insurance-funds¹³ are called to work closely together¹⁴ to guarantee an efficient, regional, community based (*wohnortnah*) and coordinated in- and outpatient care of the population (§ 8 para 2 SGB XI). Yet, the insurance funds are obliged to guarantee the long-term care of all insured (*Sicherstellungsauftrag*) (§ 12 para SGB XI) and therefore are seen as a central actor (Gerlinger and Röber 2009, 71, referring to Roth 1999, 429ff.). The States are obliged to guarantee an efficient, sufficient and economic infrastructure of long-term care (§ 9 SGB XI). Some of them, e. g. North-Rhine-Westphalia, transfer this responsibility to the municipalities by long-term care laws on the State level (Ministerium für Arbeit Gesundheit und Soziales des Landes Nordrhein-Westfalen 2007). In scientific and public debates municipalities are increasingly asked to actively promote coordinating functions in the local organisation of care infrastructure. Their remit is also the provision of means tested social assistance to care (§§ 61 – 66 SGB XII, *Hilfe zur Pflege*). Additionally, they are requested to provide complementary services to address social needs of elder citizens. Basis is a quite open formulated rule in the social assistance law (§ 71 SGB XII, *Altenhilfe*). Actual provision of those kinds of services is low.¹⁵

¹¹ It introduced the possibility to commonly use long-term care service (pooling of services) and regulated the rising of benefits as well as an mechanism to regularly adapt benefits (Schmidt 2008).

¹² The law also refers to the individual responsibility to avoid care needs by a healthy life style, by participating in prevention measures, and the active compliance in cure and rehabilitation (§ 6 SGB XI, individual responsibility (*Eigenverantwortung*)).

¹³ The institutions that provide benefits under the long-term care insurance act are the long-term care insurance funds. According to the long-term care insurance act, they have to be built at every health insurance fund (§46 SGB XI). During 2009, there existed on average 202 health insurance funds and the same number of long-term care insurance funds (Bundesamt 2010, table 8.2.1, 205). Even though the long-term care insurance funds are corporations under public law with self-government, organizationally they are tightly connected with the health insurance funds: For example, the organs of the long-term care insurance funds are the organs of the health insurance funds at which they are established. Nevertheless funding of the health insurance funds and the long-term care insurance funds is strictly separated: Health insurance benefits are not capped but need-oriented. They are paid by contributions of employers and employees, extra-payments by employees to health insurance, as well as by public subsidies. Long-term care insurance funds in contrast provide only capped benefits and are paid separately. Some authors make this complicate construction responsible for conflicting interfaces between both insurers, e. g. in home nursing care or with the implementation of the principle of “rehabilitation before care” (compare Gerlinger and Röber 2009, 146). The issue of a unification or a clear separation of both branches of insurance is debated in scientific discourse; compare Gerlinger and Röber for a summary of both positions (ebd., 146-147).

¹⁴ They shall involve the Medical and Advisory Boards. These are institutions build up by the health insurers on a regional level that are charged with task of supervising quality as well as contributing to the assessment of need of care of applicants.

¹⁵ Municipal spending for not means-tested help for senior citizens outside of insitutional facilities according to § 71 SGB XI in 2008 was about 8 Mill. Euro (Statistisches Bundesamt 2008, Tab. 1); 10,488 persons living at home benefited ; their average age was 74.4 years (Statistisches Bundesamt 2008, Tab. B5). During 2008 in total 10,488 persons living outside of insitutional received benefited from Senior Citizens Help (Statistisches Bundesamt 2008, Tab. B5).

This arrangement of long-term care provision is sometimes labelled as a “new welfare mix” (Evers 2002, 85) that would integrate public, market based, family and neighbourhood generated contributions and services. In public discourse it is sometimes given a normative spin: referring to discourses on demographic change, rising costs and an anticipated drop in informal care potential such kind of “new welfare mix” is promoted as an aim that should be striven for (compare Netzwerk: Soziales neu gestalten (Hrsg.) 2009).

Who does concretely what concerning the major issues in the functioning of LTC?

In the following we will have a look on the concrete horizontal and vertical repartition of responsibilities and tasks.

Information and counselling

Long-term care insurance funds are obliged to provide information and counselling to their insured¹⁶ and their relatives. This refers to all questions related to the need of care. Insurers shall give information on their own benefits and services as well as on those of other agencies (§ 7 para 2 SGB XI). Insured who apply for benefits shall be provided a comparative list on services and prices of providers in the respective catchment area (*Einzugsbereich*) (§ 7 para 3 SGB XI).

The long-term care insurance further development law (2008) authorized the States to demand insurers to build up so-called long-term care support bases (*Pflegestützpunkte*) (§ 92c SGB XI).¹⁷ They shall perform tasks of community-based coordination of services (similar to care management) and case related counselling (similar to case management).¹⁸ Insurers are obliged to point out the next long-term care support base and the opportunity to draw on care counselling (§ 7a para 1 SGB XI).¹⁹ They shall also provide the information that all those services are free of charge (§ 7, Abs. 3 SGB XI).

Assessment

With regard to the assessment of eligibility to means of long-term care, in Germany two situations must be differentiated: on the one hand there is the assessment of eligibility to long-term care insurance-benefits. This is regulated at the federal level by the insurers and implemented at a regional level: the regional Medical Review and Advisory Services who are bodies that are built up by all

¹⁶ As long-term care insurance in Germany – either in the social or the private long-term care insurance – is mandatory (§§ 20 - 27 SGB XI) coverage and thereby formal access is almost universal. Recently, limitations to actual access to and utilization of services and benefits are discussed as a matter of social inequality (Bauer and Büscher 2008) and a question of milieu (Falk, Heusinger et al. im Erscheinen).

¹⁷ In 2009 all States apart from Saxony and Saxony-Anhalt had opted for the implementation of care support bases (Michell-Auli, Strunk-Richter et al. 2009, 14-15). The insurance funds are asked to involve the public agencies who are responsible for the local assistance to senior citizens and service providers in establishing those support bases (§ 92c).

¹⁸ The care support bases shall provide independent information and counselling on rights and duties related to social security law in general and on other social services of federal or State level (§ 92c para 2). Their remit is also the coordination of all services providing health promotion, prevention, cure, rehabilitation, medical care, social care and services that may contribute to a community based (*wohntnah*) care supply. Additionally, care support bases are meant to build up networks of coordinated services of social care and involve voluntary work (§ 92c para 2 SGB XI). As implementation is still ongoing and diverse, it is not yet possible to evaluate if and how and which long-term care support bases are able to fulfil all this tasks. The third report on a model project of 16 pilot support bases is expected to be published the end of September 2010. The first two reports focused on the implementation of such support bases (Michell-Auli, Strunk-Richter et al. 2009).

¹⁹ The right to care counselling, whose description in the law (§ 7a para SGB XI) might be interpreted as a form of case management, was established only recently in 2009 with the care development law and relates to persons who are entitled to long-term care services. Insurance funds shall provide care counsellors also in the long-term care support bases (§ 7a para 4 SGB XI).

insurers together.²⁰ On the other hand there is the assessment of eligibility of applicants to means tested social assistance to care that is conducted by municipalities.²¹

The *concept of need of care* that is fixed in the long-term care insurance-law focuses on functional limitations and the functional ability to perform activities of daily living as well as instrumental activities of daily living (ADL and iADL). Four areas are defined: personal hygiene, nutrition, basic mobility aspects and domiciliary care.²² Depending on the individual need of help²³ the law defines three *levels of need of care*, which establish eligibility (§ 15 SGB XI). A considerable threshold is implemented as a minimum time needed for care of 90 minutes a day in weekly average is required, and it has to be expected that the need of care will at least last six month (§ 14 SGB XI). At least half of the minimum time of 90 minutes has to be needed for personal care in the area of personal hygiene, nutrition or basic mobility. Additionally, several times a week home help must be needed. Applicants that successfully are assessed those prerequisites are categorized to “care level I” that is defined as “considerable need of care”.²⁴

To be eligible for long-term care insurance-benefits the insured or his/her authorized representative has to apply for benefits from his/her long-term care insurance fund. The insurer then charges the responsible regional Medical Review and Advisory Service to do the needs assessment. The assessment is regulated and agreed on in detail at the federal level by the care insurance funds in according guidelines (§ 17 SGB XI).²⁵ The assessment has to be done in the applicant’s household by qualified staff.²⁶ It comprises the systematic gathering of information on the actual situation of care, the history that led to the need of care and the medical results, including statements of the applicant and the care giver and available extern results, e. g. from the general practitioner of the applicant, an assessment of the type and area assistance is needed in, the time needed therefore by an informal carer, a screening and assessment to identify persons with considerably limited competence in everyday life tasks as well as recommendations on necessary services, also rehabilitative ones²⁷ (Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e. V. (MDS) and GKV-Spitzenverband 2009).²⁸ The Medical Review and Advisory Service provides the respective insurer with a fulfilled assessment form that documents the results of these steps in detail (ibid., 26-27). The final categorization of the care level that implies the financial decision is done by the insurer.

²⁰ At the moment there exist 15 regional units of the Medical Review and Advisory Service following more or less the borders of the States. The Medical Review and Advisory Service at the federal and regional level are working-groups of the respective health- and long-term care insurance funds and are organized in the western States of Germany as corporations under public law (*Körperschaften des öffentlichen Rechts*), in the eastern States of Germany as registered associations (*eingetragener Verein*) (http://www.mdk.de/Gliederung_Organisation.htm, access 08/27/2010).

²¹ Differences in eligibility procedures are underresearched. Empirically established are different opinions of municipalities / providers of social assistance e. g. on how broad the spectrum of activities is, means-tested social assistance might be paid for (compare Kohl-Schabram 2007, 76).

²² Covered activities in the respective areas are clearly defined in § 14, Abs. 4 SGB XI: Body care: wash, shower, bath, toothwashing, comb, shave, toilet ; nutrition: preparation in mouthadequate pieces or food ingestion; mobility: get up and got to bed independently, put on and off clothes, walk, stand, climb stairs, leaving and getting back into the department ; household (chores): shopping, cooking, cleaning the department, wash dishes, change and wash clothes, heating.

²³ Eligible are the categories: to assist, to partly or completely overtake, to supervise or to instruct the care receiving person (§ 14 para 3 SGB XI).

²⁴ To qualify for Care level II (severe need of care) the individual must need help in one of the dimensions of personal care at least three times a day, several times a week domiciliary care, at least three hours a day in weekly average, two hours of it personal care. Care level III (most severe need of care) requires a round-the-clock need of care, also during nights, and additionally several times a week domiciliary care that is at least five hours daily, four of them personal care (§ 15 SGB XI).

²⁵ The Medical Review and Advisory Service at the federal level has to be involved. For the guidelines (only in German) confer Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen und GKV-Spitzenverband (2009).

²⁶ Assessment is generally done by qualified nurses, in difficult cases by doctors/medical staff (personal communication with staff in one Medical Advisory Board).

²⁷ Provision of rehabilitation is recommended during this assessment. It does not belong to the remit of the long-term care insurance-scheme but to that of health insurance.

²⁸ This form recently seems to be fulfilled on a notebook just during the assessment in front of the applicant (personal communication with staff from a care provider and from a Medical Advisory Board).

Critiques on the results of this procedure claim too frequent rejections of applications or classifying in too low levels; furthermore the procedure itself would not provide the assessor with realistic impressions of the abilities of the applicants as the visits are short, the situation of the elderly unstable and elderly would pretend not existing capacities (Gerlinger and Röber 2009, 33).²⁹ Thus, assessment has been criticized to rather restrict access to services and function as an instrument of cost control in times of scarce resources (e.g. grades of care need have ignored the special demands of dementia patients for a long time and have just recently been adapted).

Those, who do not qualify for benefits of long-term care insurance or who because of little income and assets are not able to pay for needed benefits that are not covered by the insurance, may apply for social assistance to care (*Hilfe zur Pflege*) from the municipality to fill this gap. The respective regulation in the social assistance law (§§ 61-66 SGB XII) principally repeats the concept of need of care that is established in the long-term care insurance-law. But it does not apply the thresholds of a minimum of daily needed time for assistance and the prerequisite of the need of care lasting more than six months (§ 61 SGB XI). Additionally, it extends the range of services that may be granted.³⁰ Because of the subsidiarity of social assistance to care persons in need must primarily apply for long-term care insurance-benefits. Application for social assistance to care entails another assessment of need of care that is conducted by the municipality. Whereas the assessment conducted by the Medical Review and Advisory Service of Social Health Insurance seems to be quite standardized and universal, local assessment procedures may differ from municipality to municipality and seem to be under-investigated with regard to their distributional consequences.³¹

Provision

Long-term care insurance law (SGB XI) regulates the provision of long-term care services' supply and care infrastructure. Although the provision of long-term care supply is conceptualized as a joint task of States, municipalities, service providers, long-term care insurance-funds and the Medical Review and Advisory Services, the long-term care insurance-funds are given a central position by law (see above): They are charged to

- guarantee the availability of services,
- to contract with service providers (§ 72 SGB XI),³²
- to negotiate with them the concrete type, content and extent of their services (§ 72 SGB XI) as well as reimbursement (§ 84, § 89 SGB XI) and quality performance (§ 84, Abs. 5; § 113 SGB XI),

²⁹ Professionals from care providers e. g. experience that incontinence is an area elderly people often were shy to talk about honestly, especially if asked directly (personal communication).

³⁰ It is controversial if this extends only to personal care or also to social attendance (Kohl-Schabram 2007).

³¹ A report on steering of costs in assistance to care in 16 big cities states considerable local differences in the interpretation of legal concepts, practice of granting as well as in the implementation of legally admitted control mechanisms (con_sens 2010). Although this report refers to a necessary balance of financial and professional steering aspects, it seems that information on steering potential to control costs is the main interest ; information on quality of care is not provided.

In practice, applications for assistance to care seem to be sometimes made with the support of care service providers that are already in contact with the person in need of care. They suggest a care plan which from their perspective would fulfil the needs of the care receiving individual. In other cases, the applicants have to act on their own or with the assistance of relatives or the social workers from the municipality. Both might be seen as a symptom of the underdeveloped idea of case management in Germany. Some municipalities make the final decisions on granted benefits on bases of the assessment of the Medical Advisory Board (if available to the municipality), the municipalities' own assessment and – if existing – the need of care stated by the professional care service provider (Falk, Heusinger et al. im Erscheinen).

³² Services of a care service providing agency are only covered by long-term care insurance if the respective provider has a contract with and is admitted by the long-term care insurance-funds. Funds are obliged to admit service providers if they fulfil certain prerequisites e. g. to guarantee permanent responsibility of a qualified nurse, to guarantee efficient care provision and to implement certain measures of quality assurance as to implement an internal system of quality management (§ 72 SGB XI). Supply-planning considerations do not justify rejections. Law foresees that contracting shall happen *in agreement* with the public agencies that are on the supra-local level responsible for granting the social welfare allowance, as long the State level law does not define the local agency as responsible (§ 72, Abs. 2, SGB XI).

- to decide on guidelines on the definition of need of care and its assessment,
- to coordinate services and provide counselling,
- to decide on the categorization of applicants according to the care levels on the basis of the assessments of the regional Medical Review and Advisory Services (MDK)³³.

In contrast, municipalities shall collaborate with the long-term care insurers and other involved actors, but are not assigned “hard” steering or planning capacities under long-term care insurance-law as would be e. g. the right to a supply-oriented contraction with service providers. Nevertheless, Klie and Pfundstein ascribe at least some steering potential precisely to those coordinative functions (Klie 2010; Klie and Pfundstein 2010) – that seems to be used differently by municipalities. The respective room for manoeuvre of the States who are responsible for the provision of and the investment in the care infrastructure is debated controversial (Schmidt and Klie 1998; Ziller 1998).

Benefits

Provision of benefits related to home based long-term care in Germany is organized in four different legal contexts: the long-term care insurance (SGB XI), social assistance to care (SGB XII), social assistance for elderly citizens (SGB XII) and nursing care at home (SGB V).³⁴

Concrete benefits and services regarding home based care that – under the principle of partial coverage – shall be provided following the law of long-term care insurance are now:³⁵

- general information on care (§ 7 para 2 SGB XI) as well as extensive care counselling (§ 7a SGB XI) (see above),
- benefits in kind according to the respective care level (§ 36 SGB XI),³⁶
- cash-benefits for self-obtained care according to the respective care level (§ 37 SGB XI)³⁷, which are only about half as much as the value of benefits in kind,
- a combination of benefits in kind and cash benefits (§ 38 SGB XI),
- benefits to relieve the situation of family carers, e. g. part-time institutional care (§ 41 SGB XI), short-time care (§ 42 SGB XI) and stand-in (respite) care by near relatives or other persons (§ 39 SGB XI) as well as payment of certain social insurance contributions for caring relatives (§§ 44, 44a SGB XI) and training on care for relatives and other voluntary care givers (§ 45 SGB XI),
- nursing aids and measures to improve the persons’ living environment (§ 40 SGB XI),³⁸

³³ Actually, the Medical Review and Advisory Services are built by the health insurance funds. The long-term care insurance funds are built under the roof of the health insurers.

³⁴ The status of the law on rehabilitation and participation of persons with disabilities (SGB IX) with regard to persons in need of care recently is an issue of debate. Benefits are rarely applied for under this scheme by elderly persons in need of care. Some argue that the regulations of the law on rehabilitation and participation should be applied to older people in need of care, too (Beauftragte der Bundesregierung für die Belange behinderter Menschen oJ; Fuchs oJ).

³⁵ After a long period during which benefits had not been adapted, in 2002 began a very slow extension of benefits, and with the care-development-law of 2008 benefits have been further adopted.

³⁶ Since the care development law from 2008 benefits in kind may also be “pooled”, what means that several insured that live in little spatial distance may draw on their entitlements to benefits in kind together; in case that the provision of body care and home help are guaranteed, long-term care insurance then also covers services of social care e. g. general supervision or low threshold services (§ 36 para 1 SGB XI)

³⁷ Insured that opt for cash benefits are obliged to regularly care counselling visits by approved care service providers – in case of care level I and II every half year, in case of care level III every three months (§ 37, Abs. 3 SGB XI).

³⁸ Nursing aids intended to consumption: max. of 31,- Euro per month (§ 40 Abs. 2 SGB XI), technical nursing aids (co-payment of 10% (max. 25,- Euro) or free loan); subsidies for measures of adopting the living environment up to 2,557 Euro per measure, considering a reasonable co-payment (Bundesministerium für Gesundheit oJ).

- and supplementary benefits for persons who have a considerable general need for care and supervision, e. g. due to dementia or other psychiatric diseases (§§ 45 a-d SGB XI) (see Bundesministerium für Gesundheit oJ for the amount of the mentioned benefits).³⁹

Persons entitled to benefits may freely choose between cash benefits for self-obtained services delivered by informal or professional care givers or benefits in kind provided by professional care agencies. Benefits are strictly capped according to the respective care level. Cash benefits are worth only about half of the value provided for benefits in kind.⁴⁰ Benefits in kind comprise above all personal care in the area of personal hygiene, nutrition and basic mobility aspects and home help (§ 36 SGB XI).⁴¹ Matters of social assistance are not included. In contrast, persons that opt for cash benefits are free to choose for what kind of services they spend their lower, but hence more flexible benefits.⁴²

Social assistance to care (*Hilfe zur Pflege*) as part of the social assistance law (§§ 61 – 66 SGB XII) may provide a broader range of benefits and services, e. g. assisted mobility or some social assistance. The latter is controversial (Kohl-Schabram 2007) and implementation depends on the concrete regulation on the regional or even municipal level (con_sens 2010). Benefits of social assistance to care are not capped but only accessible on application and subsidiary as well as means tested.

At the community level, according to the social assistance law, municipalities shall provide Assistance for Senior Citizens (*Altenhilfe*) that shall contribute to avoid, overcome or moderate difficulties resulting from old age and to maintain the opportunity for old age citizens to participate in community life (§ 71 para 1 SGB XII). Those benefits and services shall not be related to the individually available income or assets (§ 71 para 4) and may include also elements of social assistance (§ 71 para 2 SGB XII).⁴³ The soft character of this regulation leaves it to the discretion of the municipalities how they concretely implement the prescriptions.⁴⁴

The law on health insurance (SGB V) regulates nursing care at home (*häusliche Krankenpflege*) in case that a person living in the same household of the insured is not able to sufficiently care for the insured person (§ 37 SGB V). Nursing care at home comprises social care, nursing care in a narrow sense and domiciliary care to avoid or to shorten hospital care for up to four weeks (§ 37 para 1 SGB V). Apart, insured are entitled to nursing care in their household or similar contexts in case this is necessary to assure the aim of a medical treatment (§ 37 para 2 SGB V).⁴⁵

³⁹ Till 1,200 Euro (basis allowance) respective 2,400 Euro (increased allowance) annually as supplementary benefits provided for long-term care patients with a considerable general need of care. Services may be e. g. services of general supervision provided by admitted outpatient-care service providers/agencies as well as low threshold services of care that have to be admitted following State law (e. g. day care in small groups, single attendance through approved helpers) that receive funding through the State or at least qualify for (Gerlinger and Röber 2009, 42). In this context the care development law encouraged the extension of such low threshold services and voluntary work (§§ 45c, 45d SGB XI) (Gerlinger and Röber 2009, 42) via a funding of 25 mill. Euro, that have to be co-financed by the States and municipalities (Gerlinger and Röber 2009, 42).

⁴⁰ In 2010 cash benefits were at monthly 225 Euro (care level I), 430 Euro (care level II) and 685 Euro (care level III) whereas benefits in kind for home-based long-term care could be required for 440 Euro per month in care level I (daily needed assistance of 90 minutes or more), 1,040 Euro per month in care level II (daily needed assistance of at least three hours a day) and 1,510 Euro per month in care level III (daily needed assistance of at least five hours a day) (Bundesministerium für Gesundheit oJ).

⁴¹ This is called basic care (*Grundpflege*).

⁴² This – together with a milieu-related care willingness of relatives (Blinkert and Klie 2004) and the overall labour market situation – might contribute to the explanation of the decreasing but persisting higher share of care receiving persons that opt for the lower cash benefits instead of benefits in kind.

⁴³ For example support to social activity, housing or counselling on age related services (§ 71 para 2 SGB XII)

⁴⁴ Decisions will probably be affected by the poor financial situation of many municipalities in Germany. The Assistance Act for Senior Citizens is a legal rule however municipalities decide about its application. Therefore local authorities are not obliged to offer as additional services, e.g. volunteer visiting schemes or volunteer companion services for elderly.

⁴⁵ Again frictions resulting from the fragmented system of care show up: The legal and merely analytical separation between personal care, nursing care at home and domiciliary care leads to difficulties in practice as they follow different payment logics: Personal care under SGB V is generally only approved for short terms while under SGB XI is rewarded via the fixed amount assigned to the

Summarizing, one can conclude that especially needs of psycho-social attendance and care, including social work and low-threshold social services as company or the facilitation of mobility as well as needs of persons with a considerable need of general supervision, e. g. because of psychiatric diagnosis as/ or dementia, are under-addressed. Additionally, case and care management are too recently introduced to allow a thoroughly evaluation of the diverse implementation on the State and municipality-level.

Training / certification of professional care-givers

In professional home based long-term care the actual level of training of the respective care givers varies: To manage an outpatient long-term care agency (*ambulante Pflegeeinrichtung*) a qualified training of about three years plus two years of working experience and the certification of a further qualification for managing functions of at least 460 hours is required (§ 71 SGB XI). In the outpatient sector about 62% of the staff who did (beneath other) basic care had a three year-training in nursing or nursing for elderly (Statistisches Bundesamt 2008, 18). Others have a one or two years training in care-helping professions or another education or any formal professional education. Nursing care has to be provided by “adequately” trained nurses (§ 37 SGB XI), in general with three years of training who are delegated those tasks by the medical doctors.

Training and education of personnel in formal care is a controversial issue in Germany. Care as profession still occupies a “subaltern status” (Gerlinger and Röber 2009, 77) towards medicine. It may be seen as a consequence that care professions and care providers seem to be less powerful facing interest conflicts compared to the medical professions (ebd.). There are calls that demand a further professionalization of the nursing profession. Capacities such as coordination and communication should be promoted. Despite respective efforts, e. g. to establish university courses of nursing studies that also encompass on such capacities, experts see barriers for their implementation in daily practice. Beneath other, they assign this to the prevailing narrow concept of care which focuses on body-near activities (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009, 363).

Remuneration of professionals (minimal wage, professional regulation, collective agreement)

In 2007, in Germany 236,162 persons (87.6% of them female), about 10% more than in 2005 (Statistisches Bundesamt 2008, 17), were employed in 11,529 outpatient social care agencies (*ambulante Pflegeeinrichtung*) (59.9% of them for-profit, 38.5% non-for-profit and 1.7% public providers) (ebd., 15). The shares of part-time (48.4%)⁴⁶ and insignificant⁴⁷ (22.5%) occupation in this sector are quite high; only about one quarter of the employees has a full-time job (26.4%) (ebd., 17). Fluctuation is relatively high in the German care sector compared to other European countries (Pick, Brüggemann et al. 2004, 41), what may be attributed to the high physical and psychological burdens (Gerlinger and Röber 2009, 64 referring to DAK/BGW 2000 and Hasselhorn et al. 2005) and – if not addressed – may contribute to the assumed future lack of care staff (Hackmann 2010).

A worker unions’ representative study on employees’ working satisfaction that included also long-term care (N=166 nurses for older people) showed a very high degree of dissatisfaction with the low level of wages in this sector as 48% of those questioned despite of working full-time earned less than 1,500 Euro gross and 24% between 1,500 and 2,000 Euro (Fuchs oJ, 10). Since 2008, long-term care insurance-funds and outpatient social care agencies may only contract if the provider guarantees to pay at least a standard local fee (§ 72 para 3 SGB XI). In 2010, additionally a minimum wage of 8.50 Euro/hour in the Western part of Germany (including Berlin) and 7.50 Euro in

respective care level; in contrast, nursing care at home is granted without time limit or financial cap. Hence, health insurance funds are interested in redefining medical care to basic care to lower expenses (Gerlinger and Röber 2009, 47 referring to Igl 1995).

⁴⁶ In 2007 32.9% of the part-time work was more than half-time, 15.5.% was half-time or less (Statistisches Bundesamt 2008, 17).

⁴⁷ Insignificant occupation is classified as employment with wages under 400,- Euro per month, the employer is obliged only to pay social security contributions at a flat-rate, the employee is not entitled to social security benefits as health or pension insurance.

the Eastern part was introduced and is to be evaluated in 2011. The minimum wage will be raised in two steps till 9.00 Euro/hour West and 8.00 Euro East in 2013 (Bundesministerium für Arbeit und Soziales 2010);⁴⁸ due to claims of the liberal coalition partner it is limited till the end of 2014. The regulation only applies to those employees who work in long-term care insurance-facilities (not for privately employed persons) and predominantly are working in the field of basic care (nutrition, personal hygiene, basic mobility/clothing), not domiciliary care. Therefore its actual effects are to be observed.

An unknown number of illegal working carers mostly coming from Eastern European countries are tolerated by the German Job Centers and Health Authorities. If officially recruited with the help of the International Placement Services (ZAV) of the German Federal Employment Agency, migrants work as home helpers, while in fact they perform carework. Meanwhile the respective directive was adapted, so that those officially recruited workers are also allowed to perform necessary daily care that is help with personal hygiene, nutrition or mobility that could be done by any person and would be expected by relatives as if to be natural (BR Drucks 810/09) (Bundesrat 2009). The regulation of minimum wages does not apply to those privately hired workers.

Role, integration, recognition of the nonprofessional helpers

The Expert Board for the Supervision of the Development in the Health Sector considers the German long-term care insurance to be arranged around the core of private, especially family solidarity (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009, 363). The introduction of long-term care insurance with cash benefits, the support of non-for-profit and for-profit outpatient care agencies and the introduction of stand-in/respite care should increase the availability of formal care to lighten the stress for family carers and informal helpers.

The success might be argued. Some see it behind the expectations, precisely because of the enhanced competition and economisation in the field of care (e. g. Pfau-Effinger, Och et al. 2008).⁴⁹ On the other hand, cash benefits for self obtained care,⁵⁰ might indeed be interpreted as institutionalized acknowledgement of the work of informal carers.⁵¹ Further, near relatives do not have to pay taxes on cash benefits what may encourage family care giving, too (Cuellar and Wiener 2000, 17). Gerlinger and Röber concede a financial relieve of relatives and a lowering of psychological stress (2009, 23-24).

The problem of compatibility of care and employment for informal carers is debated only recently. In 2008, with the Law on Care Leave an entitlement for employees who care for a near relative was introduced to be exempted from work without payment for at maximum half a year (§ 3 Law on Care Leave - *Pflegezeitgesetz*). During this time the employee is protected against dismissal (§ 5

⁴⁸ The collective agreement for the public service foresees a monthly income for care professionals with a three years' education in full-time employment of about 2,000 Euro gross in the first year of working (ver.di 2009, 4).

⁴⁹ Pfau-Effinger et al. argue that the two emancipatory aims pursued by the law – to foster the autonomy of the persons in need of care towards caring relatives, and to relieve relatives from the „duty to care“ – had been hardly successful. The consequences of economization and quasi-taylorisation of care enhanced the mismatch between care culture and values that persons in need of care and there relatives prefer (social care) on the one hand and the realized values and cultures professional (body) care realizes (2008).

⁵⁰ On application informal carers additionally may receive public contributions to pension insurance. Contributions are not paid for health insurance. Covered are premium for the unemployment insurance and the pensions insurance (conditions to qualify for both differ a little bit, e. g. to qualify for the duty to insure against unemployment there is no minimum time per week of care, as it is the case for the pensions fund premiums). There is an obligation (in fact a right) to premiums to the pensions fund that are paid by the long-term care insurance-fund (more complicated with civil servants), under several conditions: - the care-receiving person is in need of care (following the definition of the law), - the care-receiving person applies for benefits at the long-term care insurance, - the care-giving person fulfils the following requirements: * caring the care-receiving person honorary/ non-for-profit not less than 14 hours a week at his/her home, * having ones domicile in Germany, European economic area, Suisse, * caring will last for foreseeable more than two months, * the care giving person might not be employed for more than 30 hours a week (Deutsche Rentenversicherung 2009).

⁵¹ The care work of those informal carers is to be supervised by statutory care counselling visits (§ 37 para 3 SGB XI) that have to be conducted by registered care service providers or similar agencies every six (care level I and II) or three (care level III) months.

Law on Care Leave).⁵² Long-term care insurance-funds shall offer free training for informal carers; the aim was also to promote civic engagement in care (§ 45 SGB XI, Care Courses – *Pflegekurse*).⁵³ Those courses yet seem to be rarely used by informal carers.⁵⁴ They seem not to consider sufficiently the individual needs and interests of the family carers (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009, 363 referring to Dörpinghaus and Weidner 2006).

In general, the interface of formal and informal care in Germany seems to be little developed. This might be attributed to the mentioned fact service providers focus on the provision of services that are covered by long-term care insurance (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009, 360). The Expert Board for the Supervision of the Development in the Health Sector recommends an opening of the sector of outpatient social care to new tasks such as networking, health promotion, and support and supervision of caring relatives and informal helpers. Yet, this would need family-orientated care concepts instead of the given individual-focused ones (ebd., 361).⁵⁵ Comprehensive prevention and health promotion for caring relatives and other informal carers still seem to be under-addressed (comp. Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009, 363).

Family care also shows social inequalities: the willingness to care varies between different milieus, the lower milieus more willing to care than liberal-bourgeois milieus that prefer inpatient care facilities (Blinkert and Klie 2004, 128). Gerlinger and Röber consider cost arguments as important factors in the decision for care arrangements: while poor milieus aim at avoiding high costs for inpatient care facilities, liberal-bourgeois milieus would take into account higher opportunity costs (Gerlinger and Röber 2009, 51), that would arise from home care, as e. g. the cost of dropping employment and losing a second income as well as the chance to self-fulfilment.

Organization of the home-based LTC

Taking into account regulation, institutionalization, financing and provision of home-based long-term care one can summarize that long-term care in Germany is organized as a welfare mix. This mix consists of private provision of family help and financial support, of insurance-financed capped benefits that focus on personal care, in cases of severe financial need complemented by social assistance benefits and some remuneration for informal carers.⁵⁶ Enabling social inclusion is regarded little.⁵⁷

The framework for home-based long-term care insurance is set on the national level by the Law on Long-term Care Insurance (SGB XI). Much regulating power is delegated to the long-term care insurance-funds and to negotiations on the State level. Part of the implementation takes place via care laws on the State level. They set the frame for related policies on the municipality level. There

⁵² The law in general does not apply if employers hire 15 or less employees. In case of care time the exempted workers receive on application basic contributions to health care insurance and long-term care insurance that are paid by the long-term care insurance; the time of the leave is also regarded in the unemployment insurance (§ 44a SGB XI). The prolongation of the possible care leave as well as different modes of financial remuneration is debated controversially.

⁵³ Details may be contracted by the long-term care insurance-funds on the State level with those agencies that offer the courses. This, again, provides the States with room for manoeuvre and thus contributes to a horizontal variety in the implementation of the long-term care insurance law.

⁵⁴ Not at least because of the lack of replacement in caring.

⁵⁵ In contrast, § 45d SGB XI focuses on self-help and voluntary work in this area with obliging the long-term care insurance-funds to provide money that is foreseen for the further development of caring infrastructures (25 mill. Euro) and has to be co financed together by the States and municipalities also for the fostering of self-help and voluntary work for care receiving persons and their relatives. As may be judged up to now, implementation again seems to differ on the States level.

⁵⁶ There are also some public subsidies for care service providers.

⁵⁷ If the German Law on Inclusion for Persons with Disabilities (SGB IX) applies also to persons in need of care is debated controversial. It refers in its definition of disability to bodily functions, mental competences or mental health that diverge from the «age-typical» state. Actually, elderly citizens dependent on care do not or only most rarely claim for benefits according to this law. In consequence participation in society is restricted (§ 2 para 1 SGB IX). For a contrary argumentation compare Fuchs (oJ).

remains some room for manoeuvre for the municipalities which they seem to use quite differently (Hammerschmidt 2010, 29):

- in the implementation of social planning in long-term care,
- in coordination of and networking between involved actors (that is: in the implementation of care and case management as well as in organizing access to information, services and benefits),
- in the norms and concrete practice of granting social assistance to care as well as
- in the practice of providing or not low-threshold services to facilitate social participation and mobility of elderly citizens in need of care.

Relations LTC / health care system

In Germany long-term care, nursing care and medical treatment are separated with regard to regulation, institutionalisation, financing and provision, even though individual needs often are difficult to assign clearly to one area.

Statutory health care for older people with medical care needs and some kinds of nursing support (e.g. short-term nursing care up to 6 months) are covered by the social health insurance and mostly delivered as a benefit in kind. In contrast to the long term care insurance, the health insurance system aims to be fully comprehensive with some additional payments for dental facilities and medical registration.

Long-term care insurance guidelines establish the principle of “cure before of care” that should be decisive in any medical and care action. However the interplay between the different insurance systems and care sectors is shaped by a strong focus on acute medical care and sophisticated downstream interventions. Comprehensive care concepts including e.g. preventive and rehabilitative approaches or integrating different sectors as health and social care or different professions have been underdeveloped for a long time – and only recently gain some attention in German health policies. Only since the last long-term care insurance Reform in 2008 geriatric rehabilitative care is standard insurance benefit (no matter of discretion). Regulated by law every (old) patient is eligible to it.

The implementation of this principle is hindered by separated financial responsibilities of health insurance funds and long-term care insurance funds, as the former have to pay for the geriatric rehabilitative care, while the latter benefit from it.

Prerequisites for social care providers (*Pflegedienste*) as well as reimbursement for – in some cases even identic – services differ between health insurance and long-term care insurance.⁵⁸ This is an incentive for health insurance funds to redefine services of home nursing care (medical treatment care) (§ 37 SGB V) to services of basic care (according to SGB XI) to reduce costs (Cuellar and Wiener 2000, 11; Gerlinger and Röber 2009, 47 referring to Igl, 1995).

Nursing care at home according to health insurance law is only provided in “households”. Therefore, the concept of “household” that is applied in health insurance law is a crucial point. The Law to Foster Competition in Health Insurance extended the concept of « household » also to housing arrangements that are difficult to attribute clearly to the out- or inpatient sector (ebd., 47-48).

Organization of the 3 dimensions of LTC: health care / daily life / social care

Whether elderly people with care needs can live autonomously and participate socially is not only the result of access to social and domiciliary care as it is covered by the long-term care insurance⁵⁹

⁵⁸ Many care providing agencies are registered to provide nursing care as well as social care and charge according to Health Insurance Law as well as to Long-term Care Insurance Law.

⁵⁹ Long-term Care Insurance Law includes activation and communication in its concept of care (§ 28 para 4 SGB XI). Yet, communication is conceptualized as a feature of the quality of service performance and part of social care that in the outpatient sector is

in Germany. It also depends on access to information about support and counselling, social relations and contact, and – as an important facilitator to achieve all this – outdoor mobility (Falk, Heusinger et al. im Erscheinen). Yet, services to support in daily life and low-threshold services that support social contact are under-addressed by the long-term care insurance. It only recently introduced a right to individual counselling that comes near to case management. In contrast to the inpatient sector social attendance is not covered by the long-term care insurance. Neither are services to facilitate outdoor mobility covered by long-term care insurance benefits in kind. The provision of such services by municipalities varies, too.

The Assistance Act for Senior Citizens is a legal rule, however, municipalities decide about its application. Therefore local authorities are not obliged to offer social care as additional services, e.g. voluntary visiting schemes or voluntary companion services for elderly or participative efforts. Depending on the financial situation and the political priority, municipalities allocate social care in an unequal policy. This benefit based on the Assistance Act for Senior Citizens is not income-related.

System governance and planning

As mentioned above, the Long-term Care Insurance Law establishes a joint responsibility of the States, municipalities, service providers and long-term care insurance-funds to cooperate for an efficient, regional, community based (*wohnnah*) and coordinated in- and outpatient care of the population (§ 8, Abs. 1 SGB XI). Long-term care insurance law hence, follows a cooperative model of responsibility (Schmidt and Klie 1998, 310). The municipalities are given an increasing significance in governing the design of the local welfare mix (Ziller 1998; Klie and Blaumeiser 2002; Netzwerk: Soziales neu gestalten (Hrsg.) 2009; Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009, 302). Yet, municipal steering instruments are limited to coordinative and communicative functions as well as to the decision about social assistance to care (§ 61 – 66 SGB XI) and help for senior citizens (§ 71 SGB XI). The provision of additional services is a voluntary task that takes place against the background of most often scarce financial resources.⁶⁰

Despite the model of cooperative responsibility, the Long-term Care Insurance Law leaves agreements (accreditation) and control (including quality issues) in large part to the long-term care insurance funds, to service providers and agencies, and their respective associations. Tasks of public supervision are assigned to the federal and State level (Gerlinger and Röber 2009, 69).

- agreements (accreditation) and control (quality issues as well)

Agreements

On the State level, the associations of the long-term care funds and the associations of the outpatient social care agencies (*Träger der ambulanten Pflegeeinrichtungen*) negotiate *framing agreements* (§ 75 SGB XI - *Rahmenverträge*). Those agreements regulate – beneath other – the content of care services, the general conditions of care including costs, principles for an economic provision of the agencies regarding staff and equipment. Part of those agreements shall also be procedures on the State level to determine the need of staff or time needed for care. Thereby the special needs of care requiring persons with mental disabilities, psychiatric diagnoses, or limitations in competences due to dementia and other complaints of the neuronal system shall be taken into account (§ 75 SGB XI para 3). In the outpatient sector the associations of the local providers of social assistance (the municipalities) have to be involved as a contracting partner (§ 75 SGB XI para 1 sent 3).

The accreditation of service providers also is the remit of the associations of the long-term care insurers at the State level. In the outpatient sector they have to involve the local providers of social

ascribed to relatives or other near persons. Social attendance (*soziale Betreuung*) is not covered as an extra benefit by long-term care insurance (Gerlinger and Röber 2009, 26 referring to Klie and Kraemer 2000 § 41 Rn 15).

⁶⁰ Corresponding, some observed also a retreat of municipalities from planning and designing responsibility in the realm of help and support for senior citizens (Ziller 1998, 394; Gerlinger and Röber 2009, 24).

assistance (municipalities) (§ 72 SGB XI)⁶¹ in negotiating the respective agreements on care with the service providers (*Versorgungsvertrag*). Long-term care insurance funds may only cover costs for benefits in kind that are provided by accredited care service agencies (§ 72 SGB XI para 1). Agreements on care define the character, content and extent of the care services that are to be provided (§ 72 SGB XI para 1). In the outpatient sector the catchment area of the agency has to be defined. Differentiated performance profiles of care service agencies are rare (Gerlinger and Röber 2009, 75). Accreditation may only be given if the respective agencies fulfil some defined prerequisites (leadership by a qualified nurse, economic performance, paying according to a local standard, implementation of a quality management system and application of expert guidelines (see below)) (§ 72 SGB XI para 3). In the case of fulfilled prerequisites, accreditation may not be rejected. If selection is necessary, the law gives priority to non-for-profit and for-profit agencies over public ones (ebd.). This rule contributes to competition between providers, but limits the scope for the planning of care infrastructure by local authorities.

Reimbursement under the Long-term Care Insurance Law follows the principle of performance accounting (§ 82 para 1 SGB XI) instead of the former existing mode of covering costs (Schmidt and Klie 2002, 8). This promotes the quasi-taylorisation of formal care (Pfau-Effinger, Och et al. 2008, 85). As the level of contributions to long-term care insurance is fixed by law, agreements on reimbursement actually regulate the purchasing power of the long-term care insurance benefits (Gerlinger and Röber 2009, 80).

Control

The Long-term Care Insurance Law builds the legal basis for the regulation of quality assurance in outpatient long-term care in Germany and has been extended over the years, mainly in chapter 11.⁶² The insurers, together with the Medical Review and Advisory Services, care agencies' associations and the associations of the local and supra-local providers of social assistance are the actors that are in charge to concrete the legal regulations by directives. The nursing professions' associations as well as important organizations of interest representation and self-help of persons in need of care and with disabilities must also be involved (§ 113 SGB XI). One might differentiate three important elements: the development of norms as e. g. measures and criteria for quality assurance and expert standards, internal quality management and external quality control and transparency of results. The implementation of the latter is debated controversially. External quality controls in outpatient care are initiated by the long-term care funds. They shall charge the Medical Review and Advisory Services to control all registered long-term care facilities at least once a year. This may be reduced considering results of external controls or internal quality management (§ 114 SGB XI).

- pathway coordination and case management

The development of care pathways and case management has been underdeveloped in the German system for long but is seen as very important (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009, 363-364). Those tasks had not been clearly assigned to any actor involved in the care of older people with complex needs. The fragmentation of the German system of health and long-term care was an additional barrier to pathway coordination. In prac-

⁶¹ In case that funds and municipalities do not agree on contracts till 2002 the funds could outvote the municipalities. Since 2002 with the law on quality assurance, in case of being outvoted by the funds municipalities may appeal to an arbitration board (§ 76 SGB XI) (Gerlinger and Röber 2009, 74).

⁶² Important measures are the above mentioned framing agreements (§ 75 SGB XI), the foreseen development of principles and criterions for quality assurance and development (§ 113 SGB XI), the development of expert standards (§ 113a SGB XI), extern quality controls and transparency of results of extern quality controls (§§ 114 – 115 SGB XI). The development of principles and criterions for quality assurance and development as well as intern quality management systems is assigned to the long-term care funds', the associations of the local and supra-local providers of social assistance (Bundesvereinigung der kommunalen Spitzenverbände und Bundesarbeitsgemeinschaft der überörtlichen Sozialhilfeträger) and the care facilities associations on the federal level. They have to involve the Medical Review and Advisory Services of Social Health Insurance, the nursing professions' associations as well as important associations of interest representation and self-help of persons in need of care and with disabilities (§ 113 SGB XI). Those agreements are directly valid for all long-term care funds and accredited long-term care facilities.

tice this task is often performed by engaged individuals, e. g. social workers in outpatient long-term care agencies or general practitioners. With the Long-term Care Further Development Law in 2008 the States were given the opportunity to decide on the implementation of long-term care support bases on the local level that should – beneath other – assume a case management task. Apart from Saxonia all States opted for the implementation. It still has to be evaluated how they will perform. Their work is still in the beginning and varies a lot between the States. Questions concern especially the accessibility, quality and neutrality of their counselling. The Expert Board for the Supervision of the Development in the Health Sector additionally emphasizes the importance of overcoming the general system fragmentation and reproaches continuing hierarchical and separatist patterns of co-operation and allocation of responsibilities (2009, 363).

Long-term Care Insurance assigns care management – i. e. coordination and networking of related agencies, professions and actors – also to the new long-term care support bases as well as – on a more general level – to the municipalities. Future development will show if the long-term care support bases – that strongly depend on the long-term care insurance funds’ will to cooperation – will be able to fulfil this expectations. Municipalities, confronted with growing costs for means tested social assistance to care, more and more seem develop an interest to influence cost development also by assuming a stronger role in the governance of the local provision of long-term care.⁶³

Analyzing the financial situation of 3 “typical cases”

Note: The German system of social security is very complicated because of its fragmentation and segmentation. Therefore, the following estimations are prone to errors. Public social assistance may be underestimated. The services that may be obtained may be overestimated. Generally, local administrations have a lot of discretionary powers with regard to the benefits they grant. The presented examples are based on the assumption that all care receivers find access to the system and good counselling. This would be necessary to apply for all possible benefits. Application may result difficult due to complicate and bureaucratic application forms and procedures. Additionally, persons newly requiring care often find themselves in a difficult situation and under time pressure to make important decisions on the living arrangement. So, probably not all presented needs would be covered in the real world.

- Case A: Beneficiary A is an 80 years old woman, living alone, with a monthly income of 1200 Euros, and has the following needs:
 - 1 hour daily of nursing care;
 - daily meal delivery;
 - 4 hours a week of housekeeping.

Case A1: In the following vignette we assume that in the case-description above “nursing care” means medical care, e. g. changing thrombose socks or giving injections, to secure the aim of a medical treatment, or care to avoid a hospital stay.

We assume that Mrs A1 lives in a one-room flat in Berlin. This is important because prices for rents, meals and services differ throughout the country. She pays 300 Euro monthly for her nice apartment. Mrs A1 does not need social care but nursing care. So she does not qualify for long-term care insurance benefits. The health care insurer will pay for her nursing care. Co-payment for nursing care is 10 € per prescription and 10% of daily costs to a maximum of 28 days per year (we assume here: 6,80 monthly). Mrs A1 has to pay about 150 Euro per month for the daily meal delivery. The 4 hours of housekeeping a week are done by a neighbour. Mrs A1 pays her 20 a week, 80 Euro

⁶³ In order to enhance and strengthen the structures of care on the municipal level some German states (e.g. Hamburg, North Rhine-Westphalia and Berlin) stipulate the implementation of “care conferences”. The main task of these conferences is to participate in the development of care structures in the municipalities (the planning of care, the coordination of the tasks of all relevant groups and actors related to care). The care conferences can be considered as a direct reaction to the often criticised and unclear rules of responsibility in the long-term care insurance (Rosendahl, 1999: 157).

monthly. She considered charging a long-term care service provider to do the housekeeping because her neighbour is already in her 70ies and has difficulties to do the housekeeping for her. But as she does not qualify for long-term care benefits she would have to pay this on her own. Four hours a week of housekeeping include cleaning, the washing, shopping and would cost about 60 weekly. Therefore Mrs A1 dropped this idea.

Case A2: In the following vignette we assume that in the case description above nursing care means personal care, e. g. washing, teeth brushing, clothing, help to get out and into the bed, help to get to the toilet.

We assume that Mrs A2 lives in a one-room flat in Berlin. This is important because prices for rents, meals and services differ throughout the country. She pays 300 Euro monthly for her nice apartment. The only son of Mrs A2 lives 600km away. His wife is a nurse and she successfully encouraged Mrs A2 to apply for long-term care insurance benefits. She is categorized in care level I. So she could select between 440 Euros for benefits in kind or 225 Euros for cash benefits monthly. Mrs A2 opted for the benefits in kind and contracted with a non-for-profit long-term care agency. Its care workers visit her twice a day. They help her with the morning and evening toilet; they also do the housekeeping, shopping and cooking. The agency charges 362 Euro weekly for those services. So, monthly care and house keeping costs sum up to 1,450 Euro. The long-term care insurer pays 440 Euro. Mrs A2 has to pay 1,010 Euro monthly on her own, what is almost her complete monthly income. With her income of 1,200 Euro monthly she does not qualify for social assistance allowance. She neither qualifies for social assistance to care because this is means-tested, and Mrs A2 still owns about 60,000 Euro from the heritage of her deceased husband. So, Mrs. A2 will have to continue to pay privately for the care services not covered by the benefits of long-term care insurance until her heritage will be almost spent. (She might keep a basic asset of 2,600 Euro that will not be taken into regard by the administration). Then she may apply for social assistance to care. Depending on the income of her near relatives, she might qualify for about 590 Euro of social assistance to care. But as her son is working full-time as a teacher and his wife works part-time as nurse, her application for social assistance to care is denied. She becomes dependent on the financial support of her relatives. To save some money she goes without the daily shower she liked so much in earlier times.

- Case B: an 65 years old disabled man, living alone, with a monthly income of 400 Euros and has the following needs:
 - 2 hours daily of professional care (including: morning toilet, evening bedtime)
 - 1 hour daily of social care
 - daily meal delivery;
 - 4 hours a week of housekeeping;

Mr. B lives also in Berlin, in a socially disadvantaged neighbourhood. He rents a flat for 270 Euro per month. Lately, he passed two weeks in hospital after a fall. The social workers in hospital helped him with the application for long-term care insurance benefits. He needs three and a half hours support daily.⁶⁴ Nevertheless, Mr. B only qualifies for care level I, because long-term care insurance does not cover social assistance (communication, going for a walk, meeting other people). Mr. B has no relatives and little contact to his neighbours. So, he opts for benefits in kind. The agency charges 1,470 Euro monthly for the professional care and 390 Euro per month for housekeeping, in total 1,860 Euro. The long-term care insurance covers professional care and housekeeping services including cooking up to an amount of 440 Euro monthly. The difference of 1,420 Euro is covered by social assistance to care. Additionally Mr. B receives 350 Euro social assistance al-

⁶⁴ (2 hours professional care * 7) + (1 hour social care * 7) + 4 hours a week = 25 h /week = 3.57 hours daily.

lowance per month. The municipality does not pay for one hour daily of social care for Mr. B, because professional care shall include activation and communication. But the social worker from the municipal administration encourages Mr. B to talk to his neighbours more often. He also grants Mr. B a weekly visit of an employee of a low-threshold service. With this support Mr. B takes a walk through his neighbourhood once a week. This benefit is covered by the law on inclusion of disabled persons.

- Case C: Beneficiary C is a couple (Man 78 is sick of Alzheimer, Woman 77 is healthy), with a monthly total income of 1000 Euros, and have the following needs;
 - 2 hours daily of professional care (including: morning toilet, evening bedtime)
 - 1 or 2 days a week of day care;
 - 3 times a year, institutional care for the husband (vacations of the care-giving wife), total amount of 4 weeks a year;

Couple C rents an apartment for 600 Euro monthly. Mr. C was classified to care level I. This entitles him to 440 Euro per month for benefits in kind plus 220 Euro for day care. Day care may be more expensive, but this reduces the money for benefits in kind. Because of his Alzheimer's disease Mr. C has considerable limitations in daily competences. This has been assessed, too. So Mr. C is entitled additionally to a basic allowance of supplementary benefits of 1,200 Euro per year. He has to present bills to be reimbursed those 1,200 Euro. Mr. C further is entitled to 1,510 Euro per year for short-time care.

Mr. C uses long-term care services for 780 Euro monthly; one day a week he goes to a day care facility and one day a week he visits a group for persons with dementia. The four days of day care cost 320 per month. 50 Euro thereof are charged for so called hotel costs (living and food). They are not covered by the long-term care insurance. The four days a month in the dementia group cost 176 Euro. Thirty days of short-time care a year cost 2,700 Euro, thereof 450 Euro "hotel costs".

The long-term care insurance pays Mr. C 660 Euro a month for professional care and one day of day care per week. So, he has to pay 440 Euro per month privately for his care. Long-term care insurance additionally pays him 100 Euro per month to visit the dementia group. Mr. C's co-payment for this service is 75 Euro monthly. Long-term care insurance benefits for short-time care cover 1,510 Euro of the charged 2,700 Euro. So, Mr. C has to pay 1,190 Euro on his own for short-time care per year, roughly 100 Euro monthly. His co-payments for professional care, day care, the dementia group and short-time care therefore sum up to roughly 615 Euro per month.

Mrs and Mr C apply for social assistance to care. They have no children. They receive 620 Euro social assistance to care and 245 Euro social assistance allowance per month. In total, the municipality pays 865 Euro monthly for the subsistence of the couple, co-payment is 615 Euro and insurance benefits are 885 Euro.

2. Recent national reforms in HBLTC

The main reform of the German system of home based long-term care was the introduction of long-term care insurance in 1995.⁶⁵ Since then the system of home based long-term care was modified several times. This used to happen under extensive political debates, but without changing the basic principles. But in the long run a gradual change can be identified. Reforms and public debate regarded the following issues:

- the sustainability of financing of long-term care,

⁶⁵ Regarding some aspects long-term care insurance followed the construction of health insurance, but there is at least one important difference (for more compare Gerlinger and Röber 2009, 54-56): The principle of balanced financing by employers and employees as well as the principle of coverage of needs were dropped in long-term-care insurance.

- the assurance of quality,
- the coverage of needs and the design and provision of benefits,
- the governance of long-term care on the local level,
- cooperation and coordination of services,
- information, counselling and access to services,
- the ratio of institutional versus home care and the development of informal/ family care capacity.

Table. Regulation of long-term care in Germany

Year	Law	Issue	Comment
1965	Federal Law on Social Assistance	means tested basic assistance in case of care was introduced; obligation for municipalities to guarantee help and assistance to elderly citizens	
1989	Law on National Health Reform (Gesundheitsreformgesetz)	„little long-term care insurance“, introduction of home care and short-time care in cases of severe need of care	benefits eliminated with the introduction of long-term care insurance
1995	Law on Long-term Care Insurance	introduction of a compulsory long-term-care insurance (statutory social long-term care insurance as pay-as-you go, funded private long-term care insurance)	obligation to the type of insurance (social or private) followed the respective type of health insurance
2002	Caring Services Completion Law (Pflegerleistungsergänzungsgesetz, 1.1.2002)	Introduction of further benefits for eligible persons in need of care with considerable need of general supervision and care	
2002	Quality Assurance Law (Qualitätssicherungsgesetz, 1.1.2002)	Obligation of care facilities to an intern quality management	
2007	Statutory Health Insurance – Competition Fostering Law (Gesetzliche Krankenversicherung – Wettbewerbsstärkungsgesetz – GKV-WSG, 1.4.2007; parts later on)	Care might from now on be integrated in contracts on integrated care	
2008	Care Development Law (Pflegerweiterentwicklungsgesetz, 1.7.2008)	Beneath other: higher benefits (espec. for persons with special need for supervision, mainly dementia); index-linking of amount of benefits; joint use of benefits (“pooling”) to facilitate new living arrangements; obligatory transparency of external quality control; geriatric rehabilitative care as standard insurance benefit (to be paid for by the health insurance); opportunity of introduction of long-term care support bases for networking and counselling (care and case management), care counselling obligation of the funds, fostering voluntary work and self-help	But: no change in the concept of need of care and the systematics of care level assessment despite of recommendations of an expert board, no introduction of care budgets

Source: own table.

Many contents of the reforms have been reported in the antecedent chapters. In the following, the general direction of the development of long-term care in Germany is presented.

Sustainable financing of long-term care insurance

To guarantee financial sustainability is a basic goal of German long-term care policy. Deficits in the financing of the long-term care insurance have been balanced by raising contributions recently. An initial intention of introducing long-term care insurance had been to relieve the financial burden of municipalities. But their expenditures on assistance to care are rising again. According to many experts, enhancing insurance contributions will not assure financial sustainability in the long run.⁶⁶

Thus, the debate on the issue of pay-as-you-go versus funding is continuing. The coalition of Conservatives and Social-democrats of 2005 had projected to introduce complementary elements of funding as well as to establish a financial balance between social and private long-term care insurance (Rothgang, Kulik et al. 2009, 38ff.). Neither of these plans was realized (ibid.). The conservative-liberal coalition also formulated the intention to introduce funding as a complementary element of financing (CDU CSU FDP 2009, 93). The decision between both principles seems to be initiative for a fundamental debate of further principles of the German welfare system.

Regulating quality assurance

From the very beginning of the long-term care insurance, quality assurance has been an important aspect of reforms (Rothgang 2010, 448), emphasizing the inpatient care sector and widely neglecting home based long-term care:

With the Law on Quality Assurance (2002) in- and outpatient long-term care agencies were obliged to introduce internal quality management systems that aim at continuous improvement of quality. Those systems may apply top-down (standards and regulations) as well as bottom-up approaches (e. g. staff quality committees) of quality assurance. With regard to structural quality the development of procedures to define adequate staff ratios was prescribed. Measures of external control had also been subject to modification: For long the Medical Review and Advisory Board did only complaint-induced controls. With the Care Further Development Law (2008) annual inspections were made obligatory. Furthermore, the issue of transparency was addressed: The reports on the results of the external inspections are to be made public by the Medical Review and Advisory Board. This aims at enhancing quality efforts of care providers and at providing potential users with information.

With regard to informal care, there are only few regulations: In informal settings of long-term care that benefit from the long-term care insurance, regular⁶⁷ care counselling visits by accredited long-term care agencies are obligatory. These visits are criticized for low efficiency (Gerlinger and Röber 2009, 40).

Quality assurance is a controversial issue. From early on, quality standards early on have been criticized to be “minimal, [...] vaguely worded, and stress mostly structural issues, not outcomes” (Cuellar and Wiener 2000, 20 conferring to Pick 1998). Critiques still reproach the system for focusing on procedural and structural issues and neglecting outcomes. But also the concept of outcome itself is discussed. There is no consensus about the kind of outcome, e. g. medical outcomes versus quality of life, and the adequate ratio of objective and subjective outcome components. Furthermore, the lack of reliable and valid instruments for external quality control is discussed. Another issue of debate is the education of staff in long-term care and the professionalization of care work. Claims for higher professionalization are challenged by recurring suggestions of politicians (from the conservative as well as from the social-democratic party) to increasingly employ long-term unemployed persons in long-term care.

Yet, the maintenance of dignity of care recipients becomes more and more important in public discourse. One expression thereof is the “Charter of rights for people in need of long-term care and

⁶⁶ For an overview of the different financing concepts that are discussed cf. the final report of Heinz Rothgang for the Hans Böckler Stiftung (Hans Böckler Stiftung and Rothgang 2007).

⁶⁷ In care level I and II the visits have to take place every six months, in care level III every three months (§37 SGB XI).

assistance” of 2005, that was worked out during a several years long process by about 200 experts from States, local authorities, service providers, welfare associations, private service providers associations, insurers, scientists, interest organizations of senior citizens, and others. It is a point of reference for public discourse and additionally works over the self-binding of agencies to this agreement. Its application in a pilot benchmarking project as a measure to evaluate outcome quality in structured self-evaluations in the outpatient sector showed the necessity to discuss the range of responsibility of long-term care service providers against several tensions (Sulmann 2010, 5-7).

Coverage of needs, design and provision of benefits

Coverage of needs and design and provision of benefits were addressed by several reforms. The concept of need of care that was implemented with the long-term care insurance did not cover the needs of persons with dementia and similar conditions.⁶⁸ Their special care needs had been systematically neglected by the established assessment procedure. With the Caring Services Completion Law (2002) benefits were extended slightly: Persons categorized to a care level who additionally were in considerable general need of care were granted a small amount of money (460 Euro annually) for supplementary services. The Care Further Development Law (2008) extended eligibility to those who did not qualify for a care level but were in considerable general need of care. With the same law, the amount of most benefits was raised. The ratio of the financial value of benefits was not principally modified: Benefits-in-kind are still almost double as high as cash benefits in the respective care level.

Another issue is the structure of provided services. It is strongly connected to questions of need coverage and benefit provision. The supply of home based long-term care services follows the structure of benefits established by long-term care insurance to a great extent. Flexible living arrangements between in- and outpatient care as well as low threshold services of social assistance such as communication or company are underdeveloped. The Care Further Development Law included adaptations to permit more flexible living arrangements and – under strict conditions – to extend the coverage of benefits.⁶⁹

Parallel to these stepwise adaptations, an expert board had been charged by the conservative – social democratic coalition to principally evaluate the concept of need of care in the long-term care insurance as well as the related assessment procedure. The board suggested a fundamental change: The assessment of need of care should no longer be based on the time needed for care but on the evaluation of the restriction of a person’s independence (*Selbständigkeit*) (Bundesministerium für Gesundheit 2009, 44). This should contribute to better address the neglected needs of persons with dementia. A corresponding assessment procedure was also suggested. The ministry under social democratic leadership declared that the report and the suggestions were pointing the way, and commissioned the testing of the suggested procedure. Results were presented in May 2009 (Bundesministerium für Gesundheit 2009). After the elections in September 2009 the new conservative – liberal coalition also demanded a new and more differentiated concept of need of care in its coalition treaty (CDU CSU FDP 2009, 93), but up to 2012 without implementing it.

Governing local long-term care

Local governance is another issue of debate in the context of long-term care. Early on, with the introduction of long-term care insurance, some observers noticed a withdrawal of municipalities from designing local long-term care regimes (Ziller 1998, Gerlinger and Röber 2009). This was attributed

⁶⁸ A fundamental criticism argued that despite a quite comprehensive concept of care, the concept of need of care was reductionist, economically motivated and as well medically oriented (Priester 2004, 98). People in need of help and support would be denied the financing of benefits (ibid., 98). And people in need of care would be kept from certain services (ibid., 98), because of partial coverage and the definition of need of care that introduced a high threshold to qualify for services.

⁶⁹ Persons who are entitled to benefits and live close to each other might use their benefits together (the so called « pooling of services »). If this saves money and certain conditions are fulfilled they are allowed to buy services that generally are not covered by long-term care insurance in outpatient care (e. g. social attendance).

to the powerful position the law gave to the insurance funds and to the lack of budgetary and steering options left with the municipalities.

Reforms did not address this topic directly. Instead, in scientific and public discourses the responsibility of municipalities to shape the conditions for local arrangements of long-term care was increasingly emphasized. In some pilot projects municipal opportunities for action and innovative forms of local governance are investigated and tested. In those projects, municipalities often play a moderating or coordination role, aiming at involving other actors, e. g. for-profit and non-for-profit agencies, or at enabling the participation of the local population. Problems are to guarantee continuity or to secure financing in times of shrinking municipal finances. Apart from such projects, a clear municipal mandate for the governance of local long-term care still is missing. As a consequence, municipalities engage quite differently in the issue of local long-term care governance.

Coordination of services (care management), information and counselling (case management)

The long-term care insurance law introduced a cooperative element in the provision of long-term care: it made the provision of long-term care a task on which insurers, States and municipalities should work jointly (§ 8 SGB XI). Yet, in professional and scientific discourse, the missing of coordinated services in the sense of care and case management was criticised over the years (SVR 2009). The Care Further Development Law (2008) enabled the States to regulate the establishment of Long-term Care Support Bases by the insurers and so introduced an element of a community care-approach: The Long-term Care Support Bases should coordinate services and involve the respective actors as well as voluntary initiatives on a local level.⁷⁰

Other critique referred to a lack of equal and easy access to information and independent and comprehensive counselling on issues of long-term care. Additionally, patient pathways are often criticized to be unclear because of fragmented health and long-term care delivery. There is no clear responsibility for case management in the German system. In practice, this task sometimes is performed by highly engaged professionals, e. g. social workers in long-term care agencies or general practitioners. The Long-term Care Further Development Law addressed this issue by charging the Long-term Care Support Bases to provide independent and comprehensive information and counselling on all issues related to long-term care insurance to people (probably) entitled to benefits and their relatives (§ 92c SGB XI). Additionally, insurers are obliged to provide an individual, comprehensive and professionally qualified care counselling (§ 7 SGB XI). This may be regarded as the first element of a right to case management for persons entitled to benefits.

During the legislation process the introduction of Long-term Care Support Bases was highly controversial. The conservative party opposed. It argued that the establishment of such Support Bases would result in double structures in those municipalities where similar institutions would already exist. The finally adopted compromise enabled the States to decide on the implementation of such Support Bases. Meanwhile, all States have opted for the establishment of Long-term Care Support bases apart from Saxonia and Saxonia-Anhalt. The implementation and provision as well as the resources granted (Schmidt 2008) are quite diverse. Due to this, the evaluation of the potential of Long-term Care Support Bases to coordinate services, provide an efficient care management and comprehensive counselling is still to be expected.

Another debate, referring to the general fragmentation of the German system of health and long-term care delivery and the coordination of services, concerns the relation of health and long-term care insurance.⁷¹ Gerlinger and Röbler provide a compilation of pros and cons given in the debate on a unification of both systems (2009, 146-147 referring to IGES 2002, SVR 2005, AOK-Bundesverband 2001, Rürup-Kommission 2003: 212 ff. and Rothgang 2007: 20f.). Major reforms

⁷⁰ The new law also allowed the actors who run the Long-term Care Support Bases to agree on contracts on community based integrated care to achieve better coordinated structures.

⁷¹ Major interface problems for example are identified with regard to nursing care at home (*häusliche Krankenpflege*) and the implementation of the priority of rehabilitation over long-term care.

on this issue have not been made. But with the Long-term Care Further Development Law (2008) geriatric rehabilitation was defined as a standard insurance benefit (no matter of discretion); regulated by law every (old) patient now is eligible to it.⁷²

Informal care (familiar care and voluntary work), priority of outpatient over inpatient care

From its beginning the long-term care insurance law was constructed as complementary to informal care. But soon it was criticized for insufficient support for caring relatives (Zeman 2002, 153-154). The Long-term Care Benefits Supplementing Law (2002) (Pflegeleistungsergänzungsgesetz) and the Long-term Care Further Development Law (2008) (Pflegeteilerweiterungsgesetz) included reforms to support family care and voluntary work and to maintain a priority of outpatient over inpatient care also for the increasing number of persons with dementia. In 2002, insurers were obliged to provide financial resources⁷³ to establish local pilot projects aiming at qualifying and employing voluntary helpers in low-threshold services for persons with dementia. Insurers, States and municipalities had to agree on the mode of co-financing. In 2008, respective services for people in need of care and their relatives as well as for self-help were included. The compatibility of employment and family caring should be enhanced by care leave, introduced in 2008: employees who care for near relatives may claim their exemption from work for up to a maximum of six months; they are not paid salary during this time.

Debates concerning these reforms focused on the qualification of voluntary helpers as well as on a pertaining lack of support for caring relatives. Again, implementation of the introduced reforms is diverse on the level of the States.

The described measures to support outpatient care have not been successful in reducing the institutionalization rate: Since the introduction of the long-term care insurance, the share of beneficiaries who received full-time institutional care has grown, whereas the share of those who receive home based long-term care decreased slightly (Bundesministerium für Gesundheit 2009).

Analysis of the process of change

For long, in Germany the need of long-term care had been subjected to private engagement. Publicly it was only covered by a «means-tested arrangement» (Götting, Haug et al. 1994, 285). During the 1970ies and 1980ies this increasingly was debated. It was criticized that need of care often lead to impoverishment and dependence on means-tested social assistance (Pabst 2002, 129; Roth and Rothgang 2002, 46). The introduction of long-term care insurance in contrast acknowledged need of care to be a general risk in life that should be socially secured on the basis of a solidarity principle. Thus, one may judge that a shift in the societal definition of the risk of need of care had taken place. This may be regarded as a shift in the prevailing policy paradigm according to Hall's definition (1993, 279).⁷⁴ During the implementation of this paradigm shift, several modes of institutional change according to Mahoney and Thelen (2010, 15-16)⁷⁵ were actualized. Layering seems to be the predominant characteristic of change, but there was also some displacement of rules:

⁷²At the present it is not clear whether the law "works" as intended or not. The problem is: The payers of the geriatric rehabilitative care are the health insurance funds and not the long-term nursing care funds.

⁷³ Insurers had to provide annually 25 Million Euro for the « further development of the caring infrastructures ». This money to be co-financed by States and municipalities, so that in total up to 50 Million Euro would be available. (§ 45c SGB XI)

⁷⁴ Hall argues that « policy makers customarily work within a framework of ideas and standards that specifies not only the goals of policy and the kind of instruments that can be used to attain them, but also the very nature of the problems they are meant to be addressing. [...] I am going to call this interpretative framework a policy paradigm » (1993, 279).

⁷⁵ Mahoney and Thelen suggest the analytically differentiation of four modes of gradual institutional change: displacement – "the removal of existing rules and the introduction of new ones"; layering – "the introduction of new rules on top of or alongside existing ones"; drift – "the changed impact of existing rules due to shifts in the environment"; and conversion – "the changed enactment of existing rules due to their strategic redeployment" (2010, 15-16).

With the introduction of the long-term care insurance scheme new rules were installed alongside existing ones (*layering*): Means-tested social assistance to care had not been abolished. But with the (capped) benefits guaranteed by social insurance its significance was reduced.⁷⁶

With regard to the organization of service provision before the introduction of long-term care insurance, public and non-for-profit providers had been preferred by the law. Under the new scheme, this was replaced by the introduction of provider competition (*displacement*). As a consequence the steering instruments that were available to municipalities and the States changed: Before they could influence the development of the local caring infrastructure by financial incentives. Their formerly quasi-monopolistic position allowed them to determine quantity, quality and prices of long-term care supply (Pabst 2002, 132). Now, especially municipalities only command over soft instruments like coordination, moderation, negotiation and networking in the governance of local policies of long-term care.

Additionally, with the long-term care insurance the principle of covering costs had been removed in favor of the principle of performance accounting (*displacement*). This quasi-taylorisation of services affects the performance of services and deepens the cleavage between familiar care cultures and professional ones (Pfau-Effinger, Och et al. 2008).

Once established, the institution of long-term care insurance was reformed several times but did not experience profound changes: The implemented reforms mainly worked according to the logic of layering. Basic rules introduced with the long-term care insurance had neither been removed nor neglected, but new ones were introduced. Examples are the extension of the scope of beneficiaries (stepwise including the needs of persons with dementia), the denser regulation of quality aspects and, recently, modest approaches to strengthen the consideration of the perspective of beneficiaries in quality assurance.

The introduced adaptation of the level of benefits may also be regarded as layering. The respective mechanism is very soft and leaves a lot of discretion to the legislator. Furthermore, the core principle – long-term care insurance expenditure might not exceed its income – has not been changed. Nevertheless, with regard to financing one could also judge the respective reforms as a kind of institutional «drift» according to Mahoney's and Thelen's analytical frame: With an increase in the number of persons demanding long-term care services the existing rules will endanger the possibility to maintain the rule of cost redemption.

With regard to the question to what extent the introduction of the German long-term care insurance followed the logic of the German health insurance scheme there are different judgements. Some authors claim a general path dependency (Campbell 2002), or at least acknowledge some path dependency with respect to corporative negotiations that connected a shortening of health insurance benefits with the prospective introduction of long-term care benefits (Alber and Schölkopf 1999, 158-159). Alber and Schölkopf criticize this argumentation to be too deterministic (ibid., 159)⁷⁷ and emphasize some institutional tensions between the principles of long-term care insurance and those

⁷⁶ This is only valid under several restrictions: Although the municipalities had to pay less for social assistance, the reduction of the risk for persons in need of care to be dependent on social assistance to care, especially in the inpatient sector, had fallen short behind the expectations. Recently municipalities are worrying again about rising expenditures that result from partial coverage in long-term care insurance.

⁷⁷ Alber and Schölkopf instead point to a bunch of other decisive factors that influenced the introduction of the new policy solution: the complexity of the actors network involved, the strong veto-points in the German corporatist parliamentary system, German unification as external factor that strictly tightened financial room of manoeuvre, upcoming elections as well as some core beliefs of German social policy like self determination and competence up to old age and the aim to strengthening instead of substituting familiar care capacity (ibid., 159-160). Their argumentation goes that the complexity of the actors-network in this field leads to the necessity to build broad coalitions to guarantee a majority in both houses of parliament (ibid., 159). This again had led to often surprising changes in position of single actors and there consequently could not be established fixed preferences for a certain model (ibid.).

of the German social insurance model (ibid., 161).⁷⁸ They attribute explaining power to interests of the involved actors under the financial pressure of German unification as well as to the integration

With regard to the content, long-term care insurance, the new established branch of social insurance, followed the already existing structures in the German health insurance scheme in many aspects (Campbell 2002, 164-165): It was – and still is – dually financed by income-based contributions from employers and employees (pay-as-you-go-principle) and by investments of the States on infrastructure. As new institutions the long-term care insurance funds were established under the roof of the existing health insurance funds (§ 46 SGB XI). For the assessment of need of care the new funds were obliged by law to draw on the pre-existing Medical Review and Advisory Board of the health insurance funds (§ 18 SGB XI).

Yet, some remarkable differences in the construction of long-term care insurance compared to the established regime of health insurance may be noted (Gerlinger and Röber 2009):⁷⁹ above all the rejection of the principle of commodity coverage and the de-facto rejection of the balanced financing by employers' and employees' contributions,⁸⁰ as well as the definition of the rate of contribution only by law, not through the funds (ibid., 55).

Gerlinger and Röber resume that reforms till today have been characterized by a priority of cost redemption and strengthening efficiency of the system under restrictive financial conditions with a focus on quality issues (Gerlinger and Röber 2009, 147). They suppose that this way of incremental change will continue (ibid., 148).

3. The national structures and the issue of policy change in the domain

Characteristics of the structure of the German home based long-term care system are:

1. Regarding the home based long-term care system in general:

- Horizontal fragmentation. The system is highly fragmented and consists of different pillars (long-term care insurance, social assistance to care, private payments, health care insurance) and involves different actors (federal and State level, leading to the need of joint-decision making (Scharpf 1988), long-term care insurers, providers, local authorities, health insurers, employers, employees) or the same actors in different interest constellations. Thus, *comprehensive reforms* at the federal level have to pay regard to a bunch of diverging interests. Broad majorities are necessary for reform what makes compromises probable and innovation more difficult. Generally, in great part of the involved actors (apart from providers and users of services) there is a strong interest for cost containment. With the insurers important financiers of benefits are given a relatively powerful position in the system. Lobby of those who need services of home based long-term care is small and weak. Under electoral point of view they are no group of big interest.

2. Regarding long-term care insurance:

- Vertical fragmentation. Long-term care insurance is characterized by loosely regulated standards of services (recommendations) on the federal level, collective bargaining of funds, providers and local authorities at the State level (Alber 1995, 136-137) and relatively little

⁷⁸ They argue that long-term care insurance deviates from the principle of equivalence of social insurance (where benefits depend strictly on contributions, whereas in long-term care insurance benefits do not follow the paid contributions) ; in their judgement the participation of employers in financing is less plausible in long-term care insurance, than other social insurance schemes, because the contribution probably won't lead as incentive to maintain labour force [this might be doubted] ; furthermore, they find it difficult to realise the principle of adaptation of benefits to the general development of net incomes because benefits themselves are financing services whose prices dependent on the development of net incomes (Alber and Schölkopf 1999, 161).

⁷⁹ For a detailed comparison conf. Gerlinger and Röber (2009, 53-56; 73-78).

⁸⁰ During the bargaining process this had been a sharp debated issue, with the employers' side rejecting any payment and lobbying for a private funded model (Alber and Schölkopf 1999, 143). Finally, balanced finance was accepted, but employees had to renounce their right to one official holiday. This measure that had to be implemented by the States, Saxonia was the only State that rejected, so that employers here had to pay higher contributions.

room for decision at the municipal level. As for reforms on the federal and State level broad coalitions of actors are needed, comprises are foreseeable and innovations less probable.

The room for manoeuvre of local authorities for innovative measures of implementation is little what also will hinder innovation. As they command only over some soft instruments of governance of the local care regime innovation will be more probable in the realm of communication, e. g. the development of voluntary standards and models, and implementation practice than with regard to the setting of binding norms and new regulations.

- Horizontal fragmentation. At the State level there are differences in the results of collective bargaining with regard to the definition of service and prices as well as regarding policies of investment in caring infrastructure.

3. Local social assistance to care:

- Horizontal fragmentation. There is a general pressure to cost containment, but financial conditions of States and local authorities are diverse. There supposedly is a contradictory pressure to innovation at the local level: While richer States and municipalities have more resources that they can invest in reforms or concrete implementation, the poorer municipalities are likely to be affected more by rising costs of assistance to care because there lives the poorer population. So, pressure to cost containment in the latter will be high. But in the face of the foreseeable rise in age poverty and alongside this rising numbers of persons in need for assistance to care, they perhaps will also be conscious about the need to prevent future cost rising. This could lead to openness to innovation of poor States and municipalities (rather to cost containment than to expenditure expansion). Given that in the richer municipalities a need for innovation is seen, they might be more open also to cost entailing innovation.

The described structure of opportunities for reform can also be observed in the last reform. It was controversially debated between the federal and the State level⁸¹ what resulted in compromises and in room for decision for the States. An example is the case with the implementation of the newly introduced “long-term care support bases”. The introduction of a regular adaptation of benefits, as a second example, did not concede implementation power to the States, but left future governments with lots of room of decision.

4. The national HBLTC system and our analytical criteria

Finally, we will give a short and summarizing overview over the implications of the German system of home based long-term care for our analytical criteria governance, quality assurance, complementarity and methods of coordination as well as beneficiary participation.

1.a. Governance

With regard to the governance of the system of home based long-term care, it should have become clear, that governance in Germany happens under the restricting framework of joint decision making of the federal and the State level, in case of long-term care connected with a strong corporatist component. A main feature of the German system is the high degree of fragmentation of the system. Thus, different actors are subject to different logics and regulations what makes comprehensive governance even more difficult. The principle of provider competition leaves little room of decision on the development of caring infrastructure to the political realm. At the federal level, a general framework is regulated. Main issues, e. g. quality assurance, are set on the agenda, and measures for cost containment are guaranteed. The concretion of the provided framework is left to the bargaining

⁸¹ One example was the “long-term care support bases”. They shall provide counselling and local network coordination and help to integrate services. So, they may be regarded as an innovative instrument. As a result of the political bargaining process, the decision over their implementation had been left up to the States; law regulated a limited start-up financing by the insurers. Simultaneously the federal government temporally financed the start-up of 16 pilot-“long-term care support bases” with 30.000 Euro per support base.

of providers, insurers and local authorities' associations at the federal and State level.⁸² Thus, governance-related innovation at the federal or State level that is concrete and binding throughout the country would need broad coalitions and is little expectable. More expectable are general regulations that have to be implemented locally. Municipalities command only over soft instruments to govern the concrete shape of the local system of home based long-term care. But within this limited spectrum of opportunities, varying implementation and, thus, innovation at the local level is quite probable.

1.b. Quality assurance

During the fifteen years long history of long-term care insurance in Germany, quality assurance became an increasingly addressed and regulated issue. Altogether, top-down concepts of quality assurance predominate, while in the same time concretions of the generally given framework⁸³ are left again to the bargaining of providers, insurers and local authorities at the State level. Beginning with the requirement of the agreement on general recommendations, further reforms introduced

- the obligation of care providers to implement systems of internal quality management,
- the development of expert nursing guidelines (e. g. decubitus prevention, wound treatment),
- more frequent extern quality controls as well as
- the publication of reports on the aggregated results of such controls.

Yet, there remain limitations of the current system of quality assessment, as there are:

- the coverage of quality measures is mostly restricted to one single care sector (e.g. residential care) – overarching quality management instruments (for whole pathways) are still to be developed;
- similar to international scientific (public health/health services research) debates, the question of how to measure outcome quality of complex interventions as e.g. LTC remains unsolved. Available indicators and instruments often concentrate on rather narrow outcomes (e.g. decubitus prophylaxis) or structural or procedural quality parameters. Due to these measurement problems, the effectiveness of quality management as a steering instrument for proving good quality remains limited.

The “Chartha of rights for people in need of long-term care and assistance” (2005) may be regarded as a new and innovative, qualitative instrument of quality assurance.

1.c. Complementarity and methods of coordination

Complementarity of services and methods of coordination are a weak spot of the German system of home based long-term care. Different sectors (e.g. in-patient and out-patient care) are divided by barriers of different financing and regulation rules. Standards for local integrated pathways, e.g. for hospital discharge or home care arrangements, are often missing. Local authorities lack a clear legal mission for the steering of local long-term care. Care and case-management for long time have not been implemented in the long-term care insurance or as a task of local authorities. For long-term care these circumstances often lead to unclear patient pathways and intransparent choice options. An initial approach in this direction was only recently introduced with the right to comprehensive care counselling by the long-term care insurers and the long-term care support bases that should assume coordinating as well as counselling tasks. Cultures of inter-professional and inter-organisational cooperation and intermediate respective integrated care forms are underdeveloped. In

⁸² Gerlinger and Röber point to the simultaneously significance of market and competition principles on the one hand and a very high degree of regulation on the other hand (e. g. with regard to price negotiations) (2009, 23)

⁸³ As e. g. the definition of procedures to define adequate staff ratios or the negotiation of prices which are likely to have implications on quality outcomes.

most municipalities there is a lack of local negotiation processes and established local coordination structures as round tables etc.

1.d. Beneficiary participation

Legally, long-term services under the long-term care insurance scheme are meant to help the care requiring person to live an as independent and self-determined (autonomous) life as possible, that corresponds to human dignity (§ 2 SGB XI). In practice, autonomy may be endangered by several factors like the quasi-taylorisation of services and the concentration of benefits on activities of daily living (ADL) and instrumental activities of daily living (iADL) that underaddress needs for social attendance of many beneficiaries. Thus, even though activation and involvement of the care requiring person is an important and acknowledged concept in nursing care sciences, the spectrum of services that are actually covered by long-term care insurance seems to make its realisation difficult.

The “Charter of rights for people in need of long-term care and assistance” (2005) may also with regard to beneficiary participation be seen as a new and innovative, qualitative instrument whose effects in the long run will have to be established.

Regarding quality assurance, beneficiaries’ participation only recently is to be taken into account in the obligatory quality inspections that also include subjective evaluations of beneficiaries.

Another important principle of German long-term care insurance is free choice: Beneficiaries are free to select between cash benefits or benefits-in-kind. If they opt for the latter, they are free to decide on the care provider whose services they would like to use. The freedom to change service providers shall enhance the providers’ competition and striving for quality. Yet, measures to guarantee free choice of service are rare.⁸⁴

⁸⁴ Lack of useful and manageable information for beneficiaries is an often reported problem, even though long-term care insurers were obliged to provide applicants with a list of care service providers and their prices in the respective catchment area. Additionally, persons requiring professional care often find themselves in the necessity to make decisions in shortage of time, under difficult and unsettling circumstances, e. g. after a fall in hospital. Guidelines for hospital discharge and transition from in- to outpatient sector at the local level are often missing or not working. Thus, there seems to be a lack of guidelines for the finding of adequately profiled care providers. Against the background of provider competition, in practice providers sometimes doubt neutral counselling and imply recommendations to certain services or even corruption.

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The Scottish system of home based long-term care for the aged (HBLTC)

1. General structures of the Scottish home-based long-term system for the aged

In Scotland home based long-term care for the aged should be free of charge since 2002. The Scottish local authorities provide free personal care and nursing care to people who continue to live in their own homes or need residential care. In the Scottish context, personal care is defined as care dealing with needs which give rise to major additional costs associated with old age, e.g. help with personal hygiene, eating and drinking, managing problems associated with immobility, management of prescribed treatment, continence management and personal assistance such as help getting up and going to bed¹. Nursing care means care which involves the knowledge or skills of a qualified nurse². Those services are not means tested.

"Free personal care is available to people aged over 65 who have been assessed by social work as being in need of such care. Entitlement is therefore based on age and assessed need and payments are made irrespective of the individual's capital, income and marital status. Payments cannot be made for people who have not undergone a needs assessment or who have been assessed as not needing personal care services. Individual assessments can be requested from the local social work department" (Robinson 2009:3).

a. Historical development

Free personal care was one of the first flagship policies of the newly-formed devolved Scottish Parliament, which was established on July 1, 1999. Before the Scottish Parliament assumed its full powers a Royal Commission on Long Term Care was set up to had examined reform options in the UK. The Commission submitted its report "With Respect to Old Age" (the Sutherland Report) to the UK Parliament on March 1, 1999.

The Commission found that the previous system in the UK was unsatisfactory since too many people went into residential care. Besides, free help was only available to the poorest while the system led to the impoverishment of people with moderate assets. The issue of unmet needs was as well addressed and attributed to the inability of some local authorities to provide the required services. Very important disparities among the various local authorities were an important pattern of the situation in the UK. It is discussed in the British public space as "postcode lottery". The Commission thus recommended that nursing care should be provided without charge and personal care should be available after assessment, according to needs and paid for from general taxation. Concerning residential care, hotel costs should be co-paid according to means. According to the majority report, personal care should be free at the point of delivery and should be integrated into the National Health System. This was said to be the only way to establish "diagnostic equity" according to which a patient suffering from Alzheimer's shouldn't be disadvantaged or less covered than a person sick of cancer. According to the minority report, a measure of public financing of personal care would only benefit to the richest

¹ David Bell, Alison Bowes, Free Personal Care for Older People in Scotland: Issues and Implications, Social Policy & Society 6:3, Cambridge University Press 2007, p. 435-445, p. 436; Independent Review of Free Personal and Nursing Care in Scotland, a report by Lord Sutherland, published by the Scottish Government (Independent Review), April 2008, <http://www.scotland.gov.uk/Topics/Health/care/17655/SutherlandReview>, p. 16.

² Independent Review, p. 16.

part of the population, as the costs were already covered for the poorest part of the population. The English government made use of this argument to justify its decision not to take action in the aftermath of the report. Because of very high real estate prices, the older population is in the UK considered to be “asset rich”, as the rate of home owners is high, but rather “income poor”, as the British pension system is rather poor. Assets are considered in the calculation of the means tested entitlement to free care in the regular system of the United Kingdom. With a limit of 23 000 £, most home owners are not entitled to any help, besides disability schemes which are not means tested. As a consequence, frequently older people have to sell their homes in order to finance their care needs (Bell, Bowes, forthcoming 2012). Differing from the English government, the Scottish one accepted the majority report, took the next step and passed the relevant legislation in 2002, the Community Care and Health (Scotland) Act. Previously only nursing care had been free in Scotland. Funding of personal care at home was at the discretion of local authorities. In practice, some councils provided personal care at home after means testing. People whose resources were below certain thresholds received personal care for free.³

The widely acclaimed reform of the Scottish care system based on the Free Personal & Nursing Care (FPNC) policy was introduced on July 1, 2002. The legislation did not immediately change the system of care services but addressed the charges for such services. Since July 1, 2002 Scottish local authorities have to provide personal care to people who live at home free of charge and make flat-rate payments to care home operators who provide personal care to their self-funded clients, i.e. people who have the funds to pay for their care home accommodation themselves. The situation of people who are not able to pay for their care was not affected as the services they get remains funded.

FPNC is regarded as the “flagship” scheme among the Scottish specific social policies that were developed in the aftermath of devolution (Williams, Rooney: 2008; Viebrock, 2009; Keating: 2010). It has been very intensively advocated for by the central Scottish government as an important part of the specific identity of Scotland. This scheme has as well been part of a general strategy of “changing the balance of care”, aiming at increasing the proportion of people receiving domiciliary care and lowering the number of older people spending long stays at hospitals (bed blocking) or in residential care institutions. In the meantime, this perspective has been further developed as a general strategy of “shifting the balance of care” (www.shiftingthebalance.scot.nhs.uk) linking the issues of prevention (“anticipatory care”), of coordination (“continuous and integrated care”), and promoting community care.

b. Horizontal and vertical repartition of responsibilities and tasks

aa. Local authorities

According to the law, Local Authorities (LA) have to provide free personal care to all entitled person, i.e. person aged 65 or older. Personal care will only be available after a person’s need for care has been assessed by the local authority. There are 32 local councils in Scotland at the moment. They are the local administrative authorities generally responsible for providing political leadership and governance for a comprehensive range of services. Most of the LA, specifically in the urban areas, provide care services themselves. LA can as well commission private providers, lastly, they can as well contract with beneficiaries about direct payments (cash

³ Auditor General for Scotland, Accounts Commission, prepared by Audit Scotland, A review of free personal and nursing care in Scotland (Auditor General), January 2008, http://www.audit-scotland.gov.uk/docs/health/2007/nr_080201_free_personal_care.pdf, p.10.

transfers), which is rather poorly developed by now.

80% of the finances for the Free Personal Care scheme comes from grants by the central Scottish government. 20% is covered by the general budget of the Local Authorities. Initially, Edinburgh financed FPNC as a “ring-fenced” budget meaning that the Local Authorities couldn’t use this money to other purposes. Ring fencing has been abolished a few months after the introduction of the scheme.

There are many disparities affecting care provision by LA. In the first place, the urban structure affects much the costs of care delivery. In rural areas, long ways to the individual patients consume more time of the care-givers. Wage costs making most of the cost of home care delivery this surplus in time explains the higher costs in less dense areas. Secondly, the grants transferred by the central Scottish government do not cover the needs in any locality of the country. Councils have consequently to compensate for this by using some other sources of income. As LA in Scotland have no real fiscal autonomy, they have to use part of the budget they should dedicate to other competencies (culture, education, construction, waste collection service, etc.). Thirdly, important differences come from the variation in experience with the very activity of domiciliary care delivering. Bigger or better organized LA had developed such services for decades. Professional teams have been functional for long, as well as services managing timetables, co-ordinations, etc. Less experienced local authorities had to develop services, recruit, train, learn, etc. in a very short time. Costs have been very high during this period of intensive building and learning.

Finally, the consequences of these disparities on the access to services are important for the beneficiaries themselves. The law compels the Scottish local authorities to provide free personal care at home. Even if a list of services or of needs that should be covered by this notion of free personal care is widespread, local authorities concretely regulate the relations between their resources and the needs they have to cover both in the range of services they make available to the care receivers and in the entitlements granted to people in need via the assessment system. The “post code lottery” has survived the introduction of the FPNC (interview, Stirling University, 05.01.2011) even if inequalities have been reduced. There have been many disputes, and oppositions for example about the definition of meals (food preparation or delivery). The standardization of services themselves, both in terms of definition and in terms of quality, as well as the reduction of inequalities in access due to a long waiting list in some Scottish local authorities have been the most salient shortcomings of the FPNC policy demonstrated in the first national reviews of the program (Auditor general for Scotland: 2008). These evaluations as well demonstrated that the central government financing was not sufficient to cover the expenses of the local authorities. From these results the central government of Scotland launched an important bargaining with the local authorities. The government would, from 2008, complement its financing of the care expenses, but all local authorities would have to homogenize their service delivery and to cut the waiting list to improve the accessibility to the service.

bb. COSLA- Convention of Scottish Local Authorities

The Convention of Scottish Local Authorities (COSLA) is the organisation coordinating and representing the interests of the Scottish local authorities. It plays an important role in that matter of care delivery harmonization and of improvement of the consistency of the policy. This institution both assesses the disparities in the services provided and acts as an interface between the Scottish government and the local authorities. It plays an active role in the improvement strategy of improvement of the care policy by the Scottish government (Interview, Care Commission 07.01.2011 ; Interview Cosla 08.03.2011). The Joint Improvement Team is a body

of the central government of Scotland. It has been developed as an operational agency supporting the local authorities in their strategies of implementation of the most ambitious policy programs they have to implement. Free Personal Care is one of those ambitious and costly program.

cc. Regulation and coordination bodies

see quality insurance.

Domiciliary care

Care at home has traditionally been provided by local authorities. However, in recent years the number of private and voluntary sector agencies offering home care has increased. At the same time the range of services has been broadened and in a many areas care services are available 24 hours a day.

dd. The NHS' role

The NHS only supports the local authorities when general health services are needed in the process. Its structure in Scotland has changed considerably. The National Health Service Reform (Scotland) Act 2004 abolished NHS Hospital Trusts, NHS Primary Care Trusts as well as local Health Councils and required each local NHS board to introduce Community Health Partnerships (CHPs).

These CHPs are responsible for providing health services to the people who live in the health board area by working with local authorities, the voluntary sector and other stakeholders. Their exact make up may vary but CHPs are generally responsible for managing GPs, hospitals, community based health services, pharmacists, dentists and opticians. There are currently 37 CHPs in Scotland. In areas where CHPs are integrated with the local authority they are called Community Health and Care Partnerships (CHCP) or Community Health and Social Care Partnerships (CHSCP). Funding of CHPs is derived from local health boards.

A new service partnership, the Independent Advice and Support Service (IASS), was founded by Citizens Advice Scotland and local health boards in 2007. It is funded by local health boards and situated at local Citizens Advice Bureaus (CAB). The IASS replaces the local health councils and gives independent advice about health and social care services.

The division of labour between the NHS and the personal care services is both intricate from an organizational point of view, but it is as well complicate from a financial point of view. The NHS rests on very strong positions within the institutional framework organizing care in all of Britain. The situation in Northern Ireland is to some extent clearer as the NHS does both the job of care provision both for personal care and for nursery care. In Scotland, despite the transformation of the NHS structures, there is a strong competition between both services (Interview, Care Commission, 06.01.2011). Specifically, the decrease in occupied geriatric beds and the improvement in the circulation of patients has not brought about any monetary transfer from the NHS to the personal care sector. The joint commissions supposed to better coordinations between both sectors at Scottish level are still doing rather formal work. The day-to-day coordinations are still poor. This is specifically the case concerning patients needing care in a post-hospitalization period. The NHS is often criticised for being reluctant to organize a prompt transition with home based care in the framework of FNPC.

ee. Practitioners and Carers

In Scotland, service provision is organized at the level of local authorities. In Scotland, the tradition of public, local authority run social work services has developed from the end of WWII and had resisted, better than in England, the wave of privatisation of the 1980's and 1990's. In the various Scottish local authorities, care services can be provided by the social work departments of the local councils, by private providers or by voluntary sector organisations. Local authorities can also make arrangements for private or voluntary sector organisations to provide care on their behalf⁴. Care services are provided by the local councils themselves as well as private agencies. For example the Moray Council Home Care Service employs around 350 home carers⁵. These care officers are subject to a Disclosure (Scotland) search before being considered for a post, to ensure that nobody with a record of abusing vulnerable people is offered a job⁶.

All care services have to be certified by the Care Commission and continuously fulfil the conditions of section 29 of the Regulation of Care (Scotland) Act 2001, the National Care Standards and other relevant legislation⁷. The key regulation concerning care services is the Regulation of Care (Scotland) Act 2001⁸.

Regarding the fitness of care providers section 6 subsection 2 of the Act states that a person is not fit to provide a care service if he/she "is not of integrity and good character". A person who has been convicted in the UK or elsewhere of any offence which is punishable by a period of imprisonment of not less than three months and has been sentenced to imprisonment for any period without the option of a fine can also not provide care. The same applies to a person whose estate has been sequestered in Scotland or has been adjudged bankrupt elsewhere than in Scotland or in relation to whose estate a judicial factor has been appointed or who has granted a trust deed for the benefit of the person's creditors. This very light requirements are fit to care-givers benefiting from direct payments. All companies, associations, public services etc. providing care tasks on an organized basis have to compel to much more demanding criteria and control.

According to section 9 employees of care services also have to be physically and mentally fit for the purposes of the work in the care service. They are also required to have the qualifications, skills and experience necessary for care work.

Managers of care services are required in section 7 subsection 2 to fulfil the requirements of section 6 subsection 2 as well as additional conditions. The care-giver thus has to be physically and mentally fit to manage the care service but more importantly the manager has to have the skills, knowledge and experience necessary for managing the care service.

In practice, people working in domiciliary care will receive vocational training. The Scottish Social Services Council (SSSC), which was established in October 2001 by the Regulation of Care (Scotland) Act, is responsible for registering people who work in the social services and regulating their education and training. There are degrees in social care but not everyone has to have a social care qualification before taking a job. Most employees will be obliged to do work-based qualifications corresponding to the level of responsibility.⁹

⁴ Age Concern and Help the Aged, Factsheet 41s, Local authority assessment for community care services (Age Concern and Help the Aged 41s), p. 6, available at www.ageconcernandhelptheagedscotland.org.uk/documents/460.

⁵ http://www.moray.gov.uk/moray_standard/page_39826.html.

⁶ <http://www.north-ayrshire.gov.uk/SocialCareAndHealth/HelpForAdults/HelpForAdults-Care/Care-AtHome.aspx>.

⁷ http://www.carecommission.com/index.php?option=com_content&task=view&id=47&Itemid=76.

⁸ http://www.opsi.gov.uk/legislation/scotland/acts2001/asp_20010008_en_1.

⁹ <http://www.sssc.uk.com/sssc/social-service-careers/working-in-social-care.html>.

ff. Information and Counselling

The Scottish Government has put great emphasis on making information about the care system available for people who may be needing assistance. A lot of information can be found online, e.g. on the websites of the Scottish Government¹⁰, the Care Commission and local authorities.

Every care service also has to provide its customers with an introductory pack.

After an informal super-complaint by the Which Consumer group, which criticised the lack of clear information on the care system, the Office of Fair Trading on the UK Care Home Sector took action to provide ready access to clear and relevant information. The Scottish Government then set up a Steering Group which carried out a feasibility study. Since 2009 the Health Information and Self Care Advice for Scotland (NHS24) has provided a website¹¹ and a local rate telephone helpline.

gg. Decision making procedures/needs assessment

Free personal care is available to anyone aged 65 years or older after a care needs assessment. This needs assessment is sometimes called “care assessment”, “community care assessment”, “joint needs assessment” or “single shared assessment”. It is conducted by the social work department of the local authority responsible for the council area in which a person lives. The social work department is responsible – amongst other duties – for assessing people’s need for “community care services”, arranging and providing these services, and providing financial support for those who need places in care homes. The needs assessment can be carried out by a social worker, a district nurse, an occupational therapist or another care professional.

The visits, which are part of the needs assessment, take place in order of priority of need, i.e. people with urgent needs will be visited first. During an initial phone conversation some information will already be given in order to find out how urgent a person’s care needs are. If care needs are very urgent some help may be given immediately, even before the needs assessment can be arranged. The full needs assessment will then be carried out later. Several visits may be necessary for a comprehensive needs assessment.

During the assessment the care professional will ask questions to help understand a person’s care needs, how suitable their home is for their needs and whether any specialist help is needed due to disability or health conditions. The care professional will especially try to find out if the applicant needs help with personal hygiene, food and diet, mobility, behaviour management, psychological support, simple treatments and assistance with medication or personal assistance with dressing, surgical appliances, prostheses as well as assistance to get up and go to bed. If a person already has a carer they will also be interviewed. The care professional will fill all the given information into forms and ask the person applying for care to sign them. Subsequently a care plan will be created on the basis of all the information in order to set out how the assessed needs could be met.

A Single Shared Assessment (SSA) process has been introduced in order to avoid a duplication of efforts. Under SSA local authorities and National Health Service (NHS) boards work together. This also benefits the person to be assessed since basic information only has to be given once. The Scottish Government published a circular¹² which outlines how the assessment should be done. It includes an introduction to the SSA process and a minimum standard checklist for the assessment.

¹⁰ <http://www.infoscotland.com/nationalcaresstandards/52.html>, <http://www.scotland.gov.uk/Topics/Health/care/17655>.

¹¹ <http://www.nhs24.com/content/>.

¹² <http://www.scotland.gov.uk/Resource/Doc/1095/0014719.pdf>.

The poor implementation of the SSA has been recently criticised. There is often a long delay in the visit of the social work officer and there are in most cases more than one single assessment. The concrete “shared” dimension of the SSA is as well said to be very poorly achieved. In most cases, the social worker assesses on a classical unilateral basis the needs of the person in needs (Interview, care-givers association, 06.01.2011).

Types of needs assessments

There are four types of needs assessments which are implemented according to the specific indicated needs of the applicant:

- **Simple assessment:** indicated needs can be dealt with by low-level response
- **Comprehensive assessment:** a wider range and complexity of needs are indicated and the process is likely to involve more than one agency; specialist input may be necessary
- **Specialist assessment:** more in-depth investigation by a professional with recognised expertise is necessary
- **Self-assessment:** people identify their own simple needs and propose solutions, maybe with the advice of an advocate

Assessment Tools

The Circular also explains two assessment tools: the Care Needs Assessment Package for Dementia (Carenap D) and for the Elderly (Carenap E). Agencies can adopt these tools or develop their own SSA tool. Their own tools should respect the minimum standards set out in two checklists in the circular. One checklist is provided as a guideline for agencies for developing their assessment tools and processes. It explains which data, information and signatures are needed. The other is a checklist for the Scottish Executive to review SSA implementation.

The person concerned has to give written permission to share information with other care professionals since different professionals may be working together in the shared assessment process. The applicant can be represented by a friend, relative or other advocate during the assessment.

To get the needs assessment anyone can contact their local social work department themselves (self-referral) or ask another person to do so on their behalf. Any GP, district nurse, member of hospital staff, local housing officer, welfare rights officer, citizens’ advice worker, relative or carer can request a needs assessment for an elderly person. The needs assessment will often take place before or after discharge from hospital.

After the assessment the applicant will be sent the results of the assessment and how their needs may be met. This first response should also tell the applicant what they will receive and the length of time they may have to wait before receiving the services they have been assessed as needing. Services are allocated in order of priority of need so not all of the help may be received immediately.

The applicant will also be given a review date which is usually six months after the date of the assessment. It can however take place earlier if circumstances change earlier.

If the applicant disagrees with the outcome of the assessment he can ask for a further discussion of his needs. There is also the possibility of complaining about the way the assessment was conducted to the social work department.

The assessment can also be taken if a person plans to arrange and fund care services themselves to ensure that all care needs are identified and that all help available from local authorities or the NHS is known to them.

A needs assessment is also completed before anyone enters a care home. After the needs

assessment a six week assessment period and continual review take place.

If the person in question has been assessed as needing social services some of these may be charged for. The social work department will then carry out a financial assessment and determine how much the applicant will have to pay before they accept any social services.

The care needs assessment as well as any additional NHS services necessary for it are free of charge.

Regardless of income, capital assets or marital status free personal and nursing care is available to anyone who has been assessed by the local authority as needing it.

hh. Provision of benefits

The Free Personal Care Framework states that the Scottish local authority will pay with effect from April 1, 2010, the maximum amount of £ 153 to 156 per week for personal care, £ 69 to 71 per week for nursing care, or £ 222 to 227 per week if the person requires both personal and nursing care. These rate payments will normally be paid directly to the care service unless a person decides to arrange for care services themselves (direct payments).

Benefits for people with disabilities

In addition, disabled people living at home and receiving attendance allowance or disability living allowance will still be eligible to receive these benefits.

People who are disabled or chronically ill have two possibilities for obtaining benefits in Scotland. The Disability Living Allowance (DLA) is a benefit for disabled people under the age of 65. People who are disabled or sick and over 65 can apply for Attendance Allowance (AA) which does not include a mobility component. However, if a disabled person is already receiving a DLA mobility component when they become 65 years old, they will continue to do so. A new claim for a DLA mobility component after the age of 65 cannot be made. AA is paid at two rates, a higher rate (£ 71.40 per week) and a lower rate (£ 47.80 per week)¹³, which are paid according to the care need. AA is paid to the person in need.¹⁴ Those allowances are a UK wide benefit system.

Care services

Personal care services include:

- Personal hygiene: bathing, showering, hair washing, shaving, oral hygiene, nail care
- Continence management: toileting, catheter/stoma care, skin care, incontinence laundry, bed changing
- Food and diet: assistance with the preparation of food and assistance with the fulfilment of special dietary needs
- Problems with immobility: dealing with the consequences of being immobile or substantially immobile
- Counselling and support: behaviour management, psychological support, reminding devices
- Simple treatments: assistance with medication (including eye drops), application of

¹³ http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG_10012442.

¹⁴ http://www.adviceguide.org.uk/scotland/life/benefits/benefits_for_people_who_are_sick_or_disabled.htm.

http://www.adviceguide.org.uk/scotland/life/benefits/benefits_for_people_who_are_sick_or_disabled.htm#disability_living_allowance.

creams and lotions, simple dressings, oxygen therapy

- Personal assistance: assistance with dressing, surgical appliances, prostheses, mechanical, manual aids and assistance to get up and go to bed.¹⁵

Other care services such as help with housework, laundry or shopping will not be provided free of charge. Services which are provided outside the home, e.g. the cost of attending day care centres, are also not covered by personal care payments. All these other services are subject to a financial assessment and can be granted if available funds are insufficient.

Support with preparing meals is provided free of charge but the cost of the food itself is chargeable.¹⁶

ii. Quality assurance

Quality insurance is an important topic in public discourses in Scotland. Until a very recent date, there were many regulation and control bodies: the Care Commission, the SWIA (Social Work Inspection Agency), the SSSC (Scottish Social Services Council) and the JIT (Joint Improvement Team). It could be possible to add to this list Audit Scotland that provides the Auditor General of Scotland and the Accounts Commission with assessment and control reports about the efficiency and effectiveness of public money use in the country. Those both institutions analyse on regular bases the implementation, effects or finances of the FPNC scheme¹⁷ but this is not a body specific to the domain of care. As the competencies of these agencies were judged to be complex and partly overlapping, two of them, the Care Commission and the SWIA, merged by the 1st of April 2011. Before this step of simplification of the control and regulation bodies, various joint comities supposed to coordinate the activities of those, sometimes concurring and overlapping bodies, had been introduced.

- the *Care Commission*.

Care is provided by various services, which were regulated by the Care Commission with whom all services have to be registered. The Care Commission was set up under the Regulation of Care (Scotland) Act 2001 in April 2002 to oversee all adult, child and independent healthcare services in Scotland. In order to assure that National Care Standards¹⁸ are being met the Care Commission inspects all care homes as well as services and works closely with local authorities. The Regulation of Care (Scotland) Act 2001 also gives the Care Commission the power to enforce changes or to close care services. In practice, such enforcement is rare because the Care Commission supervises care services very closely. The Care Commission inspects all care services at least once a year. It regulates 15,000 services for 320,000 people. The National Care Standards have been developed as a means of quality control for every kind of care and require regular inspections after which a report will be produced and published. The main principles are dignity, privacy, choice, safety, realising potential, equality and diversity.

- the *Social Work Inspection Agency (SWIA)*

The SWIA inspects all social services in Scotland. It was in charge of controlling the Social Work departments of the local authorities and other providers of long-term care. It plays a central role in the control and monitoring of care services, at local level. It has started in 2008 a

¹⁵ <http://www.scotland.gov.uk/Topics/Health/care/17655/personalcare>.

¹⁶ <http://www.scotland.gov.uk/Topics/Health/care/17655/FAQs>.

¹⁷ http://www.accounts-commission.gov.uk/utilities/search_report.php?id=230

¹⁸ <http://www.infoscotland.com/nationalcarestandards/21.html>.

systematic work of inspection of social and care services in all the 32 Scottish local authorities that has been completed in 2010. Quality of “management”, “value for money”, “continuous improvement”, “excellence” were the keywords structuring the action of this agency. An important reorientation of the inspection practice from the previous logic based principally on scrutiny (external observation and inquiry) to a mix of scrutiny and supported self-evaluation has been launched in 2010 and was labelled “performance inspection”.

- the *Scottish Social Services Council* (SSSC)

The SSSC is a key agency in the Scottish quality insurance strategy. This agency is centred on the control, training and support of the work force of the long-term care sector. It has issued a strategic plan for the period 2011-2014. This plan claims to follow the following goals: “to set up registers of key groups of social service workers, to publish Codes of Practice for all social service workers and their employers, to regulate the education and training of the workforce, to promote education and training, to undertake the functions of the sector skills council, Skills for Care and Development (SfCD), this includes workforce planning and development¹⁹”.

The SSSC is in charge of registering the people working in social services in Scotland and regulates their education and training. It sets standards in professional skills and procedures, and plays as such a key role in the staff centred work of quality insurance.

- the *Joint Improvement Team* (JIT)

The JIT was created in 2004, is part of the division of the Scottish government health directorates in charge of partnership improvement and outcome. It primarily assists and steers the local authorities implementation activity. The focus of the agency lays in “performance measurement and management” as well as on “performance support and improvement”. This institution deals with the implementation of specific targets by the local authorities that are set by the Scottish government. For the time being, the JIT works, with networks of care providers as well as with the local authorities on the following issues: care at home, commissioning, equipment and adaptations, governance and management, housing, integrated transport with care, intermediate care, managed care networks, performance improvement, reshaping care for older people, rural and remote, talking points: user and carer involvement, telecare.

- Care Inspectorate

The merging of the Care Commission with the SWIA has been followed by a radical transformation of the forms of control activities. Systematic, annual control were abolished and replaced by random control of providers and by targeted self-assessment of the providers. In doing this, the new controlling body the Care Inspectorate²⁰, develop a policy it has initiated for a few years consisting of trying to catch the attention of providers on specific issues (recruiting a professional carer for instance). As it has been organized up to now, the Care Commission was autonomous enough to pick specific issues it wanted to improve. The publicity, accessibility of evaluation reports on the internet was a key feature of the Care Commission.

Care services has to deliver an « annual return » which is a control of the activity of the providers (clients, financial situation, etc.), whereas the annual self-assessment, is centred on « quality themes and quality statements). This new organisation builds now, with the SSSC, the bulk of the Scottish quality insurance strategy.

¹⁹ http://www.sssc.uk.com/component/option,com_docman/Itemid,486/gid,1988/task,doc_details/

²⁰ http://www.scswis.com/index.php?option=com_content&task=view&id=7563&Itemid=363

Beneficiaries participation

There are three types of instruments supposed to improve the participation of beneficiaries and of their relatives in the domain of long-term care in Scotland. There are in the first place the instruments of beneficiaries and clients information. There are as well the instruments of participation to the definition of the care needs and care packages and as well to the steering of the policy itself at local level. Finally, there are instruments dedicated to frame the issue of participation. Those instruments are elaborated by agencies of the National Scottish Government.

The Scottish Government has put great emphasis on making **information** about the care system available for people who need assistance. After an informal super-complaint by the Which Consumer group, which criticised the lack of clear information on the care system, the Office of Fair Trading on the UK Care Home Sector took action to claim for the provision of ready access to clear and relevant information. The Scottish Government then set up a Steering Group which carried out a feasibility study. Since 2009 the Health Information and Self Care Advice for Scotland (NHS24) has provided a website²¹ and a local rate telephone helpline. A lot of information can be found online, e.g. on the websites of the Scottish Government²² (and parliament), of the Care Inspectorate²³ and of local authorities. On the website of the Care Inspectorate for instance, the procedure to complain about a care provider is very clearly explained and even directly made available. All information about the quality of provision by the various, public and private providers are as well available online. Under the headline and the keyword « Get involved!», the Care Inspectorate even invites the beneficiaries to participate to the evaluation process of the various care providers. This dimension of information about all types of providers is especially important in the cases of local authorities like Edinburgh that decided to organize a long-term care provision market. Furthermore, every care service also has to provide its customers with an introductory pack informing about rights and issues of the Free Nursing and Personal Care program.

Secondly, the participation of care beneficiaries to the **definition** of their own care needs and of care packages is considered to be one of the most important element of the reform (Bell, Bowes, Dawson, 2007). The concept and the instrument of the Single Shared Assessment is not only the idea that only one assessment formula and procedure should be used by as many stakeholders institutions as possible, but as well that the potential beneficiaries should be able to participate to the assessment itself, and as well to the definition of the care packages. According to our field research however, the effectiveness in terms of participation of this tool seems to be very limited. There are as well instruments organizing the participation of beneficiaries to the **steering**, at local level, of the beneficiaries. This is for instance the case of the « checkpoint groups » in the case of Edinburgh. Those groups are a form of consultation of the various stakeholders of the domain of long-term care. There are open to the participation of service providers and associations of all sorts, but as well to the participation of beneficiaries representatives. In the case of our second local case study, in Fife, the users' panels are as well an important form of local participation and direct consultation of users.

²¹ <http://www.nhs24.com/content/>.

²² <http://www.infoscotland.com/nationalcaresstandards/52.html>, <http://www.scotland.gov.uk/Topics/Health/care/17655>.

²³ <http://www.scswis.com/>

Finally, the Scottish government has developed various institutions that produce activities aimed at actively **defining and promoting** the issue of beneficiaries' participation in the domain of long-term care. In the first place, the Care inspectorate has developed the so called « National Care Standards ». Explicitly, those standards are designed to raise the quality of long-term care delivery. However, the large publicity of those standards is as well supposed to make beneficiaries aware of their entitlements in the domain. There are supposed to be written and issued « from the user's viewpoint ». Their content is as well partly related to this dimension of participation: « dignity, privacy, choice, safety, realising potential, equality and diversity ». Those standards should as well raise the awareness of all stakeholders of long-term care for the aged that they have to reach those standards.

Even more specifically relevant to the issue of participation in the domain of long-term care is the action started by the Scottish Human Rights Commission. This important commission in the Scottish national debates has launched in cooperation with the organisation representing the private care sector, a powerful senior citizens association, the Care commission and the active support of the Scottish government, an initiative aiming at « embedding human rights in care »²⁴. This program has produced various reports, guidance about various important policy issues in the domain such as commissioning. From this program, the Scottish Human Rights Commission has started a more operational program of training aiming at concretely assisting the potential beneficiaries to understand their human rights in the context of a care relation, and to empower them to make use of those human rights. This online training course, made of information texts and videos, is not only dedicated to older people, eventually in need of care, it is as well designed to professionals or activists of the domain of long-term care. The whole instrument should as well improve the large public awareness and concern about the issue of public oversight and beneficiaries participation in the domain of long-term care for the aged.

jj. Role and recognition of non-professional helpers

People who provide substantial and regular unpaid care for a relative, partner or friend may be involved in the needs assessment of the person they care for. Apart from this they can also be entitled to a carer's assessment.

The carer's assessment is separate from the care needs assessment for the person they care for. It is an assessment carried out by the social work department in order to identify the needs of the carer. The assessment takes into consideration the amount of care which is provided, the impact on the health of the carer and the carer's personal life.

After the assessment the carer will receive a copy of the outcome with an outline of support services which the social work department can offer. This support may involve services and benefits in kind which benefit the person cared for as well as their carer or things that benefit the carer directly such as training and support at a carers' centre. Just like the care needs assessment the carer's assessment is free.

The government circular also states that carers should be recognised by all agencies as partners in the provision of care and their contribution should not be taken for granted. They should be able to access flexible, quality services to support them in their caring role and to help them meet their own needs.

Local councils provide a variety of help to carers, e.g. breaks from caring by providing support within the home, home care support such as domestic help and emotional as well as practical

²⁴ <http://www.scottishhumanrights.com/careaboutrights/welcome-embedding>

support²⁵.

Information, advice, and support for carers is also available from the Princess Royal Trust for Carers which was created on the initiative of Anne, Princess Royal, in 1991. It is the largest provider of comprehensive carers' support services in the UK, currently providing information, advice and support services to over 400,000 carers.²⁶

The well structured and organized association Carer Scotland has started a tight cooperation with the Scottish government on the issue of recognition of care-givers

c. Financing HBLTC

As in most other countries the funding of free personal care has been a widely discussed topic. The actual hourly rates of care services and the amount of direct payments made to private care agencies (aa.) have been much less controversial than the overall policy cost (bb.).

aa. The cost of HBLTC services

Since councils are free to have different charging policies the price of HBLTC services varies. 17 councils have reported that changes to their charging policies were necessary in order to be able to continue delivering services within their local budgets since personal care has become non chargeable. This has led to a relatively broad price range for home care. Here are some examples of local council's charges for one hour of home care:

- Aberdeenshire: £ 8.68²⁷
- Angus: £ 9.40²⁸
- East Ayrshire: £ 10.00²⁹
- Highland: £ 13.15³⁰

A person living at home can choose to receive personal care services from their local authority or payments to arrange for their own care services with private agencies³¹. This allocation of financial means instead of care services is now called self-directed care. It can consist of regular payments or a single transparent budget which is held on a certain person's behalf, rather like a bank account. This budget can be taken out in form of a direct payment in cash, as provision of services, or as a mixture of both. In most cases however, the local authorities provide themselves the delivery of care.

Previously it had only been possible to request direct payments to a care provider. Now people needing care can decide how they want to manage their budget. They can also opt for direct payments instead of receiving the funds themselves.³² The local authorities are obliged to offer

²⁵ <http://www.angus.gov.uk/atoz/swpdfs/leaflets/carersse.pdf>.

²⁶ <http://www.carers.org/about-us,5,GP.htm>.

²⁷ <http://www.aberdeenshire.gov.uk/care/money/ContributingTowardsTheCostofYourCareCMYK.pdf>.

²⁸ <http://www.angus.gov.uk/atoz/swpdfs/leaflets/chargefo.pdf>.

²⁹ <http://www.east-ayrshire.gov.uk/ess/socialwork/Charging.asp>.

³⁰ <http://www.highland.gov.uk/NR/rdonlyres/A6750949-22D3-4AE4-806E-4BC08C891C04/0/200909chargingnonresidential.pdf>.

³¹ <http://www.scotland.gov.uk/Topics/Health/care/17655/personalcare>.

³² Age Concern and Help the Aged, Factsheet 24s, Self-Directed Support (Direct Payments) from Social Work (Age Concern and Help the Aged 24s), p. 5, available at www.ageconcernandhelptheagedscotland.org.uk/documents/499.

self-directed support to people once they have been assessed as needing help in order to give more control over the care process to them. It is also possible to use a combination of services arranged by local authorities and self-directed support payments.³³

The payments can be used to employing personal assistants or for purchasing services from a private agencies or local authorities; since June 2003 people can also buy services from other than their own local authority's social work department.

Self-directed support can also be used to pay for respite and to purchase equipment.

Since the payment is meant to be granted instead of services that the social work department has assessed as necessary.

Payments can however not be used for the following:

- relatives living in the same household, unless they qualify as carers
- services which the NHS has duty to provide, unless a personal assistant is trained accordingly
- permanent residential care (over four weeks per year).³⁴

bb. Policy Cost

Free personal care is paid for through general taxation³⁵. Since information on the cost of personal care delivered at home was limited it was difficult to estimate the costs for the policy in 2001. After the introduction of the FPNC policy monitoring its long-term financial impact has also been insufficient.

A detailed examination of the policy's funding can be found in the review report on free personal and nursing care prepared by the Auditor General for Scotland and the Accounts Commission. The Auditor General for Scotland is the Parliament's watchdog for the spending of public funds. He ensures that public funds are spent as efficiently as possible and according to the highest standards of financial management. The Accounts Commission is a statutory, independent body which assists local authorities to achieve an efficient use of their resources.³⁶

The Auditor General estimates that the total costs of the FPNC policy for the first four years were £ 1.8 billion. During this period local authorities would have spent around £ 1.2 billion even if the policy had not been introduced.³⁷

The total financial provision for first nine months of the policy from July 2002-03 was £ 107 million, £ 143 million for 2003-04, BGP 147 million for 2004-05, £ 153 million for 2005-06, £ 162 million for 2006-07 and £ 169 million for 2007-08. Funding has thus increased every year. A slightly bigger share has been spent for free personal and nursing care in care homes than for free personal care at home.

Table: Central Government Support for the additional costs of Free Personal and Nursing Care 2002-03 to 2007-08 (£ million)³⁸

	2002-03 (9 months)	2003-04	2004-05	2005-06	2006-07	2007-08
Free Personal and	54.3	74.6	77.7	80.09	85.3	89.4

³³ Age Concern and Help the Aged 41s, p. 6 f.

³⁴ Age Concern and Help the Aged 24s, p. 8f.

³⁵ Independent Review, p. 16.

³⁶ Auditor General, p. ii.

³⁷ Auditor General, p. 4.

³⁸ Independent Review, p. 51.

Nursing Care						
Free Personal Care at Home	52.7	68.4	69.3	72.1	76.7	79.6
Total	107	143	147	153	162	169

The review reports conclude that the policy was fully funded during the first few years but that a shortfall in funding developed by 2005-06. Depending on the source the scale of this shortfall ranges from £ 25 million to £ 63 million.³⁹ The Review Group estimates that there was a shortfall in total funding of £ 38.5 million in 2005-06. More recent expenditure figures are not currently available.⁴⁰

In addition to demographic growth difficulties with funding the FPNC policy had arisen when the Department for Work and Pensions (DWP) decided that the attendance allowance, a UK-wide social security benefit for people with disabilities, would be withdrawn from Scots receiving free personal care in care homes and that the savings should fall to DWP rather than to be transferred to the Scottish budget (around £30 million a year). The Scottish Executive had expected these savings to be transferred to it by the DWP in order to contribute to the cost of the FPNC policy. When this did not happen the government had to cover the additional cost from its own budget.⁴¹ In 2002 the Scottish Executive conducted a short-term cost estimate for the first four years of the FPNC policy's implementation. The estimate was based on a cost model prepared by the Care Development Group (CDG). The total budget allocations took the loss of attendance allowance into account but other inaccuracies remained. They included the significance of additional funding which had to be allocated to local authorities and an unforeseen projected increase of an additional 40,000 older people aged over 75 years by 2016.

Moreover, the Scottish Government did not update the longer-term cost model to take these changes into account or the growing number of people receiving care.

In its report the Review Group therefore recommend that in the light of growing demand for long-term care and increased cost pressures the Scottish Government allocate more funds to sustain the policy⁴². As for other public policy issues the government should also plan how free personal care can be sustained in the longer-term. This involves a broader review and some remodelling of public funding.⁴³ The Auditor General strongly recommends more comprehensive financial estimates through central monitoring and future planning⁴⁴.

Costs for free personal and nursing care added around 10 per cent to the total public costs of care for older people in 2006 and have stayed around the level of 0.2 per cent of Scottish GDP⁴⁵. Overall social care costs constituted 1.4 per cent of Scottish GDP in 2006⁴⁶.

David Bell and Alison Bowes consider a number of simulations to explore the costs of free personal and nursing care between 2003 and 2063. They show that demographic pressure alone will lead to substantial increases of the cost of free personal care during the next fifty years. Policy actions would have to be taken to control costs and the policy would only be sustainable if

³⁹ Independent Review, p. 31.

⁴⁰ Auditor General, p. 30f.

⁴¹ Auditor General, p. 12.

⁴² Independent Review, p. 30.

⁴³ Independent Review, p. 42, 46.

⁴⁴ Auditor General, p. 30.

⁴⁵ David Bell and Alison Bowes, Lessons from the funding of long-term care in Scotland (Bell and Bowes, Lessons from the funding of long-term care in Scotland), p. vii, 56, available at <http://www.jrf.org.uk/sites/files/jrf/1859354408.pdf>.

⁴⁶ Independent Review, p. 79f.

there is sufficient political will and economic resources available.⁴⁷ The simulations show that, if payments for free personal care keep pace with inflation, costs rise modestly until 2035, then fall back. On the contrary, if payments rise in real terms at 2 per cent and the economy grows at 2 per cent, costs triple, reaching a peak of around 0.6 per cent of GDP in 2053. However, if the balance of care was shifted towards care at home this could dramatically reduce costs, unless the costs of care at home increase at a rate above average economic growth. Finally, if personal care costs rise more rapidly than the economy as a whole, the costs would reach 1 per cent of GDP by 2053; this could again be reduced if more domiciliary care than residential care was provided.⁴⁸

The following indicators precisely show that there has been a significant decline of the care provided at the hospital (ca minus 40% between 2003 and 2010). The decline of the absolute number of people receiving care in homes is more limited (minus 4%). The proportion of people receiving domiciliary care has however very decisively increased, both in relative terms (+ 33% in 7 years) and in absolute terms (increase of 112% of care expanses on domiciliary care).

Indicators of Change in the Balance of Care in Scotland 2002-2010

<i>Occupied Geriatric Long Stay Beds</i>			
Year	2003	2008	% Change
Number	2704	1661	-39%

<i>Number of Long Stay Residents Aged 65+ Supported in Care Homes</i>			
Year	2002/3	2009/10	% Change
Number	32,248	31,082	-4%

<i>Number of self-funders receiving Free Personal Care in Care Homes</i>			
Year Quarter	2002 Q2	2010 Q3	%Change
Number	7068	9922	40.4%

<i>Number of Long Stay Residents Supported in Care Homes</i>			
Year Quarter	2002 Q2	2010 Q2	%Change
Number	38529	35082	-8.9%

<i>Number of People Receiving Free Personal Care at Home</i>			
Year	2002/03	2009/10	% Change
Number	27,372	46,277	69%

<i>Local Authority Home Care Clients</i>			
Year Quarter	2004 Q2	2010 Q3	%Change
Number	69433	64839	-6.6%

<i>% of people 65+ receiving personal care at home</i>			

⁴⁷ Bell and Bowes, Lessons from the funding of long-term care in Scotland, p. xiii.

⁴⁸ Bell and Bowes, Lessons from the funding of long-term care in Scotland, p. 79.

Year	2003	2010	%Change
Per cent	44%	58%	32.9%

<i>Home Care clients aged 65+ getting 10+ hours of care per week</i>			
Year	2002/3	2009/10	% Change
Number	11,998	15,736	31%

<i>% of people 65+ with intensive needs receiving care at home</i>			
Year	2003	2010	%Change
Per cent	26%	32%	26.3%

<i>Total Hours of Home Care</i>			
Year Quarter	2004 Q2	2010 Q3	%Change
Number	545564	673521	23.5%

<i>Number of self-funders receiving Free Personal Care at Home</i>			
Year Quarter	2002 Q2	2010 Q3	%Change
Number	24312.88	47149	93.9%

<i>No. of emergency bed days in acute specialities for people aged 65+</i>			
Year	2004/05	2009/10	%Change
Number	2,811,417	2,859,999	1.7%

<i>NHS Delayed Discharges that are outwith the six week discharge planning period</i>			
Year	Jan 2001	Oct 2010	%Change
Number	1887	128	-93.2%

<i>Total Expenditure on Personal Care at Home</i>			
Year	2003-04	2008-09	%Change
Amount (£m)	128.8	273.7	112.6%

<i>Expenditure on FPC Payments in Care Homes</i>			
Year	2003-04	2008-09	%Change
Amount (£m)	65.3	79.3	21.5%

<i>Average Weekly Expenditure on Clients Receiving Free Personal Care at Home</i>			
Year	2002-03	2008-09	%Change
Amount (£)	75.3	119.1	58.2%

(Source: Scottish Government, from Bell and Bowles, forthcoming 2011).

chart : Number of clients receiving FNPC (data Scotland Statistics)

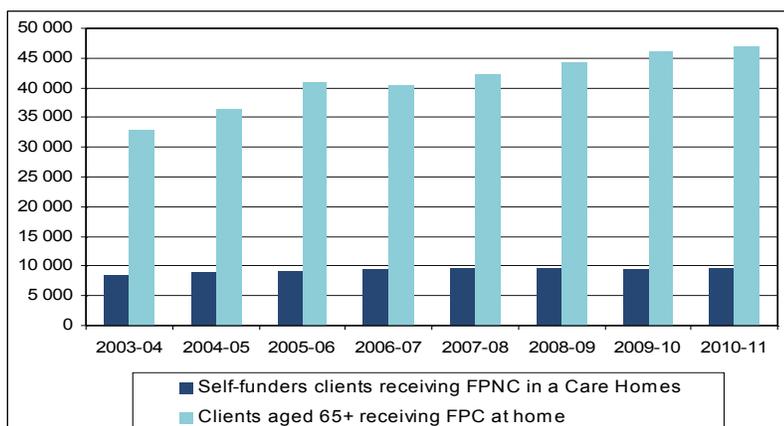
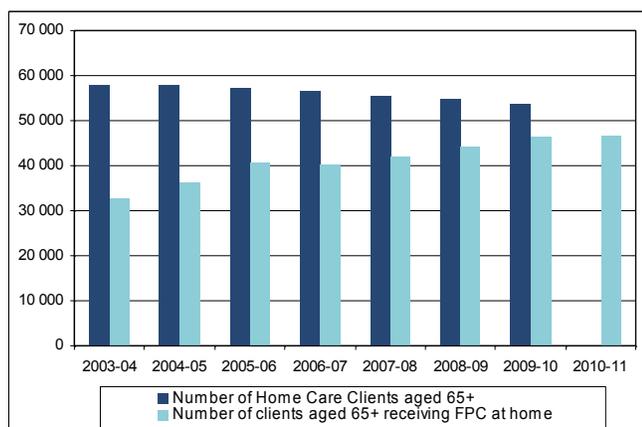


Chart 1 - Number of clients receiving FPC



cc. Examples: analyzing the financial situation of typical cases

Case A

Beneficiary A is an 80-year-old woman, living alone, with a monthly income of £ 1200. She has the following needs:

- 1 hour daily of nursing care;
- daily meal delivery;
- 4 hours a week of housekeeping;

A will receive free nursing care up to the total weekly amount of £ 69 to 71, depending on the council's or the private care agency's rates. Support with the preparation of meals is free as well. She will, however, have to pay for the other services, the delivery and the food itself. Housekeeping services are generally chargeable but subject to financial means testing. A will thus have to pay if a financial assessment shows that her financial means are sufficient to do so.

Case B

Beneficiary B is a 65-year-old disabled man, living in his home by himself. He has a monthly income of £ 400 and needs the following support services:

- 2 hours daily of personal care (including: morning toilet, evening bedtime)
- 1 hour daily of social care
- daily meal delivery;
- 4 hours a week of housekeeping;

B will receive free personal care up to a total weekly amount of £ 153 to 156, depending on the council's or the private care agency's rate. However, the other services and the food are chargeable. Social care and housekeeping services are services that are subject to means testing. It is unlikely the council will decide in B's case that he can afford to pay for these services himself. Besides, B is entitled to the AA for disabled people over the age of 65. He might also continue to receive the DLA mobility component if he did receive this component before turning 65.

2. The issue of policy change in the domain

Certain aspects of the HBLTC policy have been criticized and there is room for improvement in some areas. These are the main recommendations:

- the funding gap needs to be filled with additional funding in the short-term, i.e. for the next years
- costs should be monitored and reported accurately in order to allow a regular review and re-modelling of costs
- public information structures should be improved⁴⁹

The Review Group also points out that some local authorities have tightened their eligibility criteria for access to care and are operating waiting lists to help manage demand. Even though few people in Scotland have to wait for care, inconsistency has become a concern.⁵⁰ Access to care should also be made more transparent for older people⁵¹. Another major concern has been the issue that charging for food preparation was also inconsistent in different council areas⁵².

However, most observers agree that free personal care may be sustainable, at least in the short-term, if there is sufficient political will⁵³.

⁴⁹ Independent Review, p. 9.

⁵⁰ Independent Review, p. 23f, Auditor General, p. 51.

⁵¹ Auditor General, p. 50.

⁵² Independent Review, p. 26.

⁵³ Helen Dickinson et al., p. 472, Independent Review, p. 37.

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The Swiss System of Home Based Long-Term Care for the Aged (HBLTC)

1. General structures of the HBLTC system for the aged

The Swiss health system is characterised by its 1) federalist structure, 2) the importance of the private sector and, 3) like in most European countries, by its focus on *cure* (rather than care)¹. Health care in general, and HBLTC in particular, is a *cantonal* competence, thus there is no federal legislation on this issue. Consequently, a wide variety of legislations and practices co-exist. However, some federal legislations have implications for HBLTC, namely the public retirement insurance ²(AVS) that can contribute to the care costs for dependent elder people with modest income. In general, HBLTC is more developed and more centralised in the French speaking (e.g. Western) part of Switzerland. The *private* sector is very important with regard to HBLTC : the majority of care services – both medical and non medical (care and help) - are provided by private for profit or non profit organisations. The main national service provider is the national non profit organisation Spitex that federates 26 cantonal organisations and 570 local organisations. The main emphasis of HBLTC services is on *cure* rather than care.

HBLTC is mainly financed by a complex mixture of (mandatory) private health insurances that finance the larger part of the *medical* services, public (cantonal and municipal) subsidies and – increasingly –by the long-term care patients themselves (see below) who, under certain conditions³, are entitled to specific benefits intended to meet expenses for long-term care.

The remaining costs are on the beneficiaries of care services. The national old-age pension scheme (AVS) can contribute to care costs for elder people with a modest income (“contribution pour impondants”). Dependent elder people have no rights to specific benefits that would allow them to pay for services provided by non professional care providers (family, friends etc.).

a) Historical development

Long-term care does not have a specific locus and definition within the Swiss social security system. It refers to services and institutions that are not planned and financed in an integrated manner. It developed in a totally decentralised and uncoordinated way without being supported by an explicit political will, and at the margins of the social security system. The latter only provides an indirect practical and financial support to frail elder people, namely through health insurance when frailty leads to illness, and/or financially through supplementary income benefits when frailty and dependency cause or worsen into poverty (Despland 2008, see also Gobet 2010).

However, although decentralised and led by each canton in its own way, we can roughly distinguish four main periods in the historical development of an old age policy that have had implications for home based care.

In the first period (1960-70s), care and nursing homes were considered the most appropriate solution for elder people. The federal commission in charge of old age issues in this period explicitly drew the conclusion that entering an institutional setting was the most appropriate solution for old people as soon as they started to have health problems, even if they were still able to perform ordinary household tasks (Commission fédérale d'étude des problèmes de la

¹ Home based long term care comprises medical care and domestic economy services. Basic services include nursing care, counselling and household tasks (cleaning etc.). Cantonal care providers (mainly private for profit or non profit organisations) can include additional services such as meal delivery.

² Assurance vieillesse et survivants (Old age and survivors insurance) AVS.

³ Permanent mild to severe invalidity (“invalidity allowances”, AVS); or/and a strained financial situation (“supplementary benefits”, AVS).

vieillesse, 1966 : 220). Home based long-term care was not even considered back then. In the second period (late 1970s-early 1990s), the government gave strong impulsions for the construction of more nursing homes. The mandatory public old age pension insurance (AVS) massively financed the construction of new and the refurbishment of already existing care and nursing homes. Simultaneously, however, the first HBLTC models started developing at the cantonal level. In the 1980s, the new law on the old age pension insurance encouraged elder people to remain at home longer⁴ (Commission fédérale d'étude des problèmes de la vieillesse, 1979).

The third period (mid 1990s-2007) was the real turning point concerning HBLTC. The 1995 report of the federal commission "To grow old in Switzerland" (Vieillir en Suisse) clearly shifted the emphasis towards a *promotion of home based care*. According to this new "doctrine", nursing homes should be the last resort and the ideal was to keep elder people at home until their death. The arguments for this new policy were mainly cost-related (Cavalli 2002 : 32). In accordance with this new policy, many cantons started developing and professionalising their home based care system; some of them (like Geneva and Vaud) even stopped the construction of new nursing homes. In 1995, the private non profit organisation *Spitex Switzerland* was founded by a fusion of two federal associations. Spitex⁵ is today the main provider of home based care, and a key player in Swiss health policy. The organisation is an official partner of the federal office for social insurances (Office fédéral des assurances sociales). The 26 Swiss cantons reacted differently to the new types of incentives given by the federal authorities. Generally speaking the French speaking cantons put in place more developed long term care services than the German speaking cantons.

Finally, a fourth period was initiated in 2007, with new reforms in the field of home based care. That year, the federal government issued a strategic report on a global old age policy (Conseil fédéral 2007) that addressed issues such as mobility, housing, financial resources, social participation and health. It was elaborated by an interdepartmental group created within the federal administration, but without the participation of important interest groups (Gobet et al 2010:2). More recently various financial reforms have affected the concrete functioning of home based care, namely the new financial equalisation of 2008 that conferred more competencies to the cantons and the new regime of health care funding (2011) which introduced a new repartition key for the health care costs. The latter in particular has been contested since its introduction (see below, section "recent reforms").

The most recent reform that has direct implications for home based care for the elderly is the new legislation on hospitalisation costs (2012). Under this new regime, a patient's stay at a hospital is funded on the basis of a fixed case-based tariff (DRG), independently of the actually occurring costs. Patient organisations and HBLTC providers warn that this (equally contested) new model might lead to premature releases of patients (a concern that is not massively shared by the doctors though).

b) Horizontal and vertical repartition of responsibilities and tasks

In the Swiss federal system, health care is a *cantonal* prerogative (art. 3 of Federal Constitution), therefore each canton has its own health care system. The federal state is responsible only for health care insurance issues. As a consequence of the high degree of cantonal autonomy in all matters related to health policy, the overall system is characterised by its diversity, both on the horizontal and vertical dimensions.

⁴ <http://www.redcross.ch/activities/social/news/news-fr.php?newsid=1072>

⁵ The term "Spitex" is used in Switzerland in two slightly different meanings: on the one hand, Spitex refers to the *organisation* Spitex (Association suisse des services d'aide et de soins à domicile, ASSAD, in French). On the other hand the term "spitex" is an abbreviation, in German, of *spitalexterne Pflege*. In this second meaning, it is often used by a variety of service providers of HBC.

Vertical repartition: a federal structure

Federal competencies: insurances

With regard to home based long-term care, the *federal state* plays a minor role: it is mainly responsible for matters of *health care insurance and social insurances*. The federal state namely manages the LaMal, the federal law on health insurance⁶ that was created in 1911 and revised various times throughout the 20th century⁷, and that is implemented by the cantons and by private insurance companies. Since 1996, all residents of Switzerland are under the legal obligation to contract a health insurance with a private insurance company, in accordance with the LaMal. The mandatory basic health insurance reimburses a large part of the *medical* services provided to elder people in long-term home based care (see below for details of the reimbursement rules).

The LaMal also regulates hospital funding. Various major reform have been undertaken in this field over the last two decades. In 1994, a major reform increased the federal state's power in the field of ambulatory and residential services. As per 2012, a new reform of the hospital funding rules regime has been implemented, whose core is the introduction of case-based (DRG) hospitalisation tariffs.

The federal state also manages the *retirement insurance (AVS)*, a public mandatory insurance that constitutes the first pillar of the Swiss old age pension system⁸. This insurance's aim is to cover the most basic needs of all retired people (as well as of widows and widowers, and orphans). (see below for details).

Beyond the basic pension, the retirement insurance has three supplementary instruments that may be claimed by dependent elder people:

- income-dependent *supplementary benefits* (prestations complémentaires) that can be claimed by retired people whose basic vital needs are not sufficiently covered by the basic ordinary pension.
- A *dependence allowance* (allocation pour impotents) whose amount depends on the degree of dependence of the assured person (regardless of his/her income).

Cantonal and local competencies

The cantons are the key actors in Swiss health care policy : they are namely in charge of the implementation of the federal health insurance legislation (LaMal), and it is also them concretely organising home based long-term care. Each canton is autonomous in its decisions as to how to shape HBLTC, therefore we can speak of 26 cantonal care regimes. The cantons are grouped in *4 regional bodies* (called “conferences”) that act as coordinating entities aiming to harmonise cantonal legislations and arrangements. They consist in periodic meetings of cantonal health ministers (split by geographic regions)⁹.

Nevertheless, there are wide disparities between cantons not only in terms of long term care, but more generally in terms of old age policies: Whereas some cantons are true pioneers in the field, with a proactive and strongly institutionalisation old age policy¹⁰, many others

⁶ http://www.admin.ch/ch/f/rs/832_10/

⁷ For a general overview, see the *Handbook of Swiss Politics* (chapter on health policy), Linder et al. 2007.

⁸ The other two pillars are: second pillar: the private pension system (LPP) that is mandatory for all employees in Switzerland who earn more 20'880.-/year (art. 7 LPP). All employers have the obligation affiliate their employees to a private pension insurance company into which they pay a percentage of the employees' salary every month. The third pillar is the voluntary private life-insurance system which is managed by banks and private insurance companies.

⁹ These are: the conference of cantonal health directors of the French and Italian speaking cantons (CLASS), the conference of North-Western Switzerland (GDK-NWCH), the conference of Eastern Switzerland and Liechtenstein (GDK-Ost) and the conference of Central Switzerland (ZGSDK) (cf. Gobet et al. 2009: 15)

¹⁰ Basel-City, Basel-Country, Graubünden and Sankt Gallen (Rielle et al. 2010: 29).

have far weaker or no active bases at all¹¹. With regard to health and old age, only a handful of cantons have so far elaborated full strategic plans for health and prevention of the elder¹².

The cantons can also decide to provide further financial assistance to individuals with low income: in the form of a subsidy towards the mandatory health insurance or of a contribution to health expenses. They are also in charge of implementing some components of federal retirement insurance, namely the *complementary benefits* (“prestations complémentaires”) (see above). Some cantons (for example Geneva) add a supplementary amount to the supplementary benefits as fixed in the federal retirement law (AVS). Finally, the cantons can choose to subsidise the monthly health insurance fee (for elder people with a low pension).

The actual provision of home based long-term care is a *municipal* competence. The municipalities are crucial partners for non-governmental local organisations, especially in the fields of financing and counselling¹³.

Horizontal repartition: the importance of private organisations

Swiss HBLTC policies bear the mark of two historically anchored traditions: subsidiarity of federal to cantonal policies in all policy fields except the few that are explicitly federal prerogatives; and liberalism, with the primacy of private action over state regulation (e.g. minimal central regulation, delegation of central policy tasks to private actors etc.).

Given these principles, *private* organisations are the key actors of HBLTC. Firstly, the compulsory *health insurance* that covers a large proportion of medical services for people in home based long-term care is *private*: it is managed by a network of private insurance companies. They operate under the framework of the federal law on health insurance (LaMal) but are fully private organisations. The health insurances are federated in the national umbrella organization *SantéSuisse* that is a very powerful actor in Swiss politics. Currently, a majority of the population (about 65%) are insured with an insurance company belonging to one of the five major groupings (CSS, Groupe Mutuel, Helsana, Sanitas and Visana¹⁴).

Secondly, the vast majority (93%) of home-based care providers and one third of nursing homes and other institutional settings are *private* organisations (non profit in the case of home based care, for profit in the case of nursing homes) (OECD 2005).

In the field of home-base care more specifically, the Federal Statistical Office has inventorised a total of 1162 care providers (private, public and independent nurses) for 2011. They provided an overall total of 16 million hours services to 350'000 clients. About two thirds (64%) of these 16 million hours were medical care services (to a large extent reimbursed by the obligatory health insurance), and one third (34%) were household services and social care (not reimbursed by the health insurance).

79% of the total volume of care (*aide et soins*) is provided by *non profit* private actors, such as Spitex (and other non profit providers) and non profit foundations. 6% is provided by public organisations (municipal organisations etc.), 13% by private *for profit* organisations and than 2% by independent nurses (OFS 2011a: 6, own calculations).

The key actors in HBLTC are:

- *Spitex*¹⁵ (www.spitex.ch): a national non profit association for HBLTC, created in 1995 at

¹¹ Among the least active cantons are the cantons of central Switzerland (Nidwald, Obwald, etc.).

¹² Mainly the French speaking cantons and the cantons of the Arc jurassien.

¹³ <http://www.bsv.admin.ch/themen/gesellschaft/02825/index.html?lang=fr>.

¹⁴ http://www.santesuisse.ch/fr/kv_groups.html?&navid=2451 (10.3.2012).

¹⁵ In French : Association suisse des services d'aide et soins à domicile (Swiss association for home based care and

the federal levels, and that comprises 26 cantonal and around 600 local organisations. It is funded mostly by the health insurances and by the municipalities¹⁶. It aims to reach some degree of homogeneity by regulating service provision and tariffs. Spitex also promotes the professionalisation of home based care and is a key actor when it comes to influencing political decisions¹⁷. In recent years, Spitex has also actively promoted quality assurance measures.

- *Private for profit organisations* also offer home based care at cantonal level, at various degrees depending on the cantons. These structures are often considered more flexible and more adapted to particularly complicated cases like dementia care. According the Federal statistical office, about 15% of all home based care organisations are private for profit organisations and they provide about 13% of all HBC services (OFS 2011a: 6, own calculations).
- *Independent nurses*: They are quite numerous in terms of numbers (32% of the service providers, OFS 2011b:6) but provide a modest proportion of the overall amount of care service hours (1,9%, OFS 2011a: 6, table T3).

To these actors we can other two other that also offer support to elder people, but whose offer is entirely focused on *non medical* services:

- *Pro-Senectute* (www.pro-senectute.ch) is the oldest and most important organisation for elder people. It provides help and various social services for elder people, with a focus on social life and integration (sports, cultural activities, language and computer literacy courses etc.). Pro-Senectute also offers a variety of non medical home based care services, such as: visits to isolated elder people, transportation services, meal delivery, administrative services such as declarations and support for family carers (in the form of punctual support by non medical carers. Pro-Senectute's focus in on social integration.
- *The Swiss Red Cross* (www.redcross.ch) and *Swiss Alzheimer* (www.alz.ch), two non profit organisations, also provide a variety of services that can be claimed by elder dependent people, namely transport for people with limited mobility, punctual relief for informal carers, and alert systems for dependent elder or disabled people who live alone. Both organisations have cantonal branches.

Information and counseling

Information and counselling to elder people are provided chiefly by municipalities. However, Spitex, Pro-Senectute and the Red Cross also offer various counselling services. Spitex's homepage for instance provided a comprehensive and useful overview of the most important questions regarding available services and tariffs¹⁸.

Decision-making procedures

According to the national law on health insurance LaMal, everybody who is under an officially recognised health insurance scheme is entitled to long term care (regardless of his or her age)¹⁹. Demands for long term care have to be addressed to the local authorities or the local organisation in charge (such as Spitex). Each claim for long term care is assessed by relevant professionals mandated by home based care organisation. Nursing care for instance will be provided only upon medical prescription.

¹⁶ "Leistungsauftrag" – Spitex is mandated for the implementation of home based care.

¹⁷ <http://www.spitex.ch/index.cfm/CFA46D68-E947-FF4A-E88B14767BB81650/>

¹⁸ <http://www.ch.ch/private/00029/00041/00405/00406/index.html?lang=fr>

¹⁹ <http://www.aide-soins-domicile.ch/index.cfm/CFAD1211-C8F4-6C925B52FD8119D11097&cfid=24902559&cftxt=68554731/>.

The needs assessment is made on the basis of various evaluation systems. For home care, the only instrument promoted at the national level is a Swiss version of *RAI-HC* (Rail Home-care²⁰). It has been developed by Spitex Switzerland (Swiss Association for Home Care Services) and the private company Q-sys. It was tested in 2001 and recently improved (2009). *RAI-HC* is both a needs assessment *and* a quality assurance tool. It consists of several steps, starting with an administrative assessment of the rights of the elder person, followed by a personal visit and an assessment of the precise needs (medical, care, domestic services) of the person. This needs assessment is then processed and translated into a precise list of services that shall be provided to the person. *RAI-HC* has not yet been widely adopted at the cantonal level. (see below under “quality assurance”²¹).

Service provision

The main provider of formal HBLTC in Switzerland is the non profit organisation Spitex²² whose 570 local branches provide the bulk (near to 80%) of home based care services. The remainder is provided by other non profit organisations or foundations, independent nurses for profit organisations (see above, and also Gobet and al. 2010). Spitex currently caters to the needs of 239'000 clients annually, of which 47% are over 80 years old. Its collaborators provide 13,7 million hours of services per year: 65% for care services, 33% for household services²³.

Medical services, when judged necessary or medically prescribed, are to a large extent refunded by the health insurance. The tariffs vary from 30.- to 48.50 sfr per hour for simple services in stable situations, to 45-70.- sfr/hour for basic care in complex situations, and medical examinations. Evaluation and counselling cost 50.- to 75.-/hour. The care provider is usually paid directly by the patient's health insurance. Services that are claimed by the patient, but that are not judged necessary in the needs assessment are on the patient herself²⁴.

The cantons can decide that put a part of the costs on the patient. Various cantons have adopted different regulations in this matter, but the maximum amount that can be put on the patient (according to OPAS is 15.95 sfr/day or 5821.- sfr/year). In addition, the the patient also bears in incompressible amount (“franchise” of the health care costs (min. 300.- /year)²⁵, plus a 10% of participation in the actually occurring costs (“participation aux coûts”). The patient also pays a monthly health insurance premium whose amount varies widely from canton to canton. Currently the Swiss average is of 382.-/month²⁶.

Domestic economy services (household services) such as laundering, shopping or accompanying an elder person for a walk are *not* refunded by the health insurance (Medici/Schilliger 2012:17, see also LaMal).

The services provided include at least:

- evaluation and counselling
- nursing care
- prevention
- house care

²⁰ <http://www.qsys.ch/dwl/spitex/Fachinformation-RAI-HC-CH-11-2009-rj.pdf> (12.3.2012)

²¹ The *evaluation system* adopted in nursing homes is BESA, PLAISIR (in the French speaking cantons) or RAI+RUG (Resident assessment instrument).

²² Association suisse des services d'aide et de soins à domicile, in French.

²³ <http://www.aide-soins-domicile.ch/index.cfm/CFB2B2DC-C764-76E0-6DB1EBAA0195597C/?&lang=fr/> (10.3.2012).

²⁴ <http://www.spitex.ch/index.cfm/CFB19AFB-D246-341D-C12312B63CF61536/>

²⁵ <http://www.aide-soins-domicile.ch/index.cfm/CFB19AFB-D246-341D-C12312B63CF61536/>

²⁶ The lowest premium is currently 277.-/month (Appenzell Innerrhoden) and the highest 484.-/month (Basel-City). <http://www.bag.admin.ch/themen/krankenversicherung/00261/index.html?lang=fr>

The cantons or municipalities can add:

- meals delivery and cooking
- transport
- vacation in homes for older people
- nutrition and diet counselling
- home pedicure
- hairdresser at home
- etc.

Clients and types of services

The vast majority of old people who live at home are able to perform most everyday activities without any help, including among the oldest old (over 85). However the need for assistance increases quite linearly with age: only 1-3% of those aged 65-69 need some degree of assistance with everyday tasks, compared to 6-14% of those over 85 (Pierrig-Chiello 2010: 11).

According to the figures of the Federal statistical office (2011b: 13), 64% of the total number of hours devoted to formal home based care are *medical services (soins)* whereas 34% are domestic services (*aide*). 64% of all hours spent on homes based care services were reimbursed by the obligatory health insurances (OFS 2011b: 13).

47% of of the clients who have claimed home based care services in 2008 were over 80; 28% were aged 65-79, and 25% were below 65 (Höpflinger et al. 2011 : 83). In other words, the bulk of home based care services is provided to the eldest of the elder, and about two thirds of all services are provided to women.

Practitioners and carers

The bulk of home based care in Switzerland is provided on a *long-term* basis: 70% of the clients of home based care services (Spitex etc.) are long-term clients, only 30% are temporary clients (Pierrig-Chiello et al. 2010: 4).

Home based long-term care is very often provided by both professional (paid) *and* informal carers. According to the Swiss health survey 2007, 60% of all clients of paid care services simultaneously also received assistance from informal carers (family members, friends, neighbours) (Höpflinger et al. 2011: 88). This is true in particular for very old people (over 80) who live alone, and for whom paid care services often complement informal care.

Old people with relatively benign functional limitations often rely on informal carers only. Increasing degrees of functional limitation are usually associated to a greater use of formal paid care, even more so for elder people who live alone: they require formal care more often and earlier than elder people living with a partner.

More exactly, 33% of elder people who live alone and who require light to middle-range assistance rely on informal care only; 30% rely on a mixture of professional and informal care; 13% rely on professional care only, and 24% do not claim any form of assistance. The more extensive the care needs of the elder person, the higher the association between formal and informal care: among those who require extensive care, a majority (54%) rely on both professional and informal care.

Elder people who live with a partner claim less formal care: 48% of elder people who need low to middle-range care, and 36% of those who require extensive care, rely on informal care only. 22% of those living with a partner receive help from professional carers, informal carers within the family *and* informal carers outside the family (Höpflinger et al. 2011: 89).

Professional carers

According to the Spitex statistics for 2010, some 36'000 professionals were involved in the delivery of (paid) home based care services, most of them on part-time basis (43% average employment rate, OFS, 2011b: 9). A large proportion of paid carers (39%) have no specific training, whereas 30% are fully trained nurses²⁷. A further 21% have a basic training (for example medical assistants, nursing assistants, etc.) (OFS 2011b: 9).

The density of the professional carers' networks varies from canton to canton. The overall Swiss average is 2 full-time care jobs per 1000 inhabitants. Some cantons have a much lower density (1.1 professional carer per 1000 inhabitants in cantons like Nidwald and Glaris), some others a much higher density (3.6 carers/1000 inhabitants in Geneva, 3.7 in Basel-City, cf. OFS 2011b: 10).

Role, integration, recognition of informal carers

Informal carers play an important role in home based care in Switzerland. About one third of all care to elder people living at home is performed without payment: 10% by members of the same household, and another 20% by friends, relatives or neighbours, two thirds of them women (Schneegg and Bieri 2010²⁸). Dependant elder people in Switzerland today receive care of an average of 2.4- 2.7 informal carers (usually one main carer plus 1.4- 1.7 additional carers) (Pierrig-Chiello 2010: 35). Macro-economically, unpaid care to adults amounts to an estimated equivalent of 186 million francs per year and 700'000 working hours (Bureau de l'égalité 2010: 7-9, see also Schön-Bühlmann 2005). Finally, an estimated 21% of the Swiss resident population, especially women, provides informal help to children or adult relatives (OFS 2010). 81% of the overall informal care (including child care) in Switzerland is done by women²⁹.

Being a carer often has a negative impact of the carers' own well-being: caring partners and children have feel significantly worse than the average population (Pierrig-Chiello 2010: 32). Partners – in particular female partners – invest double the time into the care of their dependent partner as they would like to invest (Pierrig-Chiello 2010: 36).

Since 1997 Furthermore persons caring for relatives living in the same household may claim a bonus for care-taking which is considered in the calculation in the old-age pension³⁰. A pilot project ("bourse de temps") is currently under study at the federal administration: it aims to encourage informal caring to elderly people by providing carers with a credit on their own future care needs³¹. Other than that, non professional carers cannot claim any benefits from the federal level. However, the cantons may decide to compensate informal care: the canton of Fribourg for instance has passed a law that allows for some financial assistance of the carers, for example in the form of paid placement of the dependent person in home for the duration of

²⁷ Nurses level II (tertiary degree diploma) for most of them (27.8%), level I (official but non tertiary degree) for a minority (2.2%).

²⁸ The Federal Statistical Office gives a similar figure for care services to the overall adult population: about one third of care services for adults are performed without payment (OFS (ESPA survey) quoted in Bureau fédéral de l'égalité 2010: 9).

According to these figures, informal care services to adults amount to a sum of 186 millions francs per year.

²⁹ Half of the female carers (51%) look after their partner, one third (37%) after their parents. Among the male carers, a majority cares for their wife (61%) and one third for their parents (Pierrig-Chiello 2010: 23). The importance of the partner as primary carer diminishes with advancing age, whereas the importance of the *daughters* increases (2% of elder people 70-79 receive help from their daughters, against 10% of those over 85). The sons are overall less important as main helpers, however with increasing age of the parents, their role becomes equally important to the role of the daughters²⁹. Brothers and sisters do not provide a significant share of informal care, but neighbours do (about 20% of elder people say that they receive help from neighbours and friends (Höpflinger et al. 2011: 71).

³⁰ A "virtual" salary (Bonifications pour tâches d'assistance (LAVS)) that counts towards the calculation of the old age pension.

³¹ <http://www.bsv.admin.ch/themen/gesellschaft/00074/02391/index.html?lang=fr>

the carer's vacation. But this financial assistance is neither obligatory nor systematic, and is not officially recognised as such. Therefore, Weaver et al. (2008) predict a future decrease of the number of non professional carers, which could increase the costs of long term care. Therefore the Swiss Academy of Medical Sciences recommends to increase financial and structural help for informal carers.

Semi-formal carers

Interestingly, Switzerland is currently experiencing a new form of care that is at the frontier of professional paid and informal care: since the extension of the bilateral agreements with the EU in 2011, Switzerland is witnessing and increasing inflow of care workers from East Central Europe (Slovakia, Hungary, Poland and East Germany) who often live with the elder person and work under rather precarious and unclear working conditions, at the limit of legality. Many of them reside in Switzerland only temporarily (cf. Medici/Schilliger 2011)³². They are paid, but at the same time work under conditions similar to informal carers (family members in particular), with undefined working hours (night watch and other times of "presence" often not being counted as working hours, etc.)

Organization of Home based LTC

The Swiss health care system is legally grounded in the federal health insurance law (LaMal). Long term care as a specific component of the health care system does not yet have a legal basis proper: it is integrated by "bits and pieces" into the various components of the general social security system (Gobet and al 2010), such as the federal health insurance, the federal retirement and invalidity insurance (AVS-AI), and the private pension system (LPP).

Relations LTC/Health care system

HBLTC for elder people in Switzerland relies heavily on informal carers who do an estimated 30% of the care work. The remaining 70% services are delivered to a large extent (90%) by private non profit organisations, to a much smaller extent also by independent nurses and private for profit organisations (10%). Of the 16 millions hours of HBLTC delivered in 2010, two thirds (64%) were medical, one third (34%) were help with domestic tasks and 2% other (meal delivery). The strong medicalisation of HBLTC services is reinforced by the fact that the mandatory health insurance reimburses only medical care services.

Service provision is grounded on a tight cooperation of private and public actors, non profit and for profit actors, with doctors (local general practitioners) in a key position. The initial *needs assessment* is done either by local authorities or by private HBLTC providers upon mandate of the local authorities.

The actual *delivery* services is to a large extent (90%) done by the private non profit (namely Spitex) who mostly offer medical services, non medical care *and* domestic help services.

The delivery of medical services is subject to *quality assurance* standards set by the federal law and implemented by cantonal authorities. Non medical services are not subject to a uniform quality assurance control.

The *costs* for HBLTC services are borne by the mandatory health insurance that covers 60% of the *medical* of the costs for services; by the local authorities (20-40%) and by the patients themselves, in the form of an annual out-of-pocket contribution to their health care costs, a cost participation and, in most cantons, in the form of a specific contribution to long-term care costs (see below for details).

³² None of the official statistics take into account this new form of care.

HBLTC care in Switzerland relies on a tight interdependence of and collaboration between private and public actors, mainly at the local and cantonal level. The federal health insurance law only sets a general framework for the reimbursement of medical care and for quality assurance with regard to medical services. All other aspects are regulated at the cantonal and local level, often with a highly insufficient coordination.

System governance and planning

The services and institutions in home-based long term care are neither financed nor planned in an integrated way. The federal government and the 26 cantons define the main features of elder care policy. However, federal impulses (such as the recent strategic report on old age, Conseil fédéral 2007) have *no constraining force* and are *not* action plans.

The competence for the planning and governance of HBLTC (and health in general) is with the cantons. The cantonal health ministers periodically gather in two coordination forums: the so-called *federal “conference”* of health ministers (CDS-GDK), and four regional conferences of cantonal health ministers. These conferences act as coordination bodies that may reach some degree of harmonisation of legislation, however such a harmonisation is always based on a purely voluntary cooperation of the cantons.

The quality of *medical* HBLTC services is subject to quality control as defined by the federal health insurance legislation (LaMal). The quality of non medical services is not subject to a unified system of quality control (see also below). Significantly, the Swiss council of seniors deems the existing quality evaluations insufficient and hopes for an improvement of HBLT services³³.

c) Financing HBLTC

Cost structure

In 2010, the expenditure for long-term home based care was about 2.6%³⁴ (1.3 billion francs) of the overall health expenditure in Switzerland (OFS 2011b:4, figures for 2010), and 0.2% of GDP (OECD 2011)³⁵. It is expected that these costs will increase massively by 2030 in real terms (Pellegrini and all. 2006), mainly due to the increase of the cost of each case (price and volume of services). According to current projections, the increase of the number of patients will explain one third of the increase in costs, while the combined effect of increasing prices and volumes of services provides will explain two thirds of the increase in costs.

The funding of home based long-term care is characterised by a total lack of homogeneity. The only services that are funded through a homogeneous scheme are acute care and transitional care during the two weeks following hospitalisation. After this period, each canton defines its own funding regime³⁶. The only other homogeneous regulations for home-based care services are those contained in the federal health insurance law (LaMal) and that concern the reimbursement of *medical* home based care services. According to the latest revision of this law (2008), the health insurances cover 60% of the costs for medical home based care. The remaining 40% are on the public authorities and on the beneficiaries, according to

³³ www.ssr-csa.ch/.../Microsoft_Word_-_QS-Lpfl_Bericht_fr_20070424.pdf

³⁴ The total expenses for long-term care, including in residential environments (nursing homes etc.) amounts to bit less than 15% of the total health expenditure (Gobet et al. 2010: 4).

³⁵ For 2010, the Federal Statistical Office counted a total of 1162 home based care providers, employing 36'000 staff for 15'600 full-time equivalents and catering to the needs of 262'000 clients.

³⁶ Association suisse des services d'aides et soins à domicile/Spitex, personal communication, 23 February 2010, Barbara Lucas.

cantonal legislations that vary from canton to canton. Non medical care services are not reimbursed.

For 2004, Weaver et al. (2008:26) found that the overall HBC costs were borne to one third (32%) by the mandatory health insurances, to another third (32%) by direct subsidies of public authorities, and to the remaining third by private households (6%), social security (retirement insurance AVS) (24%) and other (6%).

No macro-indicators are available that would tell us exactly who pays what proportion of HBLTC services today. However, the proportion of costs borne by the HBC patients has in all likelihood increased, given that that recent changes in legislation now allow to put a supplementary costs on the beneficiaries (see below). Also, the overall contribution of the health insurances to the total HBLTC costs has decreased given that a recent change in legislation (2011) has reduced the reimbursement rate for medical home care services from 100% to 60%.

As we will see below, the definition of activities covered by the mandatory health insurance in particular has been strongly debated and the scope over health insurance coverage has been reduced over the years. The most recent reductions in the scope of funded services are: in 2011, a reduction of the reimbursement of long term care by medical personnel (doctors, nurses) to 60% (the remaining 40% are to be covered by the beneficiary himself and by the local authorities); and in 2012, a new law on hospital funding that introduces the principle of *case based funding* (cf. Lucas 2011).

The only precise figures that we currently have are figures for the structure of *generated income* of HBLTC provider organisations.

Generated income

In 2010, home based care generated a total income of 1585 million Swiss francs (OFS 2011b: 15). 52% of this income stems from billed services (care, assistance, meals and other services), 45% from public subsidies (of which 42% cantons, 58% municipalities, municipal associations, parishes, etc.), and the remaining 3% from donations, memberships fees etc. (OFS 2011b:15).

Non profit private provider organisations and public provider organisations were strongly subsidised by state institutions: in 2010 they received a total of 708 million Swiss francs subsidies, amounting to 51% of their total income. Another 45% of their income was generated through their own service provision (685 million francs), mainly through medical services (73% of all total services), domestic economy services (19%), meals (5.5%) and other (2.5%) services (OFS 2011b:15)³⁷.

In contrast, private for profit organisations generate a larger part of their income through domestic care services (34%), and a somewhat lower part through medical care (63%).

The income of independent nurses stem nearly exclusively from medical services.

Funding modalities from the point of view of the patient

Unlike Germany, the Netherlands and Japan, Switzerland has no mandatory, comprehensive, long-term care social insurance for the elderly. While long-term care is largely regarded as an individual³⁸ and family responsibility, part of the long term care expenditure is covered by the

³⁷ These figures do not tell us what the exact distribution of the total amount over the various *paying agents* were. Billed services that fall under the federal health insurance for instance are not integrally paid for by the health insurance, but distributed over the insurance (60%), the canton and the patient (to varying proportions according to cantonal legislations).

³⁸ The Swiss old age pension system reflects this emphasis on private responsibility: the mandatory public old age pension

mandatory health insurance (Health Insurance Law, LAMal), the retirement and invalidity insurance (AVS-AI), and the so-called supplementary benefits to AVS-AI pensions.

From the point of view of the HBLTC patient, the division costs goes as follows:

Medical services prescribed by a doctor are to a large extent covered by the *mandatory health insurance* (cf. federal health insurance law LAMal) organised through competing non-profit insurers to which the insuree pays a monthly premium that varies from canton to canton and from insurance to insurance (the Swiss average is of CHF 382.-/month). The health insurance covers *medical costs* exclusively³⁹, but not entirely. Three types of expenses are on the patient herself: firstly, an incompressible out-of-pocket base contribution⁴⁰, (“franchise”) of 300.- to 2500.-/year (depending on the insurance model that the patient has chosen⁴¹); secondly a 10% contribution to the actually occurring health costs up to a maximum amount of 700.-/year (“participation aux coûts”); thirdly, in some cantons, an additional contribution for home-based care services whose amount varies from canton to canton, but that is of max. 15.95/day or 5822.-/year. (see also below).

Expenses for the costs induced by long-term permanent impairments are covered under the legal framework of the public *retirement insurance (LAVS)*, through the instrument of “*invalidity allowances*”⁴² (“allocations pour impotence”). These allowances can be claimed by elder people with severe, moderate or mild⁴³ invalidities⁴⁴. The amount of the cash benefit varies depending on the degree of disability and whether they reside at home or in an institution. The amount of the benefit for a person living at home is of CHF 464.-/month for a mild disability, and of 1856.-/month for a severe disability⁴⁵. There are no restrictions on the services that can be purchased or financed with this allowance. Invalidity allowances are not means-tested, their amount depends solely on the degree of invalidity of the beneficiary.

Retired people whose basic pension is insufficient to cover their living costs can claim so-called *supplementary benefits* (“prestations complémentaires”, PC), under the framework of the *retirement insurance law (LAVS)*⁴⁶. These supplementary benefits can be used in particular to cover per-diems in nursing homes as well as home-care costs⁴⁷. The amount of the supplementary benefits is of max. CHF 90'000 per year for a single person with a severe

(AVS), the first “pillar” of the system, by constitution covers only the *basic* needs of the assured person (As per 2011, the basic pension for a single person who has paid full contributions (44 years) into the retirement insurance is of minimum 1160.- and maximum 2320.- sfr³⁸. Married couples are entitled to only 150% of the maximal individual pension. The official retirement age as per 2012 is 64 for women and 65 for men). The second pillar is a private pension that since 1997 is mandatory (http://www.admin.ch/ch/f/rs/831_40/index.html) and grounded in the LPP = Loi sur prévoyance professionnelle vieillesse, survivants et invalidité. The third pillar, finally, is a voluntary private insurance (the law allows for tax reductions for amounts paid into an insurance scheme).

³⁹ Such as defined by OPAS, the federal ordinance on the allowances of the health insurance Ordonnance fédérale sur les prestations de l'assurance des soins 832.112.31.

⁴⁰ The insuree chooses which basic amount s/he want to cover herself or himself; the higher this amount, the lower his/her monthly health insurance fee.

⁴¹ The higher the out-of-pocket base contribution of the patient, the lower the monthly insurance premium.

⁴² People under the age of retirement can claim similar allowances under the framework of the federal law on the invalidity insurance (LAI).

⁴³ Allowances for mild invalidity exist since 2011 only. see <http://www.admin.ch/ch/f/ff/2008/4751.pdf> - Loi fédérale sur le nouveau régime des soins, in particular art. 25a, al.1, 3 et 4 LAMa. See also <http://www.santesuisse.ch/datasheets/files/200807041419111.pdf>

⁴⁴ About 45'000 recipients according to OECD (2011) figures.

⁴⁵ <http://www.avs-ai.info/ahv/00164/index.html?lang=fr> – feuille d'information AVS 1.1.2012.

⁴⁶ And under the federal law on the invalidity insurance (LAVI) for those under the age of retirement.

⁴⁷ Per diems are fixed by cantons for nursing homes located on their territory. There is no upper limit for supplementary benefits (except for the reimbursement of costs due to sickness and disability). The supplementary benefit for AVS pensioner in a home for the elderly amounts to CHF 2 500 per month on average (OECD 2011).

disability (Lâamir 2012: 24). About 12% of beneficiaries of an old-age pension receive supplementary benefits.

To sum up, the patient herself bears a variety of costs related to her care needs: the premium for the mandatory health insurance (on average 4584.-/year), an incompressible out-of-pocket contribution to the medical care costs (min. 300.-/year), another incompressible contribution to actually occurring health care costs (max. 700.-/year), and in many cantons a supplementary contribution for home-based care services in particular (max. 5822.-/year)⁴⁸.

These costs are to be covered by the retired persons total income, e.g. her basic pension from the public retirement insurance (AVS) (max. 2320.-/month for a single person); if applicable her pension from the mandatory private pension insurance (LPP)⁴⁹; if the person suffers from a permanent incapacity: from the “invalidity allowances” (AVS) (max. 1856.-/month for a severe invalidity); and if the person’s total income remains modest, from “supplementary benefits” (AVS).

As these figures show, the burden the financial burden that is on the patient is considerable.

Also, supplementary benefits and invalidity allowances need to be explicitly claimed by the patient and require thus a certain amount of administrative work and a knowledge of the legislation. It can therefore be assumed that not all elder people who would be entitled to these allowances and benefits actually claim them.

Current dynamics and discussions on the financial dimension of the HBLTC system

National public debates about the elderly mostly cluster around successive revisions of the federal law on health insurance (LaMal - 1994) and on the federal law on the old age and retirement insurance (AVS)⁵⁰. Both with regard to the health system in general and with regard to home based long-term care in particular, the *financial* dimension is central to these debates. Thus, the current dominant political discourse promotes home base care as a way of cost containment.

In 2008 Switzerland adopted a new regime of financial equalisation and division of tasks (“péréquation financière”)⁵¹ that was a first step towards a new system. Under this new financial regime, the financial responsibilities of the cantons and of individual people and families have been increased⁵². The middle class is particularly affected by this transfer of charges from the confederation to the individual.

In January 2012, a new regime of hospital financing has come into force: under this new DRG regime (diagnosis related groups), hospitalisations are financed on a *case base* (“forfaits”), independently of the actually incurring costs. The opponents to this new regime fear that patients might be released from hospital too soon and that the care (and the costs) will simply be transferred to home based care. Whether these fears come true or not is yet too early to say.

2. Recent National Reforms in HBLTC

Important reforms

Given that HBLTC is integrated in a variety of legislations and the federal and cantonal level, reforms usually concern the health system in general, with specific implications for HBLTC.

⁴⁸ i.e. a total of 11'406.- per year, which is 4.5x the amount of the minimal public pension.

⁴⁹ The private pension scheme has become mandatory only in 1985.

⁵⁰ Created after the WWII

⁵¹ <http://www.efd.admin.ch/themen/finanzpolitik/02310/index.html?lang=fr>

⁵² For individuals and families, this mainly entails a increased necessity to conclude *complementary* health insurances to improve to coverage provided by the mandatory health insurance.

The recent reforms mainly occurred with regard to the federal health insurance legislation. Long-term care and its reimbursement by the mandatory health insurance is regularly an object of controversy.

Several major reforms have recently impacted on home-based long term care:

- 1) The first is the *new financial equalisation* (“péréquation financière”), voted in 2004 and in force since January 2008, which entailed a re-arrangement of competencies between the federal and the cantonal level, and a related re-arrangement of financial flows. The main goals of this reform were a) a clarification of the distribution of tasks between political levels (“désenchevêtrement des tâches”) and b) a better equalisation of finances between “poor” and “rich” cantons, thanks to re-arranged finance flows from the federal state to the cantons and between cantons, c) an improved inter-cantonal cooperation. With regard to long-term care, this reform entailed namely a new arrangement of financial support to organisations that provide care and support services to elderly and disabled people (Spitex, Pro Senectute etc.). Under the new legislation, the federal state supports only national “umbrella” organisations in this field, whereas all support to cantonal and local organisations/branches is now transferred to the cantons⁵³. Home-based medical and non medical care (including meal delivery, domestic economy services etc.) and also day care centres are now financed exclusively by the cantons (Bonassi 2007: 245).

Under the new legislation, home based care providers can now claim the reimbursement of their coordination costs that until then were entirely on their shoulders⁵⁴

- 2) The second reform concerned the *health care funding system*, in the form of a revision of the federal health insurance law LaMal (debated 2004-08, accepted in 2008, in force since January 2011). The reform had two major stakes: a) a potential increase of the financial burden on long-term home based care patients, b) the introduction of a new category of care services called “intensive transitional care” (“soins aigus et de transition”). On the first issue, the new law contains a provision allowing the cantons to put an additional financial burden of home based care beneficiaries (max 15.95/day or 5822.-/year)⁵⁵. Not all cantons have done so, but the majority have adopted this new regime, shifting 10-20% of the financial costs that are not on the health insurance to the patient⁵⁶. On the second issue, the major stake was the splitting of the financial burden for this new category of care. The new law sets a repartition key of 55% for the cantons and 45% for the health insurance for a maximum period of two weeks. Beyond this two-week period, the participation of the mandatory health insurance was reduced to 60% (the remaining 40% being on the local authorities and the patient)⁵⁷.

- 3) A third important reform is the reform of the regime of *hospital financing*⁵⁸ that

⁵³ <http://www.efd.admin.ch/dokumentation/00737/00782/00784/index.html?lang=fr>, brochure “Réforme de la péréquation financière et de la répartition des tâches entre la Confédération et les cantons”, p. 19.

⁵⁴ New art. 101bis LAVS, see http://www.admin.ch/ch/f/rs/831_10/a101bis.html

⁵⁵ <http://upload.sitesystem.ch/B2DBB48B7E/0CDC636B60/8CCE3F9F7E.pdf>

⁵⁶ For details: <http://www.parlament.ch/f/dokumentation/berichte/berichte-legislativkommissionen/kommission-fuer-soziale-sicherheit-und-gesundheit-sgk/Documents/bericht-bag-pflegefinanzierung-2011-04-26-f.pdf>

⁵⁷ A new minor revision of the LaMal (ordinance) was introduced in 2010, with the new rule that the preparation of medication by medical practitioners is now reimbursed by the mandatory health insurance.

⁵⁸ Partial revision of the federal health insurance law (LaMal). Object 04.061 Loi fédérale sur l'assurance maladie. Révision partielle. Financement hospitalier. For an overview see:

was under debate between 2000 and 2007 and has been in force since January 2012. The most important innovation from the point of view of home based long-term care⁵⁹ was the introduction of a case-based hospital financing, according to the system Swiss DRG (Diagnosis related groups): with this new system, stationary hospital treatments are now financed on the basis of a fixed tariff, depending on the medical diagnose, and independently of the actually occurring treatment costs. Home based care organisations fear that this system will lead to an increase in too early releases of (namely elder) patients from hospital, and a subsequent overload of home based care services.

- 4) The fourth important recent debate, and currently pending reform, concerns *managed care* networks: they have been debated since 2004, and a law promoting managed care networks passed parliament in 2011⁶⁰. The new law gives strong financial incentives to patients to join a *managed care* network, e.g. limiting their choice of doctors to those participating in a given network. The strongest incentives are a significantly lower participation of the patient in the incurred costs (max. 500.-/year under managed care compared to max1000.-/year under the conventional model with free choice of the doctor, plus a possible reduction in the monthly insurance fee)⁶¹.

The federal government strongly promoted managed care, against the opinion of the Swiss Medical Federation FMH that successfully launched a referendum (a “veto”)⁶² against the new law (official validation of the referendum in January 2012), which now has to be submitted to a popular vote, scheduled for June 2012. The Swiss people will make the final decision, e.g. allow the law to come into force or be abrogated. In case of acceptance of the *managed care* legislation by the people, home based long-term care is likely to be affected in the sense that it will require an increased standardisation and professionalisation of service delivery, structural adaptations of Spitex organisations and a redefinition of the self-identity of the organisation (cf. Schauplatz Spitex 4.2011, pp. 31-33, Nagel Dettling/Inauen 2007).

To this list of wide-ranging systemic reforms we can add another one that has crucial implications for *informal carers* but no wide-ranging systemic effect on the organisation of HBLTC:

- 5) The 1997 revision of the retirement insurance (AVS): the new law introduced a “virtual income” for carers who give up or reduce their professional activity to care for a dependent relative (“bonification d’assistance”). No real money is transferred but a virtual is credited on the carer’s retirement pension account and will be taken into account in the calculation of this pension at retirement (currently 41’760.-/year⁶³). Thanks to this rule, the carers can the “damage” that the years spent with

http://www.parlament.ch/f/suche/pages/legislaturrueckblick.aspx?rb_id=20040061

<http://www.admin.ch/ch/d/as/2009/4755.pdf> (law)

⁵⁹ Another crucial change was the modification of the overall repartition of costs between the health insurances and the cantons.

⁶⁰ Object 04.062. Loi fédérale sur l’assurance maladie. Révision partielle. Managed care.

<http://www.admin.ch/ch/f/ff/2011/6849.pdf> (law).

<http://www.bag.admin.ch/themen/krankenversicherung/00305/06506/06664/index.html?lang=fr>

⁶¹ <http://www.bag.admin.ch/themen/krankenversicherung/00305/06506/06664/index.html?lang=fr>

⁶² A referendum in the Swiss political system is a “veto” against a decision taken by the parliament. A veto is successful if at least 50’000 Swiss citizens sign it, and its consequence is that the decision taken by the parliament is provisionally “suspended” and has to be submitted to a popular vote whose decision will be final and authoritative.

⁶³ This amount is a “middle range” contribution to the pension rights, i.e. it ensure a pension that is about mid-way between the minimal and maximal pension (1763.-/month). Art. 29 sexties LAVS + Art. 52f RAVS.

caring for dependent relatives does to their pension entitlements⁶⁴ (Deplazes 2012: 21)⁶⁵.

Finally, it is worthwhile mentioning that two additional issues are currently pending with the federal authorities:

- In March 2012, the lower house of the federal parliament accepted a parliamentary initiative claiming the introduction of an “*assistance allowance for (informal) care givers*” (allocation d’assistance aux personnes qui prennent soin d’un proche”⁶⁶, against the opinion of the parliamentary committee in charge. The suggested allowance is thought as a proper compensation for example for carers who reduce their working time (e.g. loose part of their income) to care for a dependent relative. The parliamentary committee argued against this initiative claiming that it was too costly and not necessary. The issue is pending with the National Council (lower house) who has not yet scheduled a debate.
- In September 2011, a member of the lower house of the federal parliament introduced a demand (“postulat”) that asks the federal government to examine the introduction of a special *insurance for long-term care*, either as an autonomous insurance scheme or as part of existing insurances (retirement insurance or health insurance). The demand is pending with a parliamentary sub-committee⁶⁷. A few years ago (2004-05) both the parliament and the government had rejected the idea of introducing such an insurance.

Debates and discourses concerning the reforms

The debates over health care reforms of the last 20 years have been dominated by the issue of *cost containment*, in a context of demographic change that will foreseeably lead to a substantial increase in health costs for elder people. This focus on the financial dimension of health can also put in the context of a strong increase in the costs of the health system since the 1990s, in particular since the federal health care law of 1994 that first introduced principles of market competition in the health insurance “market”. Home based long-term care is in a somewhat ambiguous position in these debates: on the one hand, the foreseeable massive increase in the proportion of elder people over the next two decades triggers fears over an explosion in long-term care expenditure; but on the other hand, *home based* long term care is often seen as a way of containing the costs (cf. Weaver et al. 2008).

The main stake of the debates centred on the funding regime was the *repartition key* that shall apply to the division of the overall costs among various actors. One big issue was the repartition key between the *patients on the one hand and the health insurances and the public authorities on the other hand*. The above-mentioned 2008 health care funding system reform had a major implication for patients in home based care: it shifted a higher financial burden from the health insurance to the patient, by giving the cantons the possibility of putting a substantial amount of home based care (max 16.-/day or 5820.-/year) directly onto the patient. Although not all cantons made use of this possibility (or not to the full extent legally allowed),

⁶⁴ To be entitled to a full basic pension, the person needs to have paid 44 years of social security contributions into the system. Before the introduction of this virtual income, housewives simply “lost” entire years of contribution and thus were penalised at the age of retirement (each year without a minimal social security contribution leading to a proportion reduction of the pension).

⁶⁵ The amount of the pension is calculated on the basis of a) the number of years that a person has contributed to the pension system (44 years are required for a full pension) and b) the amount that s/he has contributed.

⁶⁶ http://www.parlament.ch/ab/frameset/f/n/4902/376098/f_n_4902_376098_376275.htm, initiative parlementaire Meier-Schatz Lucrezia 11.411 – Créer une allocation d’assistance pour les personnes qui prennent soin d’un proche.

⁶⁷ Postulat 11.4009, Fehr Jacqueline: “Créer une assurance de longue durée”.
http://www.parlament.ch/f/suche/pages/geschaefte.aspx?gesch_id=20114009

a majority of cantons have shifted some burden onto the patients⁶⁸. Significantly, the federal parliament discussed this issue mostly from the angle of cost containment, much less from the point of view of the implications for the patient that were far from “trivial” (5820.- is about 3.5x the amount of the minimal basic old age pension) (Guinchard 2009).

The second big issue with regard to the repartition key for funding was the *repartition of costs between the health insurances and the public authorities*: the same 2008 law also strongly reduced the contribution of the health insurances to the coverage of medical services: it passed from 100% to 60%, the remaining 40% being now onto the patients and on the public authorities (i.e. the cantons). Underlying this financial issue was a definitional as to whether long term nursing care was to be included or excluded from the scope of the mandatory health insurance. This debate was of symbolic *and* practical importance, given the foreseeable increase in long term nursing costs in the future, and given the steady increase in health insurance primes charges to the insurees over the last 20 years. The concern of the federal government in this respect was to limit the extent to which the increase in health costs due to the ageing society should be put onto the health insurances (Conseil fédéral 2005).

Finally, a third big issue with regard to the financial repartition key was the division of costs *between the federal state and the cantons*: with the financial equalisation of 2008, the financial burden for health care was shifted from the federal state to the cantons.

As Guinchard (2009) significantly found in an analysis of the parliamentary debates on the 2008 reform, most parliamentarians were very uninformed of the realities of medical and nursing care, and tended to speak of care providers mainly as “market participants”, while often neglecting the patients’ perspective. Although the female parliamentarians often adopted a more “human centred” approach, the overall debate remained very finance centred.

However, issues other than those dealt with under the *cost containment frame* have been present in recent debates as well. The first one was the issue of the *status of dependency*, whether it shall be considered as a new social risk or as an individual responsibility. This issue was discussed in the early 2000 in connection with a (failed) reform of the federal health care law. The federal government back then rejected the new social risk option and, consequently, the introduction of a specific insurance for long-term care (Despland 2009). The same issue is now on the table again, with the above-mentioned parliamentary intervention (2011) claiming the introduction of such as insurance.

A second issue in the context of recent debates was the *independence* of the doctors with regard to the health insurances: doctors (and nurses) are increasingly preoccupied by a tendency of increasing bureaucratisation and interference of the health insurances in medical decisions (and, related, to a loss of medical confidentiality), and by a risk to have to submit medical decisions to economic factors. This issue was raised in the context of the 2012 law on hospital funding (case-based DRG funding).

A third issue is the *patients’ freedom to freely choose their doctor*. This issue is currently on the table with regard to the above-mentioned pending attempt of the federal parliament to reinforce the legal basis for *managed care* networks, e.g. by giving very strong financial incentives to patients to join such a network and thereby voluntarily limit their free choice of doctors. Doctors, nurses and home based care providers fear that this new funding model will lead to doctors having to subordinate medical decisions to financial constraints. Home based care providers fear that patients will be released too early from hospital, a fear that is not massively shared by the doctors themselves⁶⁹.

⁶⁸ <http://upload.sitesystem.ch/B2DBB48B7E/0CDC636B60/4A4DDF0E64.pdf> (www.spitex.)

⁶⁹ http://www.fmh.ch/files/pdf2/2009_09_10_Positionspapier_SwissDRG_D.pdf
http://www.fmh.ch/files/pdf6/2012_01_04_SAEZ-Artikel_SwissDRG_D.pdf
http://www.ssp-vpod.ch/actualites/nouvelles/ansicht/browse/1/article/des-dizaines-dactions-dans-toute-la-suisse-et-30000-citrons-sur-la-place-federale-a-berne.html?tx_ttnews%5BbackPid%5D=34&cHash=5adcf93d78

Finally, a fourth issue that has reached the political agenda more recently is the issue of *beneficiary participation* in health care policy decisions, as part of a wider discussion on the promotion of health and autonomy, one of the strategic priorities of the European Year of Active Ageing (2012) to which Switzerland has associated itself (see also below).

Despite the dominance of the cost containment frame, other discourses and discourse coalitions have been present in the Swiss public sphere. One coalition, dominated by professional associations, defends an increased *professionalisation* of care⁷⁰. Another minority coalition would rather favour the elaboration of a global care strategy that should take into account the variety of care needs over the life-course, and promote a wide understanding of care beyond purely medical definition and beyond the current predominance of economic aspects. Such a global strategy would entail an increased recognition of informal care, new redistributive measures (such as care allowances or tax reductions for informal carers), and – importantly – an explicit sensitivity to gender equality issues. To this coalition belong key federal institutions, namely the Federal Gender Equality Office and the Federal Commission for the coordination of family issues COFF (see for instance Bureau fédéral de l'égalité 2010, COFF 2006, Lucas 2011).

“Non issues”

Significantly enough, recent debates of health care reforms have been characterised by three “non issues”, e.g. issues that are central to care in general and home based long-term care in particular, but that were hardly discussed. The first such issue is the definition of *care* itself. Interestingly enough, the term “care” has not been given any clear and global definition, neither in the current Swiss legislation nor in the political debates around structural health care reforms. To the extent that it is given some precise meaning at all, this meaning remains scattered across different legislations and is limited to a description of the reimbursable care *services*. Nowhere does the legislation take into account care as a global phenomenon that potentially entails the intervention of a variety of health care actors, professional and informal (cf. Guinchard 2009).

A second significant absence in the debates around health care reforms is *gender equality*. Swiss health care and social policies remain heavily grounded in a (modernised “bourgeois”) “male-breadwinner” model, in which women with small children work part-time or not at all⁷¹. The above-mentioned recent reforms, namely the reduction of the coverage of medical care services by the mandatory health insurance (reform of the health care funding system, in force since 2011), have gendered implications: on the one hand they increase the pressure on women to take on an even bigger share of informal care than they already do (cf. COFF 2006). On the other hand, this reform also heavily penalises elder women beneficiaries of home based care: many of elder women have a lower pension than men because the years they spent catering to their children did not count towards their pension rights⁷². Although the current reforms do not unilaterally favour a “re-familiarisation” and decommodification of care⁷³, there is a clear risk that the dominance of the *cost containment frame* in the political

<http://www.sbk-asi.ch/webseiten/francais/0default-f/Hintergrund%20Managed%20Care-f.htm>

⁷⁰ For example: the Spitex, the Swiss association of nurses, Forum helvétique sur l'accueil prolongé des personnes âgées, Swiss council of seniors (conseil suisse des aînés).

⁷¹ In two thirds of all families with children below the age of six, the father works full-time and the mother not at all (33%) or part-time below 50% (30%).

<http://www.bfs.admin.ch/bfs/portal/fr/index/themen/20/05/blank/key/Vereinbarkeit/03.html>

⁷² The bonification for care in the old age pension scheme (AVS) was introduced only in 1997, until then, the years housewives spent caring to their children did not count at all in respect to their pension rights who depended entirely on their working husband's social security contributions (see also Despland 2009).

⁷³ HBLTC services such as Spitex have developed very significantly over the last ten years and the current legislation does to

debates will lead to burdening informal carers in general and women in particular even more (see also Bureau fédéral de l'égalité 2010). This risk is all the more pronounced given the fact that gender equality issues are so to speak absent from institutional debates and relegated to negotiations between social partners, in line with Swiss neo-corporatism⁷⁴.

Finally, a third “non issue” in Swiss political debates is the integration of home based long-term care for elder people into a *global federal old age strategy* that would address the issue of elder people’s autonomy and health. Although the federal government suggested some directions for strategic approach to an old age policy in his 2007 report “Ageing in Switzerland” (Conseil fédéral 2007)⁷⁵, it did not provide any concrete means, much the less an action plan (cf. Conseil fédéral 2007: 11, cf. also Gobet et al. 2010). As result, the cantons continue to have their own way of dealing with old age policies, in very diverse and dispersed ways (Gobet et al. 2010, Rielle et al. 2010). Also, financial issue are still at the core of the debates around old age⁷⁶.

3. The National Structures and the Issue of Policy Change in the Domain

Swiss HBLTC policy – or, more accurately *policies* - are characterised by a high degree of complexity, diversity and decentralisation, due to federalism, subsidiarity and the absence of a unique definition and location of *care* within the institutional and legal framework.

The *horizontal fragmentation* of the system between cantons (health as a cantonal prerogative) on the one hand, and between private and public actors (with a dominant position of non profit private actors) on the other hand, is an *obstacle* to reforms. Public actors in charge of some aspect of elder policy (for instance the various national offices in charge of health insurances⁷⁷, or the various cantonal health departments) operate independently of each other and rarely coordinate their actions, legislations and strategies. Similarly, private actors, including the main HBLTC provider Spitex, are equally dispersed into a variety of cantonal and local organisations that do not necessarily coordinate among themselves. There is some degree of cooperation at the local level between local authorities, HBLTC providers, elder homes and medical instances (doctors, hospitals, day care homes). Also, coordination costs for home-based care are now borne by the mandatory health insurance. Nevertheless, coordination remains difficult because it comes at a high cost. In practice, it rarely goes beyond the local or regional level, nor beyond practical and operational aspects of care provision (needs assessment, service delivery).

Under these circumstances, an overall policy change is very difficult to operate and requires enormous coordination efforts. Change is possible if there is a political will and a long enough time frame to harmonise cantonal policies. But in practice, this change remains often limited to a partial “borrowing” of ideas from other cantons, without an overall strategic direction. The dominant position of private organisations in HBLTC service delivery (Spitex in particular) also makes coordination difficult, since as private actors they remain ultimately free of their actions (within the limits of the health care legislation and of quality assurance

some extent acknowledge long term care.

⁷⁴ For a discussion of gender equality issues across spheres of care, see Lucas 2010.

⁷⁵ In response to a motion by the parliamentarian Christine Leutenegger Oberholer, 03.3541, 2003, claiming the elaboration of an old age strategy. See also motion Heim, asking the federal government to define a global strategy for the encouragement of elder people’s autonomy and to improve their health (motion Heim 07.3525, 2007).

⁷⁶ A recent programmatic speech given by the Swiss minister of Internal Affairs and titled “Ageing tomorrow: new perceptions, new realities”, given in 2011 to the assembled cantonal health ministers, serves as a significant example: in this long speech, the ministers spoke at length of various economic and financial issues (social insurance reforms, the role of elder people in the labour market, elder people’s poverty)⁷⁶. At no point does he make any reference whatsoever to issues affecting *frail* elder people, dependence or formal and informal care. Didier Burkhalter, EDI, <http://www.news.admin.ch/message/index.html?lang=de&msg-id=39828>

⁷⁷ Federal office for social insurances, Federal public health office.

for nursing services). As a result, the Swiss HBLTC care suffers from a severe lack of coordination and homogenisation at all levels (services provision, costs, funding schemes).

The *vertical fragmentation* of the system between the federal state and the cantons, with health being a *cantonal* prerogative, also limits the possibilities for policy change given that the federal state has no direct power over the cantons in this field. Whereas federal debates are often dominated by private actors, in particular by the very strong health insurance lobby, changes, cantonal debates can be independent from federal debates and be different from canton to canton. Also, recent tendencies to shift the financial burden of long-term care from the federal state to the cantons (with the financial equalisation of 2008) put pressure namely on the poorer cantons with an unfavourable age structure in the population. In such a context, fiscal competition between cantons may hinder collaboration in a field such as long-term-care. Vertical fragmentation does not always need to be an obstacle to innovation though: it also allows for innovative cantons to propose original policy solutions that, if they prove efficient, might diffuse to other cantons and at some point be given a federal legal basis. This pattern of bottom-up policy-making is common in Switzerland and has allowed for major innovations in other fields of health policy in the past (for example the drug policy and Aids prevention policies of the 1980-90s that were among the most innovative in Europe, cf. Boggio et al. 1997, Cattacin, Panchaud and Lucas 1997). However, when it comes to HBLTC, there are few tangible signs of bottom-up policy innovations.

Recent reforms, and debates about past and pending reforms, show four main tendencies. Firstly, a tendency towards a reinforcement of the health care system's emphasis on the *curative* (e.g. medical) dimension and away from a reflection about *care* in a more encompassing sense (including social needs of the patients, their families and other informal carers). Secondly, there is a tendency towards shifting the financial burden for long-term care from the federal state to the cantons, and from the cantons to private individuals and households. Thirdly, recent reforms have increased the market-orientation of the mandatory health insurances that set increasing constraints or limitations on "risky" (potentially cost-intensive) patients such as elder dependent people, as well as on doctors and public hospitals. Fourthly, recent reforms implicitly tend towards an increased penalisation of women, both as the main beneficiaries of HBLTC and as the main providers of informal care, although it is also true that the role of informal carers is increasingly discussed and, to some extent, acknowledged.

Thus, although the overall recognition of HBLTC has rather increased over the last years, although HBLTC providers are becoming rather more professionalised, although a limited recognition of informal carers has been achieved, and although alternative policy paths are suggested here and there, recent years suggest that policy change currently happens mostly at the expense of local authorities, long-term patients and informal carers (women in particular). The health care system has undergone deep structural reforms over the last two decades, however change remains tightly bound by the all-powerful frame of *cost containment*. The needs of long-term patients, formal and informal carers (mostly women) have received comparatively very little attention.

4. The national HBLTC system and our analytical criteria

a. Governance

The governance of the home-based long term care system is framed by federalism and by the subsidiarity principle, which both limit the power of the federal state. Unlike Germany,

Switzerland has no mandatory, comprehensive, long-term care social insurance for the elderly.

On the vertical dimension, while long-term care is largely regarded as an individual and family responsibility, part of the long term care expenditure is covered and governed at *federal level* by the mandatory health insurance (Health Insurance Law, LAMal), the retirement and invalidity insurance (AVS-AI), and the so-called supplementary benefits to AVS-AI pensions. In this context, the main responsibility with regard to health policy is with *the cantons*, which means that each of the 26 cantons has its own home-based long term care policy. This responsibility has been increased after the new financial equalisation (“*péréquation financière*”) of 2008, which entailed a re-arrangement of competencies between the federal and the cantonal level. The federal state now supports only national “umbrella” organisations in this field of HBLTC, whereas all support to cantonal and local organisations/branches is transferred to the cantons. The cantons can also provide allowances for the financing of the health insurance fees and of health care. Moreover, the actual implementation of home based long-term care lies with the *municipalities*, however their exact responsibilities depend on the canton’s decision. The HBLTC systems in the German speaking cantons are mostly organized on a municipal or even regional basis, whereas the HBLTC systems in the French and Italian speaking cantons are organized rather on a regional or cantonal basis (Dietrich et al., 2009).

On the horizontal dimension, the governance of home based long-term care is characterised by the importance of private insurance, non profit organisations and family care. The principles of free market regulation and competition that have been introduced in the health care system in the mid-1990s and that have become ever more important since. The health insurance sector in particular is partly governed by market principles, and to some extent also the health care providers (including public hospitals).

Then, the (non profit) Spitex organisations are the main providers of HBLTC in Switzerland: they provide 90% of health/care services. The remainder is provided by independent nurses or by for profit organisations (Gobet and al. 2010). Lastly, *private households* contribute heavily to the financing of health care: six times more than in the Netherlands or France, four times more than in Germany or Sweden⁷⁸. The new federal legislation on *health care funding system* implemented since 2011 allows for a potential increase of the financial burden on long term home based care patients at cantonal level.

b. Quality assurance

In line with the fragmentation of the legal, financial and insitutional system, quality promotion and control of HBLTC appears to very fragmented too (Gobet 2010:7).

With regard to services financed by the health insurance (e.g. nursing), quality control is subject to the dispositions contained in the federal health insurance legislation and carried out by actors approved within the health insurance context.

When services are paid for by the beneficiaries themselves (with or without financial support from social insurances) quality control mostly depends upon arrangements made by the providers themselves (nursing homes, home based care provider organisations). These services (mostly non medical) and institutions are subject to oversight by cantonal authorities, based on the cantonal legislation. The cantons, then, are responsible for devising and implementing their own policies of quality control in LTC services (Nies and al 2010 : 22).

In addition to these main level of quality control, municipalities can also evaluate home based care services. Finally, professional organisations (representing doctors, nurses or other health

⁷⁸ Mission d’études et de recherche 2007 *La participation des patients aux dépenses de santé dans cinq pays européen* Haute Autorité de la Santé, Paris: 11.

care professionals) also sometimes elaborate standards or codes of good practices (cf. Gobet et al. 2010).

The national Spitex organisation, the umbrella organisation of more than 600 cantonal and local organisations, actively promotes the diffusion of quality standards. The national Spitex has so far validated only one instrument that serves both for needs assessment and quality control: RAI-Home Care, which is based on 19 quality indicators (out of which 15 that were initially devised for use in North America (Gobet et al. 2010). Spitex's efforts to encourage its members to use RAI-Home Care have so far had a limited success, for several reasons. First, most of the insurances have not formally approved this instrument; second, some of the cantonal HBLTC providers continue to use their own system and have not yet approved the idea of a single quality control system. Finally, the federation of the health insurance companies SantéSuisse has not accepted RAI-Home care either. An additional reason may be the complexity of the certification process of this tool. Three ISO standards apply to long term care⁷⁹. So far, the quality assessment instruments of less than half of the cantons (five German speaking and five French speaking cantons out of a total of 26) have been accredited on this basis, by a body called SQS (Gobet et al. 2010: 14).

In Switzerland *informal carers* are now recognised as very important to the system. New issues around the quality of family care are arising, especially in the context of recent reinforcement of *home based* long term care strategies in many cantons. In short, there is still a high level of disparity in dealing with quality issues at cantonal level in HBLTC in Switzerland (Giraud/Lucas 2010). In 2007, the Swiss Council of Seniors considered that the quality evaluations were not sufficient and that the quality of home based long-term care could be improved⁸⁰.

c. Complementarity and methods of coordination

The federalist structure of Switzerland and the wide-ranging cantonal competencies in matters of health lead to a strong institutional and organizational fragmentation of the health and care system, to the coexistence of a wide range of actors, practices and regulatory mechanisms, and overall to a comparatively underdevelopment of quality assurance⁸¹. This is in itself a massive challenge for coordination in the HBLTC system. It is further reinforced by the liberal tradition of subsidiarity that induces a wide-ranging responsibilities for private actors, often at the local level (implementation, monitoring, etc.). In the field of HBLTC, there are 600 cantonal and local home based care organisations that provide basic services such as nursing care, counselling and house-cleaning help, and sometimes also additional services such as meal delivery. Moreover, the principles of free market regulation and competition have influenced the health insurance sector and to some extent also the health care providers.

This extreme fragmentation of the system, its decentralisation and reliance on private actors is often criticised for its lack of coordination at the vertical level (between the federal state and the cantons) and horizontal level (between cantons and between public and private actors) but also at the operational level (as Spitex organisations face major coordination problems in their service delivery for each individual case). The strict separation between nursing (medical) care and (non medical) domestic and care services when it comes to funding – the former being on the health insurance, but not the latter – does not allow for inclusive care packages. This fragmentation leads to disparities in care provision. Depending

⁷⁹ ISO 17020, ISO 17021 and ISO 17022 (Gobet et al. 2010: 13)

⁸⁰ www.ssr-csa.ch/.../Microsoft_Word_-_QS-Lpfl_Bericht_fr_20070424.pdf

⁸¹ In comparison to the countries with the most developed quality assurance systems (UK, Finland, Netherlands), Switzerland has a much less extensive set of instruments (see Nies et al. 2010: 39).

on where a person in need of care lives, her trajectory within the care system (transitions from one state of vulnerability to another, his/her transfer to another type of care service or facility etc.) will be managed very differently.

However, some coordination mechanisms exist. One is the national Spitex association that gives a certain national unity to the system. It unites the 600 cantonal and local home based care organizations that provide basic services such as nursing care, counselling and house-cleaning help, and sometimes also additional services such as meal delivery. Apart from Spitex, four regional « conferences » group the cantons : they are inter-cantonal coordination bodies that aim at some degree of harmonization of cantonal rules and legislations. Lastly, the national conference of cantonal health ministers CDS-GDK (Conférence suisse des directrices et directeurs cantonaux de santé) that reunites the members of the cantonal executives in charge of health for periodic sessions of discussion and coordination. However, home based care is only one among many issues on the agenda of these bodies. A disputed new legislation on *managed care* is currently pending. In case it should be accepted, it will provide supplementary incentives for a better coordination of the various care providers (doctors, independent nurses, private home based care providers) at the local level.

d. Beneficiary participation and choice

The Swiss health care system is strongly focused on the curative dimension. This is often criticised for inducing an underdevelopment of prevention and of types of care other than purely individual and medical. In Switzerland, the debate on beneficiary participation has mainly concerned disability, and new cash for care system has been implemented since 2012 for disabled adults. Today, with the European Year of Active Ageing, elder people's social participation is framed in the context of promotion of health and autonomy (in the perspective of delaying the process of loss of autonomy). Common ways of creating some space for the promotion of elder people's active participation are forums, conferences and elder councils, both at cantonal and federal level. However two thirds of these initiatives are private, which shows that there is yet a lack of institutionalisation of participatory issues. Some degree of institutionalisation is reported for some cantons though⁸².

Regarding old-age care, and more particularly HBLTC, the debate over participation has so far been very weak. In 1995, a call for more participation was voiced in the national report « Vieillir en Suisse ». In 2007, issues of elder people's self-determination and participation were included in the new governmental strategy for old age policy (« Stratégie en matière de politique de la vieillesse de la Confédération »). This document also acknowledges the restrictions of autonomy that elder people suffer due to their dependency on others (people or institutions). Heavy reliance on other people for one's well-being is also recognised as a problem⁸³. However, the report does not mention any choice instruments such as direct payments or cash allowances for care.

This lack of concern with the participatory dimension is reflected in the INTERLINKS European Overview of quality management and quality assurance in long-term care (Nies et al. 2010: 39) that assesses the quality management systems of ten European countries⁸⁴. For Switzerland no evidence at all is reported on the dimensions « Informed consent and shared decision », « Choice », « client satisfaction » and « information »⁸⁵.

⁸² Saint-Gall, Shaffhouse, Grisons, Argovie (elderly forum), Basel Land (working group), Basel City (elderly forum), Geneva (elder council), Thurgovie (elder conference), Tessin (elder council) and Zoug (a forum for the old elder) (Rielle and al. 2010).

⁸³ Conseil Fédéral (2007). *Stratégie en matière de politique de la vieillesse*. 29 août 2007, p.42

⁸⁴ Austria, UK, Finland, France, Italy, Netherland, Slovenia, Spain, Sweden and Switzerland.

⁸⁵ The report states the the situation for Switzerland is "unknown".

Finally, no choice instruments such as direct payment or cash allowances for care are available for the elderly, contrary to disabled people for whom such instruments are now included in the new Law on Invalidity (AI) that gives disabled people - under the age of retirement only- the possibility to pay an informal (who cannot be a direct relative or a spouse) who provides informal care, in compensation for her reduction in wage loss if she needs to reduce her employment rate (“contribution d’assistance”, assistance allowance)⁸⁶.

⁸⁶ <http://www.ahv-iv.info/iv/00657/00658/index.html?lang=fr>, cf. also Loi sur l’assurance invalidité art. 42quater, 42quinquies. This new provision came into force in 2012. When a disabled person retires, she is transferred from the Invalidity Insurance to the Old Age Insurance regime, with which she loses the possibility of claiming this assistance allowance.

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Appendix: Key figures in brief

The Swiss population is on average slightly older than the OECD average: according to OECD figures (2011), about 17.3% (OECD average 15%) is over the age of 65 years with about 5% (OECD average 4%) over the age of 80 years. In 2008, 6.4% of the population over the age of 65 were recipients of long term care in an institution or health care facility, while 12.3% received care at home. Switzerland's long term care capacity ranks among the highest in the OECD comparison, with 72 beds in institutions and 7.6 long term care workers per 1000 population aged 65+ (in 2007, OECD Health data 2010). Indeed, Switzerland has a comparatively high proportion of elder people living in institutionalised settings (Ruedin and al. 2006)⁸⁷ : according to recent estimations, 57% of all elder dependent people over 65 live in institutions and only 43% at home (compared to 30/70% in Germany for instance, cf. Höpflinger, Hugentobler 2005). Home-based care services are needed mostly for the oldest elderly : 56% of HBC services are delivered to people over 80, and 68% to women (OFS 2011b:12). About one third of all elder people over 85% need care (against less than 10% of those below the age of 79, Höpflinger et al. 2011 : 9). The overall public expenditure for institutional care is accordingly high: an estimated 1.8% of GDP goes is allocated to institutional care – twice as much as the OECD average of 0.9% - whereas 0.2% of GDP only are spent for care services at home (OECD average 0.3%). In terms of total spending of long term care, Switzerland is above the OECD average (OECD 2011).

⁸⁷ 6.6% of all people over 65 live in institutional settings (figures for 2004-07). This is sensibly more than in the neighbouring countries (Germany 3.8%, France 3.1%, Italy 2.0%, Figures from Huber, Rodrigues et al. 2009, quoted by Höpflinger et al. 2011: 104).

Local case studies

The dementia care net in Aachen, North Rhine-Westphalia

1 Introduction

The following case study analyses the dementia care net in the German city of Aachen, North-Rhine-Westphalia. The dementia care net represents an innovative model of case (and care) management regarding complex cases in the context of dementia: A multidisciplinary team of case managers offers early diagnosis, counselling and further referrals in case of dementia while the involved general practitioners who receive specific qualification provide regular medical surveillance. As the dementia care net of Aachen aims at facilitating (more early) access to medical and social care as well as to counselling and opportunities for social participation and as it involves general practitioners, it addresses important shortcomings of the German system of home-based long-term care. It contributes to bridging the gap between the medical sector and the sector of social care, and thus addresses the issues of governance as well as of coordination and complementarities of services. Further, the dementia care net comprises also obligatory qualification measures of the participating actors, whereby it addresses also quality issues.

2 Descriptive section

2.1 General contextual information on the local case

Aachen is a large city of about 250.000 inhabitants¹ in the south-western part of North Rhine-Westphalia at the northern border of the Eifel Mountains. It is encompassed by the rural administrative district of Aachen with another 307,967 inhabitants² and situated in the western border triangle built of Germany, the Netherlands and Belgium.³ In 2009, city and the surrounding administrative district were merged to build the so-called city-region of Aachen that succeeded the former district in law. With about 0.5 million inhabitants it was projected as an economic counterweight to the regions of Maastricht – Amsterdam – The Hague and Brussels on the one hand (which whom Aachen builds the Euregio-Maas-region) and the Ruhr and Rhineland on the other hand. In the beginning of industrialisation the region had a strong textile sector. During the 20th century it was also an important mining and industrial region. Nowadays, after the decline of mining and industry, it is still important regarding technologies, engineering and services. In the municipal information data base of the German Bertelsmann Foundation, the city of Aachen is characterized as a remote but prospering economic centre (Bertelsmann Stiftung, 2005, p. 1) [last access: 25.12.2011]. The Rhine-Westphalian Technical University of Aachen (RWTH) contributes to this with about 33,000 students⁴ as well as its tight connections to local industries and the productive sector. The unemployment rate in the region of Aachen is with 9.7% (31.12.2010)⁵ higher than the German average of 7.1%⁶ and also higher than

¹ End of December 2009: 258,380 inhabitants (IT.NRW, 2010b, p. 40); end of December 2008: 259,269 (IT.NRW, 2009b, p. 32).

² End of December 2009 (IT.NRW, 2010b, p. 50), own counting; end of December 2008: 309 251 (Landesamt für Datenverarbeitung und Statistik Nordrhein-Westfalen, 2008, p. 32)

³ North-Rhine Westphalia is the largest German land regarding its population and the fourth largest regarding area (Statistisches Bundesamt, 2011b, p. 29). The city of Aachen is the twelfth biggest city in North-Rhine Westphalia (IT.NRW, 2010b, p. 40).

⁴ Compare "RWTH Aachen – Über die RWTH – Im Profil" <http://www.rwth-aachen.de/go/id/vex/>; last access: 25.10.2011

⁵ Landesbetrieb Information und Technik Nordrhein-Westfalen (IT.NRW), Düsseldorf, 2011. Arbeitslosenquote - kreisfreie Städte und Kreise - Stichtag zum Quartalsende. Arbeitsmarktstatistik - Arbeitslosenquote (Prozent) 2010. Düsseldorf. Url: <https://www.landesdatenbank.nrw.de/ldbnrw/online.jsessionid=D5651967E1DAC72A0A939D44D760100F?operation=abrufabelleBearbeiten&levelindex=2&levelid=1320156914400&auswahloperation=abrufabelleAuspraegungAuswaehlen&auswahlverzeichnis=ordnungssstruktur&auswahlziel=werteabruf&selectionname=13211-07iz&auswahltext=%23Z-01.01.2010&werteabruf=Werteabruf>, last access: 1.11.2011

⁶ Statistisches Bundesamt (2011). Arbeitslosenquote Deutschland in Prozent, bezogen auf alle zivilen Erwerbspersonen. Quelle: Statistik der Bundesagentur für Arbeit. Wiesbaden. Url: <http://www.destatis.de/jetspeed/portal/cms/Sites/destatis/Internet/DE/Content/Statistiken/Zeitreihen/WirtschaftAktuell/Arbeitsmarkt/Content75/arb210a,templateId=renderPrint.psm1>, last access 1.11.2011

the North Rhine-Westphalian rate of 9%⁷. And notwithstanding its relatively high but recently declining tax revenues per inhabitant, the city of Aachen faces a considerable social segregation (Bertelsmann Stiftung, 2005, p. 4) [last access: 25.12.2011]. The share of persons aged 65 years and older who receive basic social security ("Grundsicherung im Alter") is with 5.2% in 2009 in the city of Aachen considerably higher than the North Rhine-Westphalian (3.0%) or the national (2.4%) average (Statistisches Bundesamt, 2011b, p. 221).

Regarding its demographic situation, the city of Aachen is characterized by a relatively young population as it is typical for university towns: At the end of 2008 about 18% – that is about 46,000 persons – of the 259,269 inhabitants of the city of Aachen were older than 65 years. The population in the surrounding, more rural area, the former administrative district of Aachen, is slightly older but with a share of 20.1% of inhabitants aged 65 and older⁸ still under the average of North Rhine-Westphalia (20.4%⁸) and of Germany (20.7%⁹). In the whole city-region of Aachen almost 19% (108,000 persons) of the in total about 569,000 inhabitants were older than 65.¹⁰ About 16.9% of the city's population is of non-German nationality, in the region live about 13% with another than a German passport.¹¹ Regarding the share of 65+ among those with a non-German nationality data is lacking. On the basis of the German Mikrozensus for 2007 Rüter and Mika-Helfmeier estimate that in the city-region 21% of the non-migrant persons are at the age of 65 and older whereas only 9% of the migrant population are 65 years and older (18% for the whole population) (Rüter & Mika-Helfmeier, 2010, p. 15). This data corresponds to the data provided by the Bertelsmann Foundation according to which in 2009 9.4% of those aged 65 and older had no German passport (6.9% in the city-region and 5.1% in NRW).¹² According to Rüter and Mika-Helfmeier, 15% of elderly persons who have not a German nationality are 80 years and older (ibid., pp. 15-18). In the elderly migrant population the share of men is higher than in the whole population (ibid., p. 16).

Even though the German Constitution guarantees the municipalities their right to self-administration and obligates them to provide basic services for the public, their real room for manoeuvre is limited by their financial situation. Municipalities have so called obligatory and voluntary duties; if they need all their finances for the delivery of obligatory services and duties there is not much left for voluntary tasks. As mentioned above, for some years the city commanded over relatively high tax revenues, which recently declined. This may limit the readiness to invest money in tasks such as a basically preventive orientation of policies and the provision or financing of accessible information and counselling.

Municipal self-administration and politics of the city of Aachen take place in the city's council which is elected every five years (MIK NRW, 1994, §42 (1)). The mayor is elected every six years, since 1999 by the city's population (MIK NRW, 2011), he is the head of the local administration and responsible to the council (MIK NRW, 1994, §62). From 1945 until 1989, Aachen's mayors belonged to the Christian-democratic party. From 1989 until 2009 the elected mayor belonged to the social-democratic party. In 2009, he was

⁷ IT.NRW (2011). Arbeitslosenquote - Bundesländer - Stichtag zum Quartalsende. Arbeitsmarktstatistik, Arbeitslosenquote (Prozent) Nordrhein-Westfalen. Düsseldorf. Url: <https://www.landesdatenbank.nrw.de/ldb NRW/online.jsessionid=63167EB012CF9B0FE5ADC0A6743EE161?operation=abrufabelleBearbeiten&levelindex=2&levelid=1320159640215&auswahloperation=abrufabelleAuspraegungAuswaehlen&auswahlverzeichnis=ordnungsstruktur&auswahlziel=werteabruf&selectionname=13211-06ir&auswahltext=%23SBLAND-05&nummer=3&variable=1&name=BLAND&werteabruf=Werteabruf>, last access 14.12.2011

⁸ Compare Statistische Ämter des Bundes und der Länder (2011) Kreiszahlen, 30-31 (<http://www.statistikportal.de/Statistik-Portal/kreiszahlen.pdf>)

⁹ (Statistisches Bundesamt Deutschland, 2009) [last access: 28.4.2012]

¹⁰ (IT.NRW, 2011, p. 7f.) [last access: 28.4.2011]

¹¹ compare Statistisches Jahrbuch NRW 2009, 48

¹² Compare Bertelsmann Stiftung 2011 Wegweiser Kommune Kommunale Daten - Integration - Basisdaten Integration, url: http://www.wegweiser-kommune.de/datenprognosen/kommunaledaten/KommunaleDaten.action?renderPDF&gkz=05334002,05334000,05000000&zeitraum=7&datenvergleich=1&thema=5&subthema=1&pdffilename=Aachen,_Stadt_Kommunale_Daten.pdf, last access 25.12.2011. Their data is based on the statistical offices of the Länder, the central registry for foreigners in Germany, the federal agency on working policy and own countings.

replaced again by a mayor of the Christian-democratic party.¹³ Since 2009, the Christian-democratic and the green party build a coalition in which they agreed beneath other to extend counselling on living arrangements and to assure diversity in the ageing-related infrastructure (CDU / Grüne, 2009, pp. 9; 17-19). Below the city level, every five years (MIK NRW, 1994) are hold elections on the level of the seven city districts. The representative organ of the newly established council of the city-region of Aachen is the council of the city-region which was elected for the first time in 2009. As in the city, the council is dominated by a Christian-democratic – green majority.

The region of Aachen has a strong catholic tradition, but also a long protestant history. The local branches of the big welfare associations are important providers of social services in the city as well as in the city region of Aachen. There is some tradition of civil engagement, beneath other also on palliative care and dementia. The year 1989, when the Christian-democratic party lost their absolute majority in the city council, marks the beginning of and an important milestone in the city's senior citizens policy: a special staff position responsible for this policy field was set up and by and by expanded to a whole unit with the aim to facilitate staying at home as long as possible, also in need of care. The unit was for long years characterized by relatively high personal continuity; it is only recently that with the merging of city and region to build the city-region major changes in staff and responsibilities took place.

2.2 (Brief) historical description of the development of the local system of HBLTC for the elderly

2.2.1 Demographic development

In this section we give a short overview of the demographic development of the city of Aachen, the former district and the city-region that was recently build from merging both units. The following data is mainly derived from Lerche and Mika-Helfmeier (2010). Data and projections show that the region is not affected by strong tendencies of a declining and ageing population: The population of the city of Aachen as well as of the surrounding region has grown steadily since 2.000 (city) respectively 1985 (former district) (ibid., p. 13). Projections of the statistical institute of the Land NRW predict a small decline of the population of the former district until 2030 of about 0.5% compared to 2008 and a steadily growth of the city's population of about 2.5% from 2008 to 2030 (p. 13).¹⁴ For the whole region the population is predicted to grow slightly until 2025 and then moderately decline (p. 14).

Notwithstanding this development, the share of elderly persons in the population has grown and will continue to do so: Already since the 1970ies, the share of persons aged 65 and older and the share of persons aged 80 and older are growing in the city as well as the surrounding rural district and are predicted to continue to do so for the next two decades (p. 13). The share of the city's population aged 65 and older is predicted to rise from 17.8% in 2008 to 24.9% in 2030 (rise of 7.1%), while the share of those aged 65 and older in the former district is predicted to rise from 20.1% in 2008 to 27.9% in 2030 (rise of 7.8%) (NRW: 20.2% in 2008 to 27.3% in 2030) (pp. 17-18). According to this data, in 2030 26.5% of the population of the city region will be older than 65 years (p. 18). The municipal statistic unit explains the relatively low share in the city with the function of Aachen as University site with the resulting relatively high share of young persons in the population (p. 18). The share of persons aged 80 and older is predicted to rise from 4.7% (12,246) in 2008 to 6.9% (18,475) in 2030 in the city, and from 4.7% (14,621) to 7.9% (24,446) in the former district (p. 16, and own countings). This means in 2030 7.5% of the estimated 573.208 inhabitants of

¹³ Chronique of the city of Aachen
(http://www.aachen.de/de/stadt_buerger/aachen_profil/chronik/pdfs_chronik/chronik_aachen_1976_2007.pdf, 102)

¹⁴ According to the administrative department on empirical research of the city-region, this projection is doubted by the city's own statistic that foresees a short decline of the city's population (Lerche & Mika-Helfmeier, 2010, p. 13).

the city region of Aachen will be 80 and older (p. 16). The data on the share of migrants¹⁵ in the population that is provided by the research unit of the city region is partly based on official statistics, partly on estimations by local experts (compare p. 28). In 2008, about 31.4% of the city's population were migrants; with 21% their share was significantly lower in the former district. For the population aged 65 and older the share of migrants might be incorrect; it is estimated by local statistics to be about 13.9% in the city and about 10.2% in the former district (p. 28). Predictions for the future development exist only at Land level. They predict that in the age group of those 65 and older there will be the highest rise in the share of migrants from 2006 until 2020; only for those younger than 15 a decline of the share is predicted (compare p. 29).

Table 1: Share of persons 65 and older, 80 and older of the population of city, former district and city region in % (according to years)

Age group	City		Former district		City region	Migrants 2008	
	2008	2030	2008	2030	2030	City	City Region
65 and older	17.8	24.9	20.1	27.9	26.5	13.9 ¹⁶	10.2 ¹⁶
80 and older	4.7	7.0	4.7	7.9	7.5	-	-

- data not available.

Source: Lerche, J., & Mika-Helfmeier, N. (2010). Kompendium: Der demografische Wandel in der StädteRegion Aachen. Teilbericht: Regionale und kommunale Bevölkerungsprognosen bis 2030 und Auswirkungen auf ausgewählte Lebenslagen. Aachen: Stabsstelle Kultur, Empirische Forschung und Gleichstellung, pp. 16-18, 28. Own counting of percentages.

2.2.2 Care needs

Perceived care problems

Since the middle of the 1970ies public attention was drawn by and by to the situation of elderly persons in need of care in Germany (Alber & Schölkopf, 1999, p. 129). Even though it lasted until the middle of the 1990ies until the risk to be in need of care was included in the German social insurance scheme, the issues of *care needs* and the *economic situation* as well as the *dignity* of those in need of care had been raised. In 1975, the government of North Rhine-Westphalia adopted a document on municipal planning for senior citizens. According to Zängl (1999, p. 103), it focused mainly on residential care, but started from a problem description that also addressed the position of elderly people in society more generally, especially their economic, social and health situation. Nevertheless, to analyse the existing needs regarding outpatient care and complementary services was said to be impossible in those days because of the lack of data on existing infrastructure. Predictions of future needs were mainly based on the existing infrastructure. (ibid., p. 103) Planning and financing of the infrastructure in those times was in large the responsibility of the municipalities.

In the 1990ies the discourse opened and mentioned also issues of *social integration, quality aspects and community orientation of care*: In 1991, the government of NRW adopted a second planning document which now included also the issues of social integration and support for home dwelling elderly, staff recruitment, as well as a pilot project on a social municipality and the promotion of gerontology (pp. 108-109). It promoted the *principle of "outpatient before inpatient"*: Decisions on public subsidies for long-term care service providers should depart from this second planning document and should prioritize outpatient

¹⁵ According to the available statistical material the notion "migrant" encompasses all persons migrated to Germany with a foreign nationality, those born in Germany with a foreign nationality as well as those born in Germany as Germans who have at least one parent who immigrated or was born in Germany with a foreign nationality (compare Lerche & Mika-Helfmeier, 2010, p. 8).

¹⁶ Quelle: Lerche, J., & Mika-Helfmeier, N. (2010). Kompendium: Der demografische Wandel in der StädteRegion Aachen. Teilbericht: Regionale und kommunale Bevölkerungsprognosen bis 2030 und Auswirkungen auf ausgewählte Lebenslagen. Aachen: Stabsstelle Kultur, Empirische Forschung und Gleichstellung. ; the authors indicate that the values might be incorrect according to their source from the statistical Land office (Lerche & Mika-Helfmeier, 2010, p. 28).

care before part-time care and part-time care before inpatient care; regional conditions and structures should be taken into regard (p. 110). Needs of inpatient psycho geriatric long-term care were to be addressed in every inpatient long-term care facility, not in extra-institutions (ibid.). Following Zängl, for the sector of outpatient psycho geriatric long-term care cooperation with local neurologists and psychiatrics as well as the psychiatric hospitals was claimed to be necessary (p. 110).

According to the retrospection of an active promoter of outpatient psycho geriatric long-term care in Aachen, in the 1980ies there were initiatives in some cities that explicitly wanted to do something new and change something in the provision of long-term care (AC-201103211, 3). Those *civil-society driven initiatives* started from an alternative-progressive milieu. They were based on the perception that - while nursing care was provided - social care and of attendance were yet under addressed, and they wanted to change this. An important target group of professional care services then were older, home dwelling people in need of care who lived as singles and had no family members that could support them in their daily living. Care givers soon were demanding better working conditions, and some were striving for a “good care”.

According to the former activist, in those days there were *no adequate services for elderly persons who were changed mentally or affected by dementia* – a gap which the civil-society based initiative in Aachen in the 1980ies wanted to fill (AC-201103211, 9). To do so, an association was established that build up a new outpatient long-term care facility that did not provide visits that would last less than one hour (AC-201103211, 7). From the end of the 1980ies, its nursing care services could be financed by the health insurance; social care had to be financed by the elderly persons themselves or, in case of indigence, by social welfare. This service soon was accomplished by the city’s first day care facility that could be established with public funding. In the following years public awareness of the needs of persons affected by dementia seems to have risen only very slowly, but during the 1990ies six more day care facilities were founded and promoted by non-for-profit organizations. Today, there are in total 86 places in six day-care facilities in the city of Aachen (compared e. g. to 58 in Bonn or 155 in Köln (IT.NRW, 2009a, p. 28)).

In 1989, the municipality of Aachen established a specialized staff unit to address *the interests of senior citizens* by employing a social planner. The staff unit had been developed out of a telephone hotline of the municipality. Senior citizens with questions regarding ageing-related issues could call this service and were given information or forwarded to other units. Further projects aimed to facilitate staying at home and preventing needs of residential care, e. g. by mediating the contact between landlords and potential tenants of barrier-free flats. Another project aimed at enhancing the quality of dementia care in the day care facilities: In a joint working group staff members from the different day care facilities mutually visited their work and did a kind of “*dementia care mapping*”: they documented care processes and jointly searched for measures to enhance the quality of the caring process.

With the small expansion of the benefits from the long-term care insurance in 2002 the focus turned again on the *needs of persons who were affected by dementia*. In 2004 the Kuratorium Deutsche Altershilfe (KDA)¹⁷ initiated an initiative for dementia-service in NRW. The still existing "Land-initiative for dementia-service" encompasses a bundle of projects to provide information, qualification, support for networking activities and the further development of community services (Kuratorium Deutsche Altershilfe, 2010). To promote this, beneath other measures, 13 service centres on dementia issues were established throughout NRW. Their responsibility was to provide counselling for persons affected by dementia and their relatives. With the change in financing in 2009¹⁸ their focus changed: Nowadays their main responsibilities are counselling and networking for local organisations and initiatives that provide low threshold services of attendance for

¹⁷ The KDA is an institution for policy research and counselling on the consequences of ageing and by this an important stakeholder in the Land NRW, but also at the federal level, regarding ageing-related policies.

¹⁸ Since 2009 the dementia service centres in NRW are financed structurally as innovative agencies from the balancing fund from the long-term care insurance fund. This requires the co-financing of the Land.

people who are affected by dementia, to promote and qualify civil engagement in this sector, to promote the cooperation of in- and outpatient medical care with long term care, and psycho-social, voluntary and professional services of attendance, and last not least to promote the removal of taboos (ibid., p. 2).

Notwithstanding these activities, still important stakeholders in the health care system as well as the general public seem to lack information on the issue of dementia, and stigma still seems to be big, even though there are made many public relations efforts such as films, brochures and other. Another problem that our interviewees who work on dementia issues frequently mention is that of *late access* to the existing services. This is partly contributed to a lack of information, finances or readiness to pay for those services as well as to the prevailing shame and stigma. Furthermore, interview partners from counselling institutions, from the insurers, from long-term care service providers, but also from the side of physicians lament the *deficient knowledge* regarding dementia issues and supporting of general practitioners as well as the *lacking readiness* of general practitioners and specialists *to do home-visits and to cooperate* to guarantee integrated caring paths.

Against the background of projections of the demographic change and accompanying assumptions on the development of care needs and regarding costs, *the situation of caring relatives* as well as *changes in individual social networks* became also a more important issue in public and scientific discourses on all levels.

During the 1980ies in the context of the slowly developing hospice movement, also the awareness of hitherto *unmet needs in palliative care* and at the end of life slowly began to rise. In the city of Aachen, it was again a civil-society driven initiative that then established the so-called Aachen hospice conversations. Based on the agency of some local activists as well as on the financial support of the municipality of Aachen (and the former administrative district as well as the Land) an office for information, counselling, and qualification was founded. Recently also an interdisciplinary palliative care team was established. It took advantage from the right to a so-called specialised outpatient palliative care that was guaranteed in the German health insurance in 2007 but is said to be realized only very hesitantly.

Some of our interview partners mentioned *the probably rising share of poverty among elderly as an upcoming issue* which was situated in the context of declining public finances.

Elderly migrants are the population group whose share is predicted to rise most during the next decades and *who are in a high risk to suffer from poverty* due to labour market inequalities (Rüter & Mika-Helfmeier, 2010, p. 32) and dependant on their legal status restricted access to the German social system. They are in a much higher risk to be dependent on social assistance: In 2009, 11.6% of elderly migrants aged 65 years and older in Aachen (NRW: 13.2%) received the basic social allowance (Grundsicherung im Alter) - compared to 5.2% of all Aachen inhabitants aged 65 and older (NRW: 3.0%) (Bertelsmann Stiftung, 2011, last access: 25.12.2012). Nevertheless their and their families' situation and needs are neither in public discourse nor in actions of the local stakeholders in the city and city-region of Aachen a prominent issue – apart from two reports elaborated by the social planner of the city of Aachen on health and care of elderly migrants that seem to have had little consequences for the development of infrastructure. In 2005 the social planner did an enquiry on the share of migrant clients in local services; according to the providers who participated - it is not indicated how many this were - providers of household near services reported to have 10% migrant clients, in the day care facilities the share was 14% and the residential care homes reported that 4% of their clients were migrants (Köster, 2005, last access: 26.12.2012). Remarkably, only few local actors are aware of this lack of awareness as well action. The relatively low engagement is explained with the lack of stakeholders who could develop this issue, lacking staff with a migrant background in the relevant positions (AC_03232, 76-77).

Development of share of need of care

Estimations on the share of persons who are in need of care always depend on the definition of what is actually meant with the notion “need of care”. In official statistics in Germany the share of the population in need of care is commonly defined as the share of persons who receive benefits of the long-term care insurance (Statistisches Bundesamt, 2011a, p. 29). This excludes certain conditions of being in need of help or care: Entitlement of benefits of the long-term care insurance requires the existence of a considerable need of care (“erheblicher Pflegebedarf”); persons who are in need of care but do not fulfil the requirements to receive benefits thus are not counted in official statistics on care needs,¹⁹ neither are those who do not apply for benefits even if they would qualify for them – may it be because of lacking information, competence or any other reason. According to results from a German representative cross-sectional study by Schneekloth and Leven (2003) the share of persons in private households who are not (yet) in need of care but in need of help is about 2.14 times higher than that of persons who are in need of care in 2002 (own counting based on the data given by Schneekloth & Leven, 2003, p. 7).

Notwithstanding these restrictions, in the following we refer to beneficiaries of long-term care insurance when we talk about persons in need of care. In the city of Aachen their share was about 2.8% (7.261 persons) in 2007, rank 8 of 23 cities in NRW (StädteRegion Aachen, 2010, p. 31) and thereby only slightly higher than the NRW (ibid., p. 31) and German average of 2.7% (Statistisches Bundesamt, 2008, p. 14). In the former district the share was 3.43% (10.644 persons) – the highest rank of all of the 31 districts in NRW (StädteRegion Aachen, 2010, p. 31). In 2007, almost three quarters of those in need of care in the city-region were cared for at home; more than 50% of all beneficiaries received only cash benefits, about 19% relied on professional care service providers (ibid., p. 33). Whereas in the rural area 75.8% of the beneficiaries had been cared for at home, in the city of Aachen only 68.1% had been living at home (ibid., p. 33). In the city, almost 46% of the beneficiaries received only cash benefits, about 22% did also rely on professional care service providers (IT.NRW, 2009a, p. 43, own countings). In the urban area the institutionalization rate of all in need of care was considerably higher (31.9%) than in the rural area (24.2%), where 58.7% of all beneficiaries received only cash benefits, but 1%-point lower than the average of the other district-free cities (ibid., pp. 43-44, own countings). Of the beneficiaries who are older than 65 in NRW 35% are institutionalized, of those beneficiaries older than 80 years 40% are institutionalized (ibid.). For Aachen itself numbers were not accessible. The number of beneficiaries has grown faster in the region than in Land-average (StädteRegion Aachen, 2010, p. 41) and there is a trend to professional care (ibid., p. 39).

Regarding the share of persons who are affected by dementia there are only projections: For 2008 those estimations assume about 6,000 persons in the city of Aachen (this would be 2.4% of the city’s population and 13% of the population aged 65 and older), about one third of them cared for at home (Theilig, Duisberg, & Schirra-Weirich, 2011, p. 7). Taking into account that projections which are based on meta-studies assume a prevalence of 6.5% to 7.3% for the whole German population aged 65 and older, weighted according to the age structure of the population (Weyerer, 2005), the estimation of Theilig et al. for Aachen seems to be relatively high.²⁰ Even if one assumes a prevalence of 7.3 amongst the whole age group of those at the age of 65 and older there should only be about 3,400 persons affected by dementia in the city of Aachen in 2008. For the whole city-region with about 108,000 inhabitants in 2008 there would be an estimated number of about 7,900 persons affected by dementia.²¹ This projection does not take into account any differences in the

¹⁹ One could add the numbers of those who receive municipal social assistance allowance to cover their need of care but do not receive benefits from long-term care insurance.

²⁰ In 2008 about 17.8% (that is 46,280 persons) of about 259,000 inhabitants in the city of Aachen are 65 years and older; 6,000 persons who be affected by dementia would be almost 13% of the population at the age of 65 and older.

²¹ The social planner of the city-region assumes a number of 7,500 to 7,800 persons who are older than 65 years in the city-region to be affected by dementia; this projection is based on the average rate of prevalence given by the German Alzheimer’s Society (Rüter & Mika-Helfmeier, 2010, p. 46).

age structure of the elderly population between the different levels of state, Land, city and city-region and therefore maybe only held as a very rough approximation.

2.2.3 The care market

The introduction of long-term care insurance has changed the local care market in Aachen remarkably, as it did in whole Germany. Before the introduction of long-term care insurance, needs of long-term care had been predominantly met by caring relatives, a few non-for-profit outpatient long-term care facilities - often run by church or welfare associations and financially supported with public subsidies - and some senior citizens residences which later developed into residential care homes. Services had to be financed by the clients' households, in case of diligence by social assistance allowance.²²

In Aachen, like in some other regions in Germany, a first differentiation of the care market took place during the early 1980ies. In the context of the upcoming social movements, there were founded civil-society based initiatives for a more human long-term care in some cities. Those initiatives that were in loose contact with each other aimed at facilitating to stay at home as long as possible and receiving a holistic and comprehensive care when necessary; e. g. one of the (former) principles of the alternative outpatient long-term care provider in Aachen was to spend never less than one hour at a client's house.

The introduction of the long-term care insurance in 1995 induced a development of fragmentation and increasing privatisation of the local care markets in Germany: non-for-profit providers were deprived their privilege of receiving public subsidies. The Länder were made responsible for guaranteeing a sufficient and efficient caring infrastructure (§9 SGB XI). But there was a tension between this responsibility, which was included in the law after lobbying of the Länder, and the intention of the law to foster competition between providers (Rothgang & Wessel, 2008, p. 150): Public investment subsidies had to be granted to all providers - non-for-profit as well as for-profit ones - who would demand it and fulfil defined minimal standards. The necessity to document an existing demand or need for the infrastructure was contested. Competition between providers was further encouraged as they had to negotiate their prices with the insurers. We have no data on the numbers of long-term care service providers *before* the introduction of long-term care insurers. But in 1999 there were already 29 providers in the city of Aachen and 35 providers in the surrounding administrative district (Landesamt für Datenverarbeitung und Statistik Nordrhein-Westfalen, 2002, p. 16). After this phase of expansion and the establishment of non-for-profit providers, competition and accompanying pressures for professionalisation then led to a stage of concentration and consolidation with a slight decline in the number of providers but increasing numbers of clients per provider. In 2005 there were still 21 providers in the city and 28 in the administrative district.²³

Nowadays, the provision of outpatient long-term care in the city and former district of Aachen is highly fragmented. In 2011 the city administration provides information on again 32 providers of outpatient long-term care services. Almost two thirds of them are for profit-organisations; slightly more than one third are non-for-profit service providers.²⁴ In the non-profit sector the Catholic welfare organisation, Caritas, is the biggest player with 5 outpatient long-term care facilities. A public provider of outpatient long-term care

²² It was not before the health care reform act of 1989 that the statutory health insurance for the first time covered some limited home care in the case of considerable need of care (Gerlinger & Röber, 2009, p. 18).

²³ The average number of clients per provider had risen from 39 clients per provider in the city in 1999 (administrative district: 37) (Landesamt für Datenverarbeitung und Statistik Nordrhein-Westfalen, 2002, pp. 16-17) to 62 clients per provider in 2005 (65 in the administrative district) (Landesamt für Datenverarbeitung und Statistik Nordrhein-Westfalen, 2007, pp. 18-19). With the since then again rising number of providers there is a minimal decline in the number of clients per provider in 2009 (Landesamt für Datenverarbeitung und Statistik Nordrhein-Westfalen, 2011, pp. 18-19).

²⁴ For the local level, we had no access to exact data on the share of for-profit and non-for-profit services; the information above is based on own recherche. On the level of the Land NRW about 60% of the providers of outpatient long-term care services are for-profit organisations and about 40% are non-for-profit ones, the share of public providers is about 0.7% (Statistisches Bundesamt, 2009, p. 7). On average, the for-profit organisations are smaller than the non-for-profit ones: while the former care for 48.8% of the clients in NRW, the non-for-profit organisations care for 50.7% (public providers: 0.4% of the clients).

services does not exist.²⁵ Price-lists give an overview of the different prices and are spread by the local long-term care insurers and the providers themselves. There are considerable price-spans between different providers. Providers under the roof of welfare associations are in general more expensive than for-profit providers who have less overhead.²⁶

Summarizing, we may note that the care market in Aachen is characterised by a distinctive plurality of services and high fragmentation which is promoted by the strong competition in the sector of outpatient long-term care. There are considerable price-spans between providers; while some big players, e. g. the local Catholic welfare organisation but also other non-for-profit services, can afford high(er) prices other providers provide the nominally same service for much less money.

2.2.4 Governance, complementarities and coordination, quality assurance, participation

The following paragraphs give a short overview of the historical development of the dementia care net and its context of implementation regarding our four analytical issues of governance, coordination and cooperation, quality and participation.

Regarding the *governance* of long-term care issues, the historical overview reveals a shift in the responsibility and opportunities for action from the Land level to the long-term care insurers and the providers. Notwithstanding, the Länder had and still have considerable room for manoeuvre in the implementation of the federal legislation on long-term care. NRW is a Land that makes use from this. In the beginning of the establishment of the first, outpatient long-term care service providers, often municipal or church-bound ones, some municipalities supported this development, e. g. by subsidies, or to decide to provide municipal out- or inpatient services. In NRW, much of the early infrastructure could be established thanks to public subsidies from Land level. Its active role was accomplished by the development of a demand- and indicator-based and social planning of long-term care infrastructure (Zängl, 1999, p. 25) and supported by two scientific, but practice-oriented institutions: the Kuratorium Deutsche Altershilfe and a chair at the University of Dortmund and his colleagues who still is involved in these issues today. The introduction of the long-term care insurance limited room for manoeuvre of the State as it entitled all providers who would fulfil certain conditions to be admitted to the care market - and the existence of a demand for such services was not part of these conditions. Notwithstanding this, the Land stuck to its active role: With the State law on long-term care of 1996, the government of social democrats and greens made the municipalities responsible for guaranteeing a sufficient infrastructure of long-term care that would correspond to the local requirements. Thereby the State transferred also the financial responsibility for investment to the municipalities, referring to the municipal savings that would result from reduced costs for social assistance allowance.

So, municipalities were continuously called on by the Land level to engage in the planning of the infrastructure of inpatient long-term care, and more and more also outpatient long-term care and accompanying social services. Yet, there was a tension between the aim of a free care market that had been introduced with the long-term care insurance and planning ambitions. These tensions were even strengthened by external factors like EU-market liberalisation and jurisdiction that also set limits for public investment policies with a clear steering approach. As an answer to this, representatives of the responsible - meanwhile conservative - ministry of the Land and some engaged municipalities developed recommendations for municipal social planning of local caring infrastructures (Ministerium für Arbeit Gesundheit und Soziales des Landes Nordrhein-Westfalen, 2007). The recommendations applied a somewhat "systemic" strategy by

²⁵ The law long-term care insurance prescribes that if a selection between several eligible providers is necessary, for-profit and non-for-profit providers should be preferred contracting partners (against public providers) (SGB XI, §11 (2)). The contracts are made between insurers and providers, in consent with the financing bodies of social assistance allowance (SGB XI, §72 (2)).

²⁶ To give an example, the prices for a comprehensive washing that includes washing, shower or bath, mouth care, shave, skin and nail care, clothing and tidying up the care implements in 2011 ranged from 14.35 Euro (for-profit-provider) to 17.83 Euro (non-for-profit provider) (Amt für Altenarbeit der StädteRegion Aachen, 2011).

suggesting the municipalities to shape the context conditions in a manner that would make the establishment of inpatient long-term care facilities economically unattractive for potential providers; many examples and a suggestion for the local gathering of data were given (the documentation and publication of the number of empty beds in residential care homes was another element of this strategy) (ibid.). The aim was to rather turn the development of local, community-based infrastructures of outpatient long-term care more attractive (ibid., 29, 39). The city of Aachen took actively part in this process²⁷ and provided several examples of good practice for the recommendations. The important role the Land assigned to the North Rhine-Westphalian municipalities becomes also obvious in the obligation to guarantee a long-term care infrastructure which is adequate to the local needs and takes into regard the plurality of providers that had been delegated by Land to the municipalities (§ 2 (1) long-term care law NRW) (MIK NRW, 2012). Further, the long-term care insurance law of NRW obliged municipalities to provide counselling on in- and outpatient as well as complementary services, independently from certain providers (§ 4 ibid.) and introduced the instrument of the so-called “care conferences” (§ 5 ibid.). These conferences should be organised by the local authorities and involve providers, insurers, and representatives from senior citizens and self-help organisations and other affected persons (ibid.). Further, the development of counselling offices on housing and housing adaptation was funded in a model project by insurers and municipalities (Ministerium für Gesundheit, 2012).

The municipal administration of Aachen had early concentrated on soft steering instruments such as communication, investments in preventive measures (counselling and a hot line for senior citizens, outpatient complementary services) and coordinative measures. All these measures should make the establishment of residential homes economically unattractive by menacing with a low degree of capacity utilisation. The municipality even tried actively to discourage providers to establish new residential care homes by gathering and publishing data on open places in the existing homes and by communicating that there would be no municipal support at all to find clients for new places (interview).

The marketisation that had been introduced with the long-term care insurance seems to have had also notably *consequences for the coordination and cooperation* between the providers at the local level: Interviewed representatives of outpatient non-for-profit providers report that before the introduction of the long-term care insurance they met regularly to find common positions to negotiate with the local administration. With the introduction of long-term care insurance and the evolving care market, cooperation seems to have reduced considerably and now happens only punctually on certain topics. While chief managers of the residential care homes of the city (see below) are said to meet regularly in a working group there seems to be no functioning network of the long-term care insurance service providers in Aachen today. Nowadays the providers experience support for price-negotiation by their respective roof organisations. Notwithstanding this, insurers still doubt the existence of real competition and therefore would like to promote it. There are hints to another kind of economic incentive for providers and insurers to avoid price-differentiation: providers would negotiate jointly via their respective associations; and - in front of 2.259 providers for outpatient long-term care in NRW in 2009 - insurers were interested in limiting the number of necessary negotiations.

Economisation and the pressure to professionalization that were induced by the introduction of long-term care insurance led to a *modernisation in the culture of service provision* what had also quality implications. Outpatient long-term care formerly had basically been perceived as a universalistic action between human beings which was by and by outsourced from the private, intimate sphere of relatives to help provided by non-for-profit organisations, often by nuns and based on a principle of grace of charity. Now it was transformed into a quasi-taylorised (Pfau-Effinger, Och, & Eichler, 2008, pp. 85-86) and marketised "service" that was provided for "clients" and consisted of different modules that could be combined individually, were performed by specialized staff with different levels of qualification and charged per

²⁷ It was represented by its social planner who had experience from this position since the late 1980ies.

service not per time unit. This development made some of the catholic sisters to distance themselves from this work (interview AC_03251, 61-63). A representative of a big church near service provider in the region finds perceives still today the challenge to find a balance between the logic of economics and the logic of Christian ethics (interview AC_03251, 63). Other service providers dropped former highly-held quality principles, e. g. the provider who had started of from the alternative-progressive background found itself forced to drop the principle of doing no home visit shorter than one hour because of economic reasons.

Quality assurance had formerly not been a prominent issue. Since the introduction of long-term care insurance, by and by, the concept gains importance. While in the beginning, elements of quality assurance, like modes of the documentation of delivered services, had been developed in a bottom-up manner from the daily practice, long-term care insurance formulated conditions regarding structural quality that had to be fulfilled by providers to be admitted to the market. The - then more top-down - focus was to make the introduction of quality management systems an obligatory prerequisite for accreditation. More recent developments in quality assurance aim at raising the transparency of quality of care for consumers, search for an integration of the outcome-dimension in quality assessment criteria as well as regarding the user's perspective, and last not least recognizing the value of bottom-up processes for quality assurance.

Beneath this general development, in the city and former district of Aachen there were different attempts to improve quality in service delivery. These projects were initiated by staff of the municipal departments which were responsible for senior citizens' interests but followed a bottom-up logic. In the city, there was an initiative to establish a working group in which the staff of day care facilities mutually supervised their work and did some "dementia care mapping". In the administrative district, the development of a dementia care label for residential care homes was initiated. Later on, an Ombudsperson was introduced who did not only mediate in conflicts between residential care homes and clients or relatives but also developed another label that was assigned after voluntary surveys among the inhabitants of the long-term care facilities. Notably, only recently those activities were opened to the sector of outpatient long-term care. Here, as far as we could establish, for long years there had not been any bottom-up quality initiatives, and also attempts to organise working groups of the outpatient long-term care providers failed due to the missing interest (and the competition) between them.

Regarding *senior citizens' participation* the representative board of senior citizens in the city of Aachen was attributed not so much influence whereas the advisory board in the former district seems to involve fewer senior citizens but has more opportunities to influence local policy than the body in the city. Interesting is also the mentioned institution of the Ombudsperson, even though the Ombudsmen are still much more often appealed to by residential care homes or their clients than by outpatient long-term care service providers. This may be held as a hint to the perhaps underappreciated, isolated and endangered situation of clients and their relatives who feel dependent of their long-term care service provider and are anxious to avoid disadvantages that might result from complaining.²⁸

Generally one may conclude that despite of the individualisation and liberalisation of the care market the participation of users in the sense of informed and free decision on service delivery is not very far developed. Indeed, there is the right to choose between cash benefits and benefits in kind (even though to opt for cash benefits means to receive only half the value that is entitled when opting for benefits in kind). And in case of opting for benefits in kind, the provider may be chosen freely by the client. Actually, our interview partners report that the construct of "a free consumer" would not adequately characterize the situation of persons who perhaps suddenly get in need of care, are lacking information and under pressure to make decisions.

²⁸ Another aspect is that the independence of the ombudsperson would deserve some further research as one could imagine that they just help to appease complaints and explain restrictions that result for the facilities' work from legal prescription and thus would perform more a legitimizing task than an advocacy one.

2.3 Brief description of the local network of HBLTC for older people today

2.3.1 Available services and providers

All in all, the infrastructure of home based long-term care for older people in Aachen nowadays consists of the following elements: 19 for-profit and 13 non-for-profit outpatient long-term care service providers, seven so-called "mobile social services" that provide complementary services; 34 residential care homes that provide 2.451 beds (53 beds for each 1.000 inhabitants aged 65 and older) (Landesamt für Datenverarbeitung und Statistik Nordrhein-Westfalen, 2011, p. 28); 86 places of part-time inpatient care (compare Information und Technik Nordrhein-Westfalen, 2009, p. 28) which are spread over seven day-care facilities in the city; outpatient and inpatient medical care; and last not least several services that offer counselling on care related questions.

Beneath addressing standard care problems there is a specialisation of single actors in the local home based long-term care network on the needs of elderly persons with dementia and on the special palliative care needs of persons who are at the end of their life.

The supply with *assisted living* is under German average in the city as well as in the former administrative district (Rüter, Mika-Helfmeiers, 2010, 37-38). This does not take into regard privately organized housing adaptations or barrier poor living arrangements. The department for senior citizens affairs has initiated a project to meet needs to have access to some low threshold and complementary services in case of necessity: "service living without moving". Users have to pay a minimal flat-rate to the contracting mobile social service or outpatient long-term care provider and therefore get a defined contact person and information as well as visiting (ibd., 39). In case of need these services may be extended, but have to be paid for. Based at the local technical university for applied sciences, there is a project that aims at facilitating joint living arrangements of senior citizens and students, the so-called "living duo" (ibd., 39).

The "mobile social services" provide complementary services such as housework, social attendance, accompanying or mobility help. These services are often associated to welfare associations who receive financial subsidies from the labour market policy. In return they employ persons from the second labour market. In 2011, the subsidies in this sector were considerably reduced what may partly be explained by the shift from a conservative-social-democratic coalition to a conservative liberal one in the national labour policies. As a consequence, the providers claim that such services will become much more expensive and argue with the municipality about the price for those services in case of clients who depend on social assistance allowance ("Hilfe zur Pflege"). This seems to be a threat on an early, adequate and preventive care for elderly persons with needs but little financial resources. Some providers use the interviews to menace that they would only provide services for well-off self-payers in future. Further complementary services in Aachen are seven emergency-call services, five mobility services and ten mobile meal service that are all provided by non-for profit or private organisations; users have to pay for these services.

Counselling structures are not clearly arranged. At data gathering, counselling structures in the city, the former district and the newly founded city region were under revision. The municipality of Aachen provides a central office on ageing issues that formerly also included counselling. The latter was closed down because counselling is now provided by the local long-term care information point that had to be implemented as a consequence to the long-term care insurance further development law of 2008. A former municipal counselling centre is now run by the city region. The biggest local long-term care insurer provides two long-term care counselling points whose support is said to be only poorly requested. This insurer additionally provides care counsellors who do home visits, and a special counselling unit on dementia issues; according to the insurer patients ask for this services much more often than for the counselling points. As a consequence of the intense and civil society-based engagement, there exists an office for information on and qualification and support of hospice-work; the office finances itself by contributions for qualifications,

donations, and voluntary subsidies by the city region (interview AC-201103242, 5, 1-2). Last not least, insurers and the public hand finance a Dementia Service Centre that is run by the local association for consumer advice and part of the so-called "Land Initiative Dementia-Service NRW". The municipality does offer some additionally counselling on housing adaptation and exchange, and a hotline for senior citizens. Last not least, the psychiatric hospital runs a psycho geriatric counselling centre (PGCC) that is specialised on the needs of elder people with dementia. This short overview should show the, perhaps for potential users sometimes confusing, plurality of actual counselling structures in the city-region of Aachen. The hospital itself, which is run by a provider who has its roots in a catholic monastic order, has an own department for psycho geriatric medical care.

According to our interviews, *outpatient medical care* in the city-region of Aachen is provided by about 230 general practitioners (who are already for some decades organised in a local working group) and a number of specialists of whom especially the neurologists and psychiatrists are of special importance for the care of persons affected by dementia. Laments about the lacking willingness of physicians to do home visits are yet widespread and general practitioners and neurologists are said to avoid cooperation with each other due to a prevailing conflict between both professional groups. *Inpatient medical care* is provided by five local hospitals, including an university hospital with a chair for neurology (which seems to be allocated at the neurologists side in the above mentioned conflict) and one out of about six chairs for palliative medicine in Germany (financed by the foundation of a big pharmaceutical enterprise).

Several of the 32 providers of *outpatient long-term care* in Aachen have specialised: two have specialized on the needs of persons with psycho-geriatric conditions, few seem to have specialized on clients from countries from the former USSR, e. g. with Russian speaking staff, and there is a palliative care team consisting of physicians and outpatient long-term care facilities with specialized staff and defined standards that have to be fulfilled by interested providers.

There are two specialised networks that address two different types of complex cases: one is the dementia care net which is under investigation here; the other is the specialised palliative home care team. Apart from this, we could establish no other formalised networking activities regarding outpatient long-term care. The situation of socially disadvantaged elderly persons with care needs, e. g. their often difficult access to information and support with administrative tasks and applications or restrictions of mobility due to functional limitations and little financial resources (compare Falk, et al., 2011), are not explicitly addressed. Even though there had been a care conference in the city of Aachen, the interviewed local stakeholders convey that they do not estimate its significance very high. We could not establish any other formalised network in which the local actors would organise and discuss integrated care paths. Networking seems to be especially lacking between providers of outpatient long-term care in Aachen. Only some of the non-for-profit providers meet infrequently to negotiate common positions in front of the municipality regarding their economic interest. All interview partners describe the atmosphere among the outpatient long-term care providers in the city as very competitive - in relation to each other, but also in relation to the seven day care facilities. In the daily delivery of care, cooperation between the different actors is mainly based on bi-, and sometimes on multilateral cooperation e. g. between outpatient long-term care service providers and mobile social services, with other complementary services (which are sometimes delivered by providers that belong to the same welfare association) or with some general practitioners. These forms of loose cooperation still are not backed by a commonly defined aim or a shared idea that would legitimise to talk of a real network.

In contrast to this, over the years there has evolved an informal network of institutions and persons regarding the needs of elderly people with dementia. Its inner circle consists of the manager of the specialised outpatient long-term care service provider with alternative-progressive background, the chief physician of a local hospital that is run by a church-near association and is in charge of the psycho-geriatric care supply for the city and surrounding areas, and an employee of the mentioned counselling centre on

dementia-issues of the Land initiative; the social department of the city-region as well as the social planner of the city are also loosely involved.

An important stakeholder in the local network of HBLTC in Aachen regarding the needs of persons with dementia is the psycho geriatric counselling centre (PGCC). It provides inpatient, part-time and outpatient diagnosis and treatment of all psychiatric diseases in old age, especially dementia, a counselling centre that counsels on planning of integrated caring arrangements and provides also home visits, training and self-help groups for patients and their relatives as well as a memory ambulatory. The PGCC is said to cooperate closely with the local association of general practitioners and is located in and financed by the local (psycho geriatric) hospital and assigned to the already mentioned chief physician; thus, it is also connected to the above mentioned network. The PGCC seems to be very well networked with almost all kinds of providers (apart from neurologists in own practice): interview partners from outpatient long-term care providers, from day care facilities as well as from other counselling institutions report the PGC as an acknowledged and helpful address to which clients with dementia-related needs may be referred and questions on adequate treatment may be imposed. The PGCC seems to function as a starting point and back-up institution for the dementia care net (see below).

Since 2008, the dementia care net is part of the hitherto informal network structures on dementia care issues in the city, and recently also in the region of Aachen. It will be presented in detail in the following section.

2.3.2 Reconstruction of the governance network

Policies on home based long-term care in Aachen are shaped - as far as they are at all subject to local decision making and implementation - by a complex and informal governance network that encompasses relations between actors, i.e. organisations and persons within those organisations, who themselves belong to different networks, sectors and levels. They are also shaped by conflicting interests among some of those actors. The following paragraph gives a short overview of their roles and activities, methods of finance as well as a short insight in intern relationships and ideas, values and aims of the governance network.

Most actors who are part of the governance network have already been mentioned in the previous paragraphs. They belong to different levels of public administration and politics, insurers, the non-for-profit sector, out- and inpatient medical care, counselling infrastructure, and scientific institutions. In detail, it is

- the municipal departments on senior citizens affairs of city and city region,
- the social affairs department of city and city region,
- the insurers' at Land level with their regional dependencies,
- the local and regional welfare associations as well as their joint working group, the so-called "liga",
- the local psychiatric hospital with its psycho geriatric counselling centre (PGCC),
- the dementia service centre,
- the representative of the alternative provider of an outpatient-long-term care and the city's first day care facility,
- the local Alzheimer's Association,
- the local association of general practitioners,
- the local neurologists in private practice,
- the chairs for neurology and palliative medicine at the Aachen hospital,
- the manager of the hospice counselling office,
- the local Catholic University for applied sciences,
- the Kuratorium Deutsche Altershilfe,
- the department for gerontology at the University of Dortmund,
- the ministry for health, emancipation, care and ageing at Land level,

- and some politicians from the social democrat, the conservative and the green party at local, regional, Land, and national level.

A considerable number of the mentioned actors assume quite active roles in shaping the local system of home based long-term care, notwithstanding the overall relatively little room of discretion therefore in Germany:

Both *municipal agencies on senior citizens affairs, in city and region*, are financed from the municipal budgets and distinctively shaped by the engagement of two employees who both are working in these institutions for more than one decade. The one in the city focuses on policies that intent to facilitate staying at home as long as possible even in need of care: he built up the municipal agency for senior citizens affairs out of a telephone hotline in the end of the 1980ies and since then has established social planning on senior citizens needs and done several reports on the situation of elderly people in Aachen (in cooperation with the local Technical University for Applied Science where he is a lecturer); as municipal social planner he also participated in the formulation process of the ministerial recommendations to municipal planning on long-term care that we mentioned above. Further he argues for an active municipal role in front of providers, who plan to establish (more) residential care homes. Beneath this, this actor has initiated and/ or accompanied several projects in the city: an initiative for dementia care mapping, service-housing without moving and dual-housing. He is part of the advisory board of the dementia care net. His counterpart in the former administrative district has focused on the development of qualification and quality assurance in the districts long-term care facilities for which he is highly acknowledged from several actors in the city region with whom we had interviews. While the former is said to sympathise with social democrat ideas - and himself says to be proud of his independence - the latter is referred to as one of the very early members of the green party in a municipality of the district. We could not establish evidence about intense cooperation between them; on the contrary, from other interviews we got hints of a latent competition between both actors. The social planner of the former administrative district, now of the city region, is formally assigned to another department, but seems to be actually quite close to the agency for senior citizens affairs and the social department. She is responsible for very detailed reports on the demographic development which are provided by the municipality.

The manager of the *regional office for counselling on hospice issues* has also factually created her own institution, job and financing by working voluntarily and intense on this issue for many years, organizing events and the Aachen hospice talks (together with other engaged persons) and lobbying for the creation of such an institution. The hospice counselling office is financed from public funding, revenues from trainings and seminars for staff of long-term care facilities as well as from charitable donations. The office engages a lot for the assurance of quality of care at the end of life through adequate attendance by interdisciplinary, specialised teams, but also by qualifying the regular staff in long-term care homes. Thus, human dignity, qualification and an alignment of organisation and process of care that facilitates dignity in care but also good working conditions for the staff are important issues to this actor.

Competitiveness seems to be also the correct characterization for the relation of two *medical professions* in the city of Aachen: general practitioners, many of them organized in a working group which is meeting regularly already for many years, and neurologists in own practice. While relations of (many) of the general practitioners are reported to be excellent with the local psycho geriatric hospital, there are reproaches that cooperation with the neurologists in own practise as well as at the University would be difficult due to lacking cooperation from the neurologists' side.²⁹ This latent conflict may have been reinforced by the fact that national representatives of both professional groups came from the region, too, some years ago.

²⁹ We did not have an interview with someone from the neurologist profession.

As we mentioned above, there seems to be *hardly any cooperation between different outpatient long-term care providers*. This statement has to be modified in the sense that in case of urgent questions which are of direct, financial importance to the non-for-profit providers, they indeed might make use of the working group of their respective associations to jointly negotiate their position. An example gives the negotiation of the chairman of the association of the local welfare associations with the head of the social department of the city-region regarding the municipal reimbursement for complementary services in case of indigence. On the level of the Land, the welfare associations participate in negotiating the basic contract on outpatient long-term care ("Versorgungsvertrag") and on the prices for services, which both are negotiated between providers or their representing associations and the insurers, in consent with the public financiers of social assistance allowance. Claim and mission of the welfare associations is to contribute to societal welfare, but in the same time they are enterprises that follow an economic logic. These contrasting ideas are reflected in the tension of concepts, such as between the altruistic and holistic concept of care as it has been pursued by the nuns and the later speech of "consumers" or "customers" (Kunden) and instruments like quality management systems that stem from the realm of industries and production. The outpatient long-term care providers are financed by the insurance benefits and private contributions of their clients, by payments of the municipal social assistance allowance for clients in need and by public subsidies (for parts of their investment costs). Non-for-profit facilities have to pay contributions to their respective welfare association from their revenues.

The biggest insurer in the federal State (Land NRW) as well as an insurers' association belong to the actors with the highest ambitions to shape the regional system of home based long-term care. In NRW, they (or some of their representatives in charge who are in contact with each other) make actively use of the room for manoeuvre that is provided to the stakeholders at the Land level in the German system of long-term care; for example by lobbying with regard to the content of a directive of the government of the Land on financing of new structures and model projects. As a result, there is a wide spectrum of low threshold services according to SGB XI §45c, which clients may be reimbursed for with up to 100 or 200 Euro per month according to SGB XI §45b on "additional services of attendance". Facilitation of an earlier and easier access to household near aids – what is intended thereby – surely addresses a widespread, but hitherto unmet need and might even have preventive effects. Such low-threshold services are relative flexible and generally reimbursed per hour, what reminds to the logic of comprehensive care before introduction of the long-term care insurance when home care had generally been reimbursed per hour as far as it had been paid for by the municipalities. At the same time, such an arrangement follows the explicit interest of the insurers' side to promote competition between providers and put prices under pressure. We will see this steering ambition again in the analytical section regarding the dementia care net.

There are further *structural incentives to avoid costs for the health insurers and instead charge the long-term care insurer*. Regarding the financing of the long-term care insurers' staff, it seems worthwhile to note that they are formally employed and also paid from the budget of the health insurers; long-term care insurance has to pay a fee for this. Thus, the interest constellation of those actors seems to be quite ambivalent between the health insurer's and the long-term care insurer's interest; long-term care insurance will probably have an institutional interest to act in favour of the health insurer. This is even supported by the fact that negative accounting balances of the long-term care insurers are apportioned between all long-term care insurers (apart from the private ones), whereas debts of the health insurers have to be paid by the insurers on their own.³⁰

³⁰ This is modified by a complex system, the so-called morbidity-oriented risk adjustment mechanism which takes into account the structure of the insured populations and their conditions, and by extra-payments which the health insurers impose their clients in case of deficient balancing (Rosenbrock & Gerlinger, im Erscheinen).

An important frame for the activities of the described local dementia care network is set by the Land level.³¹ *At the Land level is passed the implementing law on long-term care insurance.* The Land has to co-finance innovative projects that may be funded from the balancing fund of the long-term care insurers. And the Land and the welfare associations at Land level jointly administer the NRW fund for welfare from which a lot of projects in this sector receive funding.

Some of the very engaged actors from the overall network on home-based long-term care in Aachen build a thematic sub-network that focuses on the issue of outpatient dementia care. The inner circle of this sub-network is built by the chief physician of the psycho geriatric hospital with its psycho geriatric counselling centre (PGCC), the manager of the alternative provider of outpatient-long-term care and the city's first day care facility, one representative of the dementia service centre (which has its office in a small municipality in the former administrative district of Aachen). While the manager of the alternative provider is working on this issue in the city since the early 1980ies, the others are there for "just" about a decade or a little bit less; thus, all in all, personal continuity in this sub-network is high. Together, these stakeholders develop and adopt different projects³² which are in accordance with their common problem perception and also with their respective interests as institutions which have to be balanced. Regarding their *problem perception* and shared interest, these actors agree in the analysis that the main problem today is the too late access of people with dementia as well as their relatives to information, diagnosis, adequate care, treatment and services; they point to the still existing problem of stigmatisation and shame which were related to dementia. Thus they focus their activities on enhancing early diagnosis and access to the different services they offer. *To develop and realize their projects, they link more or less selectively with further actors or even networks and make use of different scales what will be shown more detailed in the following chapters.* More or less closely associated via certain of its members are e. g. the working group of the local general practitioners, personally one of their ex-(vice-) chairmen, the agencies on senior citizens affairs of city and city region, the department on social affairs of the city region, the manager of the counselling office on palliative and hospice issues, the Kuratorium Deutsche Altershilfe (as a coordinator of the dementia service centres). Additionally the medical director of the psycho geriatric hospital is in quite close contact with the insurers' representatives that we introduced above. The latter seem to observe the activities and projects of the network closely and also make use of different scales to actively shape their realization. Further, the chief physician works on improving the relations with the neurologists in the city with whom relations have been interfered due to the competitiveness in caring for people with dementia. And last not least, this stakeholder is said to do intense lobbying at Land- and national level. Coincidentally, the former federal minister for health, Ulla Schmidt, who belongs to the social democrat party, comes from the city of Aachen. Some of our interview partners hinted at the point she would get along well with the chairman of the board of the biggest insurer in the region. On Land level during the years of the conservative-liberal coalition, from 2005-2010, Karl-Josef Laumann from the Christ-democratic party was the responsible minister for issues of long-term care.

2.3.3 The local authority system

As was already reported, on the municipal level there are relatively little formal options for a directive decision making with regard to shaping the infrastructure of outpatient long-term care in Germany. Yet, there are opportunities to set incentives for the outpatient sector, provided that municipalities are able and willing to spend some money on voluntary tasks or to adopt communicative and negotiating measures. We also already noticed that in NRW the municipalities were early demanded to do some indicator-based planning of

³¹ Regrettably we could not achieve an interview with a representative from the Land level. We were given the reason that due to the high number of requests for such research-related interviews our intended interview partner had decided not to give any interviews.

³² One of these projects is the dementia net Aachen. Another is their cooperation in the local Alzheimer's Society which was merged with the one in the city region and hires the flats for the two local flat-sharing communities for persons with dementia that are cared for by the alternative non-for-profit outpatient long-term care provider. A third project was the edition of a brochures on dementia care services in the city-region of Aachen that encompasses information on dementia, conditions for the entitlement of benefits as well as on services and their providers themselves.

their care infrastructure and that they have been transferred the obligation to guarantee a sufficient and efficient infrastructure. Incentives in the municipality of Aachen have been set on the basis of the principle "outpatient before inpatient" and by making use of existing resources: persons, knowledge, motivation, networks. As an example serves the support for the Aachen hospice talks and the network on palliative care that was developed from there as well as the respective counselling office. It would deserve a deeper analysis, but our superficial insight in the formation of the infrastructure on hospice work and palliative care in Aachen suggest that during her governance, the federal minister of health, Ulla Schmidt, may also have focused on palliative care because of the high importance that the issue had gained in her home city. With the promotion of a change in the health insurance law she then provided a framework for the advancement of specialised palliative care at federal level - and thereby again set the basis for the further professionalization of the in Aachen existing palliative care network.

In the former administrative district the agency on senior citizens' affairs decided to establish an Ombudsperson for the interests of persons in need of care who live in institutions. This decision was reported to be a reaction to the public discourse on situations of negligence in residential care homes that had taken place before but without the consequence of new regulations. A pragmatic and practical attitude seems to prevail, and doing something instead of lamenting seems to be highly esteemed. This is also true for many projects of the agency on senior citizens' affairs in the city of Aachen like e. g. the early established telephone hotline or the implementation of a simplified form of dementia care mapping. It could be a far going interpretation, but perhaps this widespread culture of pragmatism and action orientation reflects a culture of engineering that may stem from the technical University for Applied sciences as well as the various spin-offs that sprang from there; additionally, also position in the border-triangle of the Netherlands, Belgium and Germany may contribute to some open-mindedness and practical orientation.

A pragmatic, action-oriented culture and a shared aim or vision in a network both seem to facilitate to advance a certain policy rather by implementing projects than by adopting regulations and directives. Equally important seems to be the command over at least some budget and political backing. All this was given in the case of the Aachen dementia care net.

3 Analytical section

In the following section we shortly describe the Dementia Care Net (DCN) of Aachen (3.1) and give an overview of the process of change, its actors, motives, facilitators, barriers, and consequences regarding the four analytical dimensions (3.2). After having laid this basis, we will go into the more detailed analysis of the addressed problem (3.2.1), the type of change (3.2.2) and factors that may explain the character of the change process (3.2.3). Finally we will evaluate the result of the change: has it facilitated continuity or brought a categorical break (3.2.4)? We will close with a look on the question about perhaps unforeseen and unintended consequences of the DCN of Aachen (3.2.5).

3.1 Description of the innovative long-term-care model for the elderly: the Dementia Care Net in Aachen

The Dementia Care Net (DCN) in Aachen represents an innovative model of case (and care) management regarding complex cases in the context of dementia. It aims at enhancing the quality of care for elderly persons with dementia and - if existent - their caring relatives by facilitating (early) access to diagnosis, medical and social care, counselling and social participation, and by enhancing the integration of those services. It targets at two groups: at the persons with dementia themselves but also at their caring relatives; finally its aim is to support the overall home-based care arrangement. The DCN addresses the problem of late access to adequate support. This is perceived as one of the most important problems by the dementia-related sub-network which we described above. Another addressed problem is the insufficient coordination of medical and social care and attendance (psycho-social care). The DCN thus aims at making the already

existing infrastructure - for counselling, self-help, social participation, medical care, specialised outpatient long-term care, complementary services, and day care - earlier and more easily accessible and at promoting a better coordination of those services by introducing a form of case and care management and involving GPs and specialists in the network. In the end, this should stabilize the situation of home-dwelling persons with dementia as well as their surrounding arrangement of care and support and thereby avoid or postpone needs of hospitalisation.

The DCN consists of a multidisciplinary team of four case managers, two nurses and two social workers,³³ who are situated at the local psycho geriatric hospital in the city of Aachen and directed by the medical director of the psycho geriatric department. The team is completed by a medical doctor and a psychologist who are responsible for establishing the care management in the city-region. Further partners are the cooperating general practitioners who signed in the program,³⁴ and in the second phase of the project also the working group of the Aachen neurologists, the administration of city-region (with its social department), the Kuratorium Deutsche Altershilfe (KDA), the Alzheimer Association in the city-region, and the Dementia Service Centre (DSC). The case managers offer early diagnosis, assessment of needs and resources, counselling, and further referrals in case of dementia. Together with the clients and their relatives, they develop a comprehensive care plan which is based on the assessed needs, preconditions and preferences.

A special feature compared to other projects which offer case management is the successful involvement of the general practitioners and recently also neurologists. Physicians who opt for participating in the DCN receive some reimbursement for inscription. They are obliged to participate in regular quality circles on dementia related issues and offered to send also their staff to similar trainings. Participating physicians agree to take part in these qualification measures, to offer their clients to refer them to the DCN, to provide their dement clients a medical assessment every three months, and to cooperate with the case managers. Basis for the successful involvement of the physicians seems to be their reimbursement for inscribing themselves, referring clients and regularly assessing them.

The case management process is initiated by the physician: The GP or specialist does a first orienting test and analysis of the patient's environment, inscribes the client in the program (the client's consent presupposed) and refers him or her to the case managers of the DCN.³⁵ All inscribed patients undergo a standardised initial diagnosis according to existing guidelines (Theilig, Duisberg, et al., 2011, p. 5). Precondition for inscription is that the client would fulfil three access-criteria: a dementia condition (or suspicion for this), sufficient readiness of the affected person or his/her relatives to cooperate, and, centrally, a manifest or menacing complex situation which is defined as manifest or menacing decompensation; this might be psycho-social, physical or regarding the status of care. After having received the information from the general practitioner, the case manager contacts the family, introduces him- or herself and asks for the wished form of contact. In general, the case manager gets a first picture of the situation through the home visit ("intake").³⁶ In a following visit the situation is thoroughly assessed by a standardised assessment and an extensive interview with the client and the client's relatives ("assessment"). Together with the caring person - if existent - is done a revision of needs, resources, and preferences; the most urgent next step is defined. In coordination with the general practitioner and other actors that may already be involved in the caring arrangement, such as a long-term care provider, neighbours or relatives in other cities, who are all kept informed about the process, a care plan is developed ("planning") and implemented ("intervention"). The care plan and progress of implementation are regularly monitored and communicated to all involved

³³ In the first project phase from 2008 - 2010 also a psychologist was part of the team.

³⁴ In the first phase of the project participated in total 120 out of about 190 GPs in the city and region; that is about two thirds of the GPs (numbers according to interview partners). In the second phase, a first inscription wave brought 83 patients who were inscribed by 62 GPs and specialists, among them eight or nine out of 40 neurologists in Aachen (Theilig, Schirra-Weirich, & Duisberg, 2011, p. 9).

³⁵ Clients may also contact the case managers on their own and apply for being included in the program. This is only possible if their general practitioner agrees in participating, and if they fulfil the access criteria.

³⁶ For an overview of the process of case management compare Theilig, Schirra-Weirich et al. (2011, p. 8).

actors ("monitoring"). Effects of the intervention are qualitatively assessed and documented ("evaluation"). They build the basis for eventually next steps.

One finding from the first project phase was that it seems to be very important to the GPs to feel to stay owner of the process and to be always kept informed; even though the practical coordinative work - such as extensive telephone calls with relatives, accompanying a client for the first visit at a potential day care centre, or other - is done by the case managers. Thus, it is important that the case managers communicate all steps to the GPs. In the beginning of the first phase this resulted difficult because the general practitioners preferred different modes of communication, one interview partner reported that some lamented not to have received all information. As a consequence, the case managers now provide their information to all participants using all communication channels (mail, fax, and phone) - and accept laments about information that was received twice. Another experience from the first implementation of the project was that personal contact is very important to establish a good flow of information between the case managers and all other actors. According to one of our interview partners, case managers had to invest approximately one quarter of their working time into the communication with the medical doctors to establish the network, but also to present themselves to the managers of other providers, e. g. a day care facility or residential care home.

As the case managers inform the clients about the locally available services for support and help as well as on opportunities to receive financial aids, the DCN affects not only general practitioners but also other local providers, such as outpatient long-term care providers, complementary services, or day care facilities. Clients who do not fulfil the access criteria may be referred to the subsidiary counselling structures in Aachen, such as the psycho geriatric counselling centre (PGCC) at the psycho geriatric hospital, the dementia service centre, though this has no longer a focus on single case counselling, or the long-term care service point. Thus, also these structures are indirectly affected by the network.

The initiators of the project involved almost all actors that we introduced in the previous chapter into the planning phase of the model (see below). This may explain why it is known with many actors of the home based long-term care network of Aachen with whom we had interviews. From fieldwork we got the impression that it was least known with the long-term care service providers, who have not specialised on dementia. Notwithstanding, to them the PGC was a known and important address in case of questions on caring problems that resulted from dementia. It seems that the difference between both facilities is not very clear to those actors.

The DCN Aachen hitherto has been realized in two phases from two different financial sources (see below) and due to this - at least officially - different aims and organisation. In the second phase one important aim is to initiate a comprehensive care management that encompasses the infrastructure in the whole city-region, and to identify potential barriers to the integration of the infrastructure of care. Better integrated structures shall contribute to their accessibility and thus make for example structures in the rural area accessible to inhabitants of the city and vice versa. The medical doctor in the DCN team who is responsible for this task is therefore cooperating closely with the team of the case managers and the project director.

Regarding its different tasks, the DCN thus is operating on several levels of the home based long-term care network at once: on the one hand it provides case management what means to facilitate the *case-related* coordination between actors who participate in the provision of care. Thereby it might also induce a better general coordination of actors at a *systemic level*; this promotion of integrated care may be called care management. This aim became, at least for the financing side, the most important for the second phase and additionally was regionally extended to the whole city-region.

The different actors assume different roles in this network: The *psycho geriatric facility* is active in service provision, network organisation and administration as well as acquisition of financial resources. For the network organisation and service provision the local working group of the *general practitioners* is an

important partner. The model project is scientifically accompanied by staff from the local *Catholic University of Applied Sciences*. Both *municipal administrations, in the city and the city-region*, are supportive and involved in the advisory board of the project. The DCN receives also the support of *political representatives* from the region who partially provided their influence and networks. Provider organisations such as the welfare associations seem to be linked only loosely to the project; some of them are involved in the direct service delivery and report to sometimes communicate with the case managers and to refer clients there. It seems that the for-profit providers are even less linked to the DCN, but are also contacted by the case managers if they are already caring for a client who newly attends the network. The important role of the *medical doctors in own practice* - to refer and accompany clients and to supervise the process of case management - was already explained above. It is interesting that also neurologists could be motivated to participate despite the latent conflict between general practitioners and neurologists. The *counselling structures* are involved diversely: while the *Dementia Service Centre* is closely involved in the development of the care management in the second phase, the long-term care support bases are, if at all, more involved in case-related cooperation, less in the overarching networking; the recent changes they have underwent may explain this. *Insurers* and the *ministry for long-term care at Land level* are financers of the project. During our research, one insurer showed a strong interest to influence the content of the second phase of the model project. This insurer invests in own counselling structures and has established an own coordination centre for dementia related issues where caring relatives can ask for further information on special caring and respite services, on care-related questions as well as in situations of acute crisis. This stakeholder expresses the clear expectation that the activities of the DCN should development and consolidate the networking of the caring infrastructure in the city-region, so that a managing body would no longer be needed after the end of the funding period.

3.2 Historic-analytical description and evaluation of the change

The process of change, that is: the beginning of the development of the DCN Aachen, started from the local psycho geriatric hospital, more concretely from its assistant medical director who later on became one of the two chief physicians of the hospital. Motivation for its development was at least a threefold: First, due to the fact that patients might choose their hospital freely, there was an interest to develop the hospital's attractiveness for potential patients (*specialisation due to competition*). Secondly, as it was foreseeable that insurers would raise the pressure to reduce beds in the inpatient sector, there was an interest to expand the hospital's ambulatory services (*outpatient before inpatient care due to insurers-initiated reduction of beds*). Both led to a re-alignment of the psycho geriatric department a decade ago and the development of its self-understanding as a psycho-socially, community oriented institution ("sozialpsychiatrisch ausgerichtetes Haus") that was not only interested in the patients' treatment but also in the caring path before and after.³⁷ The foundation of the psycho geriatric counselling centre (PGCC) few years later expanded the hospital's ambulatory services (*institutionalisation, building of infrastructure*). It started as a very small institution with one counsellor, a bicycle, a little room, and a telephone. Anyone could call for free and with regard to any problem of psycho geriatric care and ask for a home visit. The approach of going to the patients' homes addressed the problem that home visits by GPs and medical specialists were often lacking (*modalities: low threshold approach*). There was a high demand for this service that - in the opinion of the chief physician - could contribute to avoid hospitalisation as the problem was more often one of organising the provision of care than of medical treatment. The third aspect that built the background for the development of the DCN in Aachen was the perception that patients with dementia would often utilize hospital beds what the insurers later would evaluate to have been unnecessary. So, the problem was that patients with dementia would lead to unnecessary utilisation of hospital beds (*avoiding misallocation*). To provide those patients from utilising hospital beds unnecessarily the first idea had been to ask GPs to inform the PGCC before they would admit

³⁷ At least, this is what told us an interview partner who is closely related to the institution; but actually all interview partners describe the hospital's work quite appreciating.

the patient to hospital. During the communication with the representative of the local general practitioners' association it became clear that to them the issue of outpatient care for patients with dementia and their resulting special needs was also a very urgent one. General practitioners felt that to meet the needs of these patients they would have to provide services for which they neither had the time nor they were qualified, e. g. take care of the relatives, to counsel on issues like the financing of services or the organisation of care, and make many financially little attractive home visits. From this constellation was born the idea to expand what the PGCC already was doing in a basic form: to provide a team of case managers that could be called by GPs, or relatives or the elderly person with dementia on his/ her own, and that would come for a home visit, check needs, resources, potential support to be initiated, and keep the GP informed, who would provide the needed medical treatment. Parallel there had been developed the memory ambulatory with the service of differentiated and special diagnosis. The promised relieve of the GPs and their interest to provide good care then led to a basic agreement to cooperate on this issue.

With this basic agreement only financing was lacking. According to a member of the project consortium, a first attempt to establish a contract on integrated care that was calculated with less money and patients than the projects later on was rejected by the insurers at Land level. In the following year there was a call from the federal ministry for health for "lighthouse projects" on issues of dementia care. A sub-call was on the further development and scientific evaluation of infrastructures of care. The prepared project was accomplished by the evaluative dimension and a new project partner: the Catholic University for Applied Sciences in Aachen. We got no hints from our interviews about what had motivated this selection, but it seems to be plausible that the common catholic background of the project leading institution and the evaluating one could have contributed. The project was admitted to the program³⁸ and financed from April 2008 until the end of February 2010. The budget covered the costs for 2.5 positions for case managers, 0.5 positions of a secretary, some material costs, and - the biggest share of the budget - the reimbursement of the GPs. The project had two thematic foci: it should promote more early diagnosis and it should qualitatively enhance the medical, social and psycho-social care of elderly people with dementia by providing access to coordinated services. According to a member of the project consortium, the underlying aim was to find an access to patients before the decompensation of their eventually overburdened caring arrangements, so that case management could stabilise the situation and avoid hospital stays. The GPs were conceived as the actors, who could most probably find this early access. For this reason there should be motivated as many GPs as possible to engage in this issue. As GPs are addressed by many, also rewarding programs, it was necessary to provide financial reward, too, and to secure that participating was not linked with too much organising effort for the GPs. It is this reimbursement as well as the already existing network of GPs in Aachen to which our interview partners attribute the relatively high share of participating GPs in the first phase. Not all of the inscribed GPs had patients in the program; some just participated in the qualification measures or other informational activities. With this approach almost 250 families could be attended in the three years of the first phase of the project. In this phase, neurologists or psychiatrists have not yet been included in the program. This was explained by some of our interview partners from the medical sector with the latent conflict between the medical specialists and the GPs who were competing about the distribution of reimbursement between both professional groups. As the (vice-) chairmen of the boards of the involved professional-political associations came all from the Aachen region the conflict seems to have become manifest here.

Early during the first phase, at the end of 2008, negotiations for further financing started. It was again taken into regard to establish a contract on integrated care; the alternative was to apply for funding as a model project for the development of modern caring infrastructures according to §45c SGB XI. This paragraph is applicable to fund model projects on the further development of dementia-related caring infrastructures. An interview partner from the project consortium holds as an advantage of a contract on integrated care the

³⁸ It surely calls the attention that, back in those days of the "big coalition" of conservatives and social democrats, the federal ministry of health who belongs to the social democratic party had won her mandate in the city of Aachen.

sustainability of such an arrangement. In the interview it did not become clear if to have failed in the first attempt did not disqualify this approach. The advantage of the second alternative was that there were less contracting partners to negotiate with. To establish a contract on integrated care one has to involve all insurers whose clients should later be admitted to participate in the program. GPs would have had to reject patients who were insured with non-contracting insurers to participate in the program. In contrast, the model project according to §45c SGB XI needed only to be negotiated with the responsible representative from the ministry for long-term care at Land level as well as with the representative of the insurer, who was set in charge by the community of insurers to negotiate this issue as their proxy.

To be financed as a model project according to §45c SGB XI, content and aim of the intended project had to be changed because this funding form is only possible for new projects and not as funding for a follow-up. The direction of the re-alignment of the project seems to reflect also the insurers' interests: The results of the first phase had touched the discourse on what were the original duties of GPs and what were additional services that should be reimbursed separately - a very relevant issue among the medical professions themselves as well as between the insurers and the GPs.³⁹ Evaluation results suggested that case management in a middle or late stadium of the dementia process led to a higher utilization rate of complementary services as well as of services for social attendance - that is: to services that are (co-)financed by benefits of the long-term care insurance (Theilig, Schirra-Weirich, et al., 2011, p. 35). This relieved the burden of the caring relatives and facilitated a stabilisation of the home based caring arrangement (ibid.). Retrospective analysis of hospital stays brought also hints that they may be reduced by case management in number as well as in duration (ibid.). The results also pointed to the aspect that some GPs would take over tasks which would not originally belong to their duties, like the counselling on and the organisation of long-term care (ibid., pp. 36-37). Anyhow, the perspective of the caring relatives would only very seldom be included, and there would be a considerable difference between the standards for the medical treatment of persons with a dementia condition and the realised practices (ibid.). Regarding the case management, the results claim an effect on the level of the single cases (stabilisation of the caring arrangement and support and relieve for the caring relatives) as well as on the systemic level (development of the care network) (ibid., p. 37).

While the project partners were motivated build the second phase of the project on the basis of the already established structures and the results, the negotiating partners from the insurers and the Land insisted on several changes in the application of the new project. There are rumours that the former minister of health has intervened with the director of the biggest of the regional insurers to give way to this project which finally was adopted for a phase of three years from October 2010 till the end of September 2013 with a budget of about 1.5 million Euro. From spring 2010 until the beginning of the paying for the second phase of the DCN Aachen in autumn 2010, the provider of the psycho geriatric hospital paid half a year for the project costs to prevent the dismissal of all staff due to the gap in the financing period.

There were three important modifications of the project in this second phase: first, its scope was extended and now included the whole city-region of Aachen, i.e. also the surrounding rural areas; second, the admission of patients to the case management was bound to the above-mentioned criteria (before admission was more open);⁴⁰ and third, care management - the assessment of the already existing infrastructure of (dementia-related) care in the whole city-region as well as its further development and the identification of barriers to networking at this systemic level - became an official and important part of the mission of the project. Beneath the working group of the GPs in Aachen, now also the working group of the Aachen neurologists, the city-region (with its social department), the Kuratorium Deutsche Altershilfe (KDA), the

³⁹ Thus, it seems to fit into the image that insurers seem to have not been satisfied with the validity of the evaluative results. The evaluation gave only hints but could - due to the gathered data and applied methodology - not prove statistically significant results.

⁴⁰ According to an involved interview partner, these criteria had to be introduced to define the target group of the case management more clearly; in the same time such criteria would be necessary in case that the project would be transferred to standard care coverage.

Alzheimer Association in the city-region, and the Dementia Service Centre (DSC) are nominated as formal collaborating partners.

There are some hints that point to an eventual scepticism of the insurers' side in front of the project and its evaluative mission in the second phase. The evaluative interest of the project is documented in the progress report on the second phase. This publicly accessible report announces an analysis of the health-economic effects of the case management on basis of the patient data of the participating health- and long-term care insurers (Theilig, 2011) [last access: 2.1.2012]. The interest to get insight into data of the insurers might explain the opposition of the long-term care insurance to the evaluative interest. However, one of our interview partners argued that the health-economical effects of case management would have already been assessed by another project and therefore another evaluation would not be necessary.

A sceptical attitude might also be understandable with regard to the competing interests between the insurer, who has developed own counselling infrastructures, and the project, that aims at being transferred to standard coverage for providing an insurer-independent case management.

Also the financing modalities could explain a sceptical attitude of the insurers: At the moment the costs for the model project are covered from the 25 million Euro fund for the further development of caring infrastructure. This fund is fed from the balancing fund of the long-term care insurance (§45c, 1 SGB XI). The balancing fund of the long-term care insurance consists of the contributions from the pensions, of the overplus from the current assets and from the financial reserve that has to be transferred by the long-term care insurers, as well as of the contributions from the health care fund ("Gesundheitsfonds") (compare §65 SGB XI). Also the private long-term care insurers have to contribute 2.5 million Euro to the fund for the financing of model projects according to §45c SGB XI. Costs for benefits ("Leistungsaufwendungen") and administrative costs of the long-term care insurers are paid jointly by all insurers in relation to their revenues (compare §66 SGB XI). The inclusion of the model into standard coverage of care would mean that its costs, including the reimbursement of the GPs, would no longer be paid from the long-term care insurance funds but from those health insurers whose insured would utilize the benefit. We may assume that the biggest health insurer in the region has the highest share of insured elderly.⁴¹ A high share of elderly insured may explain an interest of an insurer's long-term care insurance branch to provide own counselling structures regarding long-term care and dementia. Given this, there seems to be little incentive for insurers with many elderly insured to advocate for the transformation of the model into a regular health care benefit, even though there are hints that case management could reduce hospitalisation costs.

Apparently, the logic of the relation (and separation) of health insurance and long-term care insurance in Germany endangers (or at least functions as a strong barrier to) not only a continuous (financial) perspective of the innovative model under research here but also its generalisation. Thus, the shortcoming that is addressed by the model - the fragmentation of the German health care system - in the same time endangers the innovation.

3.2.1 Addressed Problem

The Dementia Care Net should address several problems at once: in its first phase it should enhance early diagnosis by qualifying general practitioners as well as by facilitating the access to the existing memory ambulatory and the knowledge of the psycho geriatric counselling centre. It should also provide information about the already existing infrastructure and facilitate an earlier access to this structure. Another problem that was named by many of the local service providers was the fragmented provision of social and psycho-social

⁴¹ With the introduction of the "health care fund" in Germany in 2009, the hitherto risk-structure adjustment procedure was replaced by the so-called "morbi-rsa", the morbidity-oriented risk-structure adjustment between the insurers. This adjustment procedure at least takes into regard the differing structures of insured according to their morbidity, but is still criticised by health scientists for doing this only for the 80 conditions that are included, even though age, gender and an entitlement to reduced employment are regarded (Rosenbrock & Gerlinger, im Erscheinen, pp. 10-11).

care and medical treatment: Service providers had the perception that GPs would avoid home visits and would not feel responsible to help their patients organise a home-based caring arrangement or referring them to other services. Also, in the logic of the project, the GPs are seen in a crucial position to facilitate a more early access of patients to services and vice versa as they get to know quite early about the situation of their patients.

The problem of late access was constructed at the local level, from the providers who have an interest in the elderly people with dementia as clients to legitimise their existence,⁴² and as two-sided: In our interviews local service providers not only lament that elderly persons with dementia would have only late access to their services. Behind this also shone through the lament that the providers themselves had difficulties in reaching the elderly people in an early stadium of the dementia process. Some of them report that affected elderly people or their relatives would often postpone making use of professional services as long as possible. As a reason they give the lasting stigma of being affected by dementia as well as the lack of information at the patients' side. The providers rarely speak about what the families probably would have told if we would have had the resources to ask them: that they probably want avoid not only the stigma of using professional services but also the intervention itself and the obligation to let some "strangers" inside their private home.

Further, the insurer's perceived a lack in the coordination of services. They constructed the main problem in the underdeveloped networking between the different actors in the city and region, and thus demanded from the DCN to engage in enhancing cooperation and coordination and identifying barriers to this. The insurers yet conceived this task as a transitory one which would not need to be perpetuated through the institutionalisation of the DCN.

3.2.2 Type of change

The case of the Dementia Care Net in Aachen shows an example of a process of incremental institutional change. In Aachen, we may observe a history of the development of dementia-related services of almost three decades that has its roots in some civil-society based movement in the 1980ies with the intention to provide a (more) humanistic long-term care. This happened parallel to the hospice-movement which imposed similar claims regarding care at the end of life. From this background also the foundation of the first of the local day care centres was initiated, the welfare associations followed; the process was facilitated by financing from Land level. It was also from Land level, thus externally driven, that a specialised counselling was offered with the implementation of the Dementia Service Centres in the federal state, one of them in the administrative district of Aachen in 2004. In this time, the local hospital reacted to the menacing bed reduction with an extension of its ambulatory sector and oriented its self-understanding at a community-based, comprehensive care provision. Until then change had taken place in a form of *layering* (compare Mahoney & Thelen, 2010, p. 16; Streeck & Thelen, 2005, p. 31): New elements were attached to already existing institutions that gradually changed their status and structure.

The interest to avoid costs from misallocations of patients in hospital as well as the interest of the local GPs' association to reduce the "burden" and challenge which patients with dementia meant to their practices finally motivated the idea of the Dementia Care Net. Its concrete alignment was adapted several times according to the respective financing options.

All in all, in the case of the DCN a known institution (the reimbursement of GPs to enhance their motivation to overtake new duties) was combined with the introduction of a new actor/ institution (the case management) that slightly and moderately changed the relation of the different professions who participate in care provision. Referring to the concepts of Streeck and Thelen (2005, p. 31) and Mahoney and Thelen

⁴² This shall not diminish their also expressed interest to provide high quality care for the elderly persons with dementia.

(2010, p. 16) to grasp change modes, the logic of the DCN thus may be described as to have followed a combination of *conversion* and *layering*.

3.2.3 Explanation of the process of change (regarding the national and the regional level)

The development and implementation of the DCN was facilitated and shaped by a combination of pre-existing resources: with the Psycho Geriatric Counselling Centre and other dementia-related services the new project could build on existing knowledge-providing institutions and actors in an environment of a municipality that was also actively promoting outpatient before inpatient care; the existence of the working group of GPs in Aachen facilitated access to and involvement of this professional group which is generally characterized as to be hard-to-reach; in the institutions we encountered many highly motivated and engaged actors who often functioned as well networked social entrepreneurs. More than one interview partner had the perception that if someone in Aachen had an idea that would make sense it would be implemented jointly; perhaps this again reflects the "engineering" and pragmatic culture of this region. The DCN consequently also was built on the linkage of several, already existing networks. A further facilitating aspect may have been that the close connection of the former federal minister of health to the city of Aachen.

The facilitating institutional conditions at the local level were complemented by financing opportunities that were provided from the national and the Land level, even though these required certain adaptations of the original project.

Thus, the social entrepreneurs from the local level work together to implement ideas which allow them to pursue their interests jointly; they look for a financial frame that facilitates the implementation of their ideas. In our case at Land level there are also engaged and motivated actors who actively promote their interests by shaping the frame. To adapt the project to this frame forces the local stakeholders to at least partly re-align the project. This may also have unforeseen consequences as shows our interpretation of the perhaps fostered competition between the counselling providers in the region.

But agency of the actors is not limited to their respective level: actors from both levels, the local and the Land level, try to shape the development on higher levels, too. Examples give the social planner of the city of Aachen who actively participated in the development of the recommendations from the Land level on municipal social planning. Another example is given by the representative of an insurer who internally promotes his ideas for innovations and thereby tries to influence national long-term care policy. Last not least, the director of the DCN also directly lobbies for the generalisation of the idea of his project with the federal ministry for health. Thus, stakeholders make use of different scales to pursue their own interest and thereby implement gradually institutional changes.

There were also barriers to the process of change: one seems to be the conflict between the different medical professional association that seems to have hindered an early contract on integrated care and the involvement of more medical specialists already in the first phase of the project. As a more sustainable barrier could prove the mentioned logic of the relation (and separation) of health insurance and long-term care insurance which seems to endanger financial perpetuation and generalisation of the DCN. Additionally, the capping of benefits in long-term care insurance and their financing by the insurers according to their share of revenues might also hinder to admit the case and care management to the standard health care provision. As case and care management theoretically should be provided by the long-term care support bases, this seems an even less realistic option. Even though it seems that long-term care support bases are not equipped sufficiently to guarantee a comprehensive case management for each client and further organise the local caring networks; it is not astonishing that the director of the DCN sees both institutions as complementary.

3.2.4 Evaluation of the result of change: continuity or discontinuity regarding our four dimensions

The establishment of the DCN in Aachen also affected governance, complementarities and coordination as well as quality and participation.

Governance. The generally strong separation between medical care and social care, but also complementary services and social participation was bridged on case level as well as on systemic level by the introduced case management, the networking activities, and, notably enough, the involvement of GPs, and even neurologists.

Coordination and complementarities. The case management contributed to a better coordination of already existing services and thus to a more integrated care. In the same time, there was exerted a pressure on the existing services, especially the counselling ones, to reflect on their special function in the network of (dementia-related) home based long-term care in Aachen. Anyhow, the analysis pointed also to services with a similar function but yet different logic or incentive behind (e. g. the case management structures established by the long-term care insurer itself and the case management of the DCN). Continuity seems to lie in the little attention which is spend on the needs of elderly migrants with dementia and their families as well as on the situation of socially disadvantaged elderly persons.

Quality. The evaluation results of the first project legitimate to assume an enhancement in the quality of the provision of medical and long-term care, including complementary services and social attendance, for elderly people with dementia and their relatives who have access to the DCN. The aims of the project – bridging the gap between medical and social care and providing early access to existing infrastructures – refer to the structure, process and outcome dimension of quality. By establishing the effect of the case management on the caring relatives the user perspective was not only included but also extended. One could critically ask for the perspective of the patients themselves.

Participation. In facilitating access to services and benefits to which the patients are entitled but about which they are not well informed, the case management also enhanced the participation of the patients. They were provided more opportunities for the individual design of the caring arrangement. This has empowered the patients in their role as consumers. By facilitating access to benefits they are entitled to, the social rights of the patients as citizens have been implemented.

3.2.5 Unforeseen consequences

One unforeseen consequence of the new counselling structure that was established with the DCN could be that it turned the already very complex counselling structures in city and city-region even more complex. On the other hand it seems more the conjunction of modifications of the early established counselling structure that led to this problem: on the Land-level, municipalities were already in 1993 obliged to provide counselling for their elderly citizens on questions related to ageing and care as well as on living arrangements. The municipality of Aachen provided a hotline for senior citizens as well as counselling. The former district funded a counselling office which was provided by the consumers' counselling association. These facilities were complemented since 2003 by the Dementia Service Centre in the former district and the Psycho Geriatric Counselling Office in the city as counselling structures that were specialised on dementia issues. Several changes turned this quite clear arrangement in a complex landscape of counselling opportunities and possibly led to a disorientation of clients and local providers: with the introduction of the long-term care support bases and with the merging of city-region and city into an new administrative unit, the pre-existing municipal structures were partly transformed into one of the new long-term care support bases, partly they were assigned to the new administrative entity. The big regional insurer established another long-term care support base, and further developed an own counselling structure of case managers by the establishment of a coordination centre on dementia issues. Almost at the same time the alignment of the Dementia Service Centre was modified, and it was deprived its mission of single-case counselling.

During these processes the Dementia Care Net was established. The only counselling structures that provided continuity were the counselling office on palliative care and the Psycho Geriatric Counselling Centre.

Another unforeseen consequence could be the further negligence of certain target groups as elderly migrants or socially disadvantaged elderly as well as elderly who live as singles without any caring family. They seem to be less addressed by the Dementia Care Net.

3.2.6 Summary of the analysis and evaluation of the change

The process of change was motivated by the interest of a community-oriented local hospital with psycho-geriatric specialisation to find an earlier access to elderly persons with a dementia condition whose home-based caring arrangement might be in danger of decompensation. The aim behind this was to avoid hospitalisation, enhance the sustainability of home-based caring arrangements, and by all this save costs in the system of health- and long-term care. During the process of change, beneath the initiating hospital and the participating GPs, all other actors that are engaged in dementia-related care in the city of Aachen and later on also the city-region, were affected by this process because the case management entered the stage as a new player who potentially would refer patients. Regarding the planning of the project, the insurers had early been involved but seem to have stayed somewhat sceptical in front of the project what may be attributed to their interest to avoid new costs which would be attributed to the health insurance. The establishment of the project was facilitated by the pre-existence of network structures (as the GPs network or the plurality of dementia-related care infrastructure), the readiness of the protagonists to look for modes of financing and their flexibility to adapt their original project ideas several times to the respective logic of the funding source, as well as to lobby for their project on different political levels - that is: by making use of different scales. The main barrier to the project, especially to its perpetuation, seems to result from the separation of health insurance and long-term care insurance in Germany with financing mechanisms that set an incentive to keep the costs for benefits in the (capped) realm of the long-term care insurance. The establishment of the case and care management of the DCN in Aachen also affected governance (reducing the fragmentation of health and long-term care on case and local level), complementarities and coordination (better coordination of services) as well as quality (stabilised caring arrangements, better quality of life of caring relatives, eventually reduced hospital stays) and participation (better informed patients and relatives, more room for autonomous decisions (consumer aspect), better access to services (citizenship aspect), better chance to social participation). However, the shortcoming that is addressed by the model – the fragmentation of the German health care system – in the same time endangers the innovation.

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Hamburg: Care conferences

1. Descriptive Section

1.1. General contextual information on the local case

The Free and Hanseatic City of Hamburg is with about 1.78 inhabitants in 2010 the second-largest city in Germany and the seventh-largest city in the European Union. The Hamburg Metropolitan Region has about 4,3 million inhabitants, including parts of the neighbouring Federal States of Lower Saxony and Schleswig-Holstein.

Politics

Hamburg is its own state, one of sixteen in Germany, as well as a municipality. Those two administrative tasks aren't separated. Therefore the governance deals several details of state politics and community politics. It takes place in two ranks; a city-wide and state administration, and a local rank for the boroughs. Hamburg has seven boroughs: Hamburg-Mitte, Altona, Eimsbüttel, Hamburg-Nord, Wandsbek, Bergedorf and Harburg.

For most of its after-war history Hamburg's government was led by the Social Democratic Party (SPD)(1946 – 1953, 1957 – 2001). That continuity was interrupted after 44 years. In 2001 a conservative coalition emerged from the elections, led by the Christian Democrats (CDU) and completed by the liberal Free Democratic Party (FDP) as well as the defunct right-populist Law and Order Offensive Party. In February 2004 the Christian Democratic Union won an absolute majority in the state-elections to the parliament (Bürgerschaft). Four years later, in 2008, the first nationwide black-green coalition, between the Christian Democrats and the Greens was established. It gave way in February 2011 to a new Senate, led by the Social Democrats with an absolute majority under governor Andreas Scholz. In January 2012, eleven months after the election, surveys show a high degree of approval – two thirds – amongst the voters for the work of the governor and the government.¹

The results of the 2011 state-elections to the Senate are the following:

SPD 48,4%	CDU 21,9%	Greens 11,2%	FDP 6,7%	Left 6,4%	Other 5,4%
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Locale economy, labour market, wealth

Hamburg is a prospering economic centre. In 2010, Hamburg's gross domestic product was with 49640 Euro per inhabitant or 162% of the German average of 30566 Euro. The city ranks first amongst the German states and makes up for 3,5% of the total German gross domestic product.² The sheer number has to be taken with a grain of salt, because of the huge number of people commuting in for work from the metropolitan area. Still, according to most indicators, Hamburg is one of Germany's most affluent regions. From 2009 to 2010

¹ <http://www.infratest-dimap.de/umfragen-analysen/bundeslaender/hamburg/laendertrend/2012/januar/>

² Statistisches Landesamt Baden-Württemberg (2011), without pages. http://www.statistik.baden-wuerttemberg.de/arbeitskreis_vgr/VGR_FB.pdf

Hamburg's gross domestic product grew with 3.4% slightly slower than the German average with 3.6%, making Hamburg 8th amongst the growth rates of all German states that year.³

Hamburg's economic structure: The service sector makes up for 83% of the gross added value. The manufacturing industries contribute 17%. Agriculture and forestry, as well as fishery don't play any statistically relevant role. That makes Hamburg the German state with the highest percentage of service industries and the lowest of manufacturing, followed by Berlin and Mecklenburg-Vorpommern. On the other end of the German range is the state of Baden-Württemberg with 63% of its GDP coming out of the service industries and 36% from the manufacturing industries.⁴

The Hamburg metropolitan region has economic clusters in: Port and logistics (second largest in Europe), maritime economy, chemistry, regenerative energies, media and IT sector, aviation (the world's third civil aeronautics location after Seattle and Toulouse), life sciences, food manufacturing, tourism industry, engineering and vehicle manufacturing.

Hamburg has a total of about 1.14 million gainful workers and 125000 marginally employed people. About 332000 people work for public or private service providers, almost as many work in trade, tourism and the hospitality industry. 310000 work in banks, insurances and real estate. 123000 work in the manufacturing industries. 35000 are employed in building trade. Only about 5400 work in agriculture, forestry and fishery.⁵ Hamburg's unemployment rate in 2009 was 8.6% or about 78500 people (2011: 8.3%). The rate amongst inhabitants with a passport other than German was 17.5% or about 18700 people.⁶ A majority of 60% of all Hamburg inhabitants have an individually perceived optimistic outlook on their personal economic situation within the nearer future.⁷

Demographics, aging, migration

Hamburg's population is projected to continually rise till 2030 (by a quite significant plus of 7,2% relative to 2009). Whereas the population of Germany as a whole will shrink by 3,7% in the same period. As an economic and educational centre there is a significant influx of young people.

In 2010 an average of about 336.000 inhabitants of Hamburg are aged 65 or older, 18,9% of the total population.⁸ The old-age dependency rate is predicted to rise, as everywhere in Germany, but Hamburg in a relatively moderate way: Till 2030 the old-age dependency ratio is predicted to rise from 38 in 2030, from 29.7 in 2009. In this respect Hamburg ranks lowest in Germany and most favourably, followed by the other city-states Berlin and Bremen.⁹

³ Statistisches Landesamt Baden-Württemberg (2011).

⁴ Statistisches Landesamt Baden-Württemberg (2011).

⁵ Statistisches Amt für Hamburg und Schleswig-Holstein (2012), p. 91.

<http://www.hamburg.de/contentblob/1005676/data/statistisches-jahrbuch-hamburg.pdf>

⁶ Statistisches Amt für Hamburg und Schleswig-Holstein (2012), p. 96f.

⁷ <http://www.infratest-dimap.de/umfragen-analysen/bundeslaender/hamburg/laendertrend/2012/januar/>

⁸ Statistisches Amt für Hamburg und Schleswig-Holstein (2011a), 10. http://www.statistik-nord.de/uploads/tx_standocuments/A_I_3_j10.pdf, Small variations in numbers are due to different valuation days, statistical model etc. of different sources.

⁹ Statistische Ämter des Bundes und der Länder (2011), p. 28 f.

<http://www.destatis.de/jetspeed/portal/cms/Sites/destatis/Internet/DE/Content/Publikationen/Fachveroeffentlichungen/Bevoelkerung/VorausberechnungBevoelkerung/BevoelkerungsHaushaltentwicklung5871101119004,property=file.pdf>

	65 – 79, Hamburg (in % of total population)	80+, Hamburg (in % of total population)	People with migration background, Hamburg ¹⁰	All 65+, Hamburg	People in need of care, Hamburg ¹¹	People with dementia, Hamburg ¹²	People in need of care with migration background, Hamburg ¹³	People in need of care, Germany ¹⁴	Share of people in need of care of total population ¹⁵
2005			30000				2880		
2007					43000			2.2 Mio.	
2010	13.8%	4.9%		334000		24500		2.4	2.7 %
2015			53000			26500	4540		
2020	12.7%	6.1%		347000	51000	28800		2.9	3.6%
2025			79000			31200	7890		
2030	15.8%	6.7%		417000	60000 (+38.3% since 2007)			3.4	4.4%
2050	19.2%	12.1%		551000				4.3 (+100% since 2007)	

In Hamburg, as well as in the rest of the Western world, the age group of 80+ will see the most significant rise in the nearer future. In German average, the age group of 80+ will grow for almost about another 60% of its 2009-size till 2030. It is the same age group, which has the highest dependency on care. In that stage of life, the most frequent chronic ailments that lead to a need of help and care are cardiac-circulatory-diseases and dementia illnesses.

5,3 % of the people in Hamburg aged 65 or older have a citizenship other than German. Their risk of poverty in old age is significantly higher: The overall poverty rate for the group 65+ in Hamburg in 2009 was 5,2%, where as for the non-German population the rate was at 26,3%.¹⁶ A share of 13.5% of Hamburg's overall population in 2009 has had a passport other than German. The most important countries and regions of origin are: Turkey (52000), Poland (21000), Afghanistan (12000) and Serbia + Montenegro (11000).¹⁷ The percentage of people with a background in migration is higher, because it includes those, who have already adopted the German citizenship and their children: in Hamburg in 2010 27,4% of the population had a migration background.¹⁸

There are some particularities concerning the age structure. The generations who moved to Germany because of guest workers programmes in the 1960s and 970s are reaching retirement age. The "65+ with migration background" group is growing quickly and overproportionally.

Approximately 29300 people in need of care were living at home in Hamburg in 2007. That is with 67,8% the biggest percentage of all the people who recieved care and slightly under the German average of 70%. Estimations of the Land's department for social affairs, family, health and consumer protection (Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, BGS) calculate with 31300 care-recipients living at home in 2015 and

¹⁰ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 7.

¹¹ Statistische Ämter des Bundes und der Länder, Demografischer Wandel in Deutschland, Heft 2, 2010, p. 29.

¹² Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 56.

¹³ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 9.

¹⁴ Statistische Ämter des Bundes und der Länder (2010), p. 29.

¹⁵ Statistische Ämter des Bundes und der Länder, Demografischer Wandel in Deutschland, Heft 2, 2010, p. 28.

¹⁶ [http://wegweiser-](http://wegweiser-kommune.de/datenprognosen/berichte/Berichte.action?berichtstyp=demographie&gkz=02000000&datenvergleich=3&pdffilename=demographiebericht.pdf&zeigeBericht=Download+Bericht+%28pdf%29&_sourcePage=%2Fdatenprognosen%2Fberichte%2Findex.jsp&_fp=cqRyl%2BpNQ5anpGZx4tUPDQ%3D%3D)

[kommune.de/datenprognosen/berichte/Berichte.action?berichtstyp=demographie&gkz=02000000&datenvergleich=3&pdffilename=demographiebericht.pdf&zeigeBericht=Download+Bericht+%28pdf%29&_sourcePage=%2Fdatenprognosen%2Fberichte%2Findex.jsp&_fp=cqRyl%2BpNQ5anpGZx4tUPDQ%3D%3D](http://wegweiser-kommune.de/datenprognosen/berichte/Berichte.action?berichtstyp=demographie&gkz=02000000&datenvergleich=3&pdffilename=demographiebericht.pdf&zeigeBericht=Download+Bericht+%28pdf%29&_sourcePage=%2Fdatenprognosen%2Fberichte%2Findex.jsp&_fp=cqRyl%2BpNQ5anpGZx4tUPDQ%3D%3D) p. 7f.

¹⁷ Statistisches Amt für Hamburg und Schleswig-Holstein (2010), p. 1.

http://www.statistik-nord.de/uploads/tx_standuments/A_I_4_j10_H.pdf

¹⁸ http://www.bpb.de/wissen/NY3SWU.0.0,Bev%F6lkerung_mit_Migrationshintergrund_I.html

33200 in 2025.¹⁹ 13801 people (that equals 8 in 1000 inhabitants, or 36 people of 65 or older within 1000 inhabitants of 65 or older) were provided with outpatient care, either uniquely or additionally to care from attendance supported relatives. The overwhelming majority of outpatient care recipients is 65 or older, with only about 1550 under 65.²⁰ (Their distribution on the Care levels: Care level 1: 7954, care level 2: 4537, care level 3: 1310). The ratio of outpatient care providers and patients is 1:40.²¹ As well as in the rest of Germany, the biggest share of the care-dependent (17860) were looked after by their relatives, supported by an attendance allowance from the long-term care insurance (Pflegegeld) (Care level 1: 11407, care level 2: 5122, care level 3: 1331).²²

1.2. Brief description of the local network of home based long-term care for old people

Market allocation

Outpatient care services by type, December 2009²³

	Total number	Number of care recipient per service	Private, for-profit & share of total number	Private, not-for-profit & share of total number	Public & share of total number
Hamburg	345	40.0	259 75.1%	84 24.3%	2 0.6%
Germany	12026	46.2	7398 61.5%	4433 36.9%	195 1.6%

Outpatient care recipient by type of service, December 1999 & 2009²⁴

	Total number	Number of care recipients of private for-profit services & share of total number	Number of care recipients of private not-for-profit services & share of total number	Number of care recipients of public services & share of total number
Hamburg 2009	13801	9308 67.5%	4384 31.8%	109 0.8%
Germany 2009	555198	260871 47.0%	284271 51.2%	10055 1.8%
Hamburg 1999	11480	6988 60.9%	4231 36.9%	261 2.3%
Germany 1999	415289	147804 35.6%	259648 62.5%	7837 1.9%

Hamburg has with 75% the highest rate of private for-profit outpatient services of all the German states. They provide care for 68% of all outpatient care recipients. That is about 7% growth in the ten years since 1999. The range within Germany is quite wide. The importance of non-profit services (like the in traditionally protestant Hamburg the protestant-church-owned Diakonie) is only similarly low in the other city-states like Berlin (In 2009, 65.1% of outpatient care recipients cared for by private for-profit enterprises). Baden-Württemberg is at the bottom of the list with an almost reversed rate of only 27.3% of all outpatient care recipients looked after by private for-profit organisations and 68.3% receiving care from private non-profit services. In Hamburg as well as in the German average, public providers play only a marginal role, corresponding to the priority given to the other two types in SGB XI, the federal law on long-term care. The numbers reflect as well, that for-profit services are mostly smaller units than the traditional private non-profit providers.

¹⁹ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 16.

²⁰ Statistisches Amt für Hamburg und Schleswig-Holstein (2009), p. 4.

²¹ Statistisches Amt für Hamburg und Schleswig-Holstein (2009), p. 7.

²² Statistisches Amt für Hamburg und Schleswig-Holstein (2009), p. 12.

²³ Statistisches Bundesamt (2009) p. 6.

https://www.destatis.de/DE/Publikationen/Thematisch/Soziales/Pflege/LaenderAmbulantePflegedienste5224101099004.pdf?_blob=publicationFile

²⁴ Statistisches Bundesamt (2009) p. 6. Statistisches Bundesamt (2002) p. 5.

Professionals, employed in the outpatient care market: In 2009, 9762 professionals have been working in home based long-term care in Hamburg. 7798 women and 1928 men. There is high percentage of part-time employment: 6801 workers were part-time employed and 2713 were working full-time. Most of them, 6384, were providing basic care as their predominant occupation. 1714 people were mostly providing housekeeping assistance. 598 were predominantly working in administration and management. 526 professionals were providing other care services, and 504 employees were most of their time working on other tasks in outpatient care providers. 2242 people of the total were only providing care, no other tasks on the side.²⁵ From 2007 to 2009, the full-time equivalent jobs grew by almost 9% caring for about 8% more people in need. 64% of out-patient service employees are skilled workers with a degree in the field of care. The group of the unskilled aids is growing the fastest though.²⁶

Available services and providers of home-based care

Over 350 **outpatient care services** operated in Hamburg in 2009. Besides the basic offer, 126 of them named a specialization. 43 depicted the care of people with dementia and 13 palliative care as area of expertise. 80 of them had teams working with languages other than German. The federal law on care schedules a quality check for each outpatient service, as well as each stationary care facility once a year. Hamburg's outpatient care market is one of the most competitive in Germany. Quality checks are conducted by the medicals service of the health insurers (MDK). For transparency reasons, the results are online available.²⁷ The Hamburg law on living- and care quality from December 2009 includes additional quality spot-checks on the outpatient services or after complaints. They are conducted from administrative bodies on the borough-level and they are to be coordinated with the activities of other controlling agencies.²⁸ In these checks about 5% of the tested cases showed shortcomings in the quality in 2009.²⁹ The care-framework planning on the land-level wants to develop the formation of outpatient care provider employees particularly in the area of dementia.³⁰

25 services of different sizes were operating in the field of **visiting and company service** in 2009 (2005: 13). Some of the were entirely volunteer-based. Others were providing low-threshold care services as well. The supervision of the volunteers is funded, as well as expense allowances. The demand in quantity (and quality sometimes as well) can't always be met. To support the extension of the service, the Pflegestützpunkte (borough-based information providers) should recruit volunteer-providers and users, coordinate, provide advice and space. It is a goal to develop the service for people with migration background as well.

At the end of 2009 Hamburg had 20 facilities offering **day-time care** with 386 places that were used by 630 people. One facility in 2009 was specialized on muslim people with a migration background, with another one planned for 2010. The improved financing as established by the care development law in 2008 (Pflegerweiterentwicklungsgesetz) as well as – in the meantime disestablished – additional funding of investment costs by the Senate that

²⁵ Statistisches Amt für Hamburg und Schleswig-Holstein (2009), p. 5.

²⁶ Statistisches Amt für Hamburg und Schleswig-Holstein (2011c). <http://www.statistik-nord.de/daten/gesundheit-und-soziales/pflege/dokumentenansicht/personal-der-ambulanten-pflegedienste-in-hamburg-und-schleswig-holstein-2009-1/>

²⁷ www.pflegenoten.de

²⁸ <http://www.juris.de/jportal/portal/page/bshaprod.psml?showdoccase=1&doc.id=jlr-WoBetrQGHArahmen&doc.part=X&doc.origin=bs&st=lr> (§ 30, § 37)

²⁹ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 5.

³⁰ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 21

disburdened the visitor up to 9.20 Euros a day has broadened the offer quickly. In 2009 Hamburg was slightly under the average of day-care places offered in other German cities.³¹

Two facilities in Hamburg are specialized on stationary **short-term care**, offering 59 places. Together with the places offered by an oversupply of full-stationary places about 5000 people per year did use short-term care with an average-length stay of three weeks. That is judged as sufficient. There is a Hamburg-wide aid of 18 Euros per day and place, designed to advance particularly facilities who only offer stationary short-term care because they are structurally less likely to develop the intention of keeping the care-recipient for good.³²

In 2009 14 **flat-sharing communities for people in need-of care** (ambulante Wohngemeinschaften) offering 113 places. The 5-year-plan targets a number of 25 of these small sized units till 2015 and an ultimate number of about 40. These communities are provided with care by outpatient-care services that the people living there and their relatives agreed upon. From 2003 to 2006 the framework requirements were being laid. In 2006 a specialized coordinating city agency was opened (Hamburger Koordinationsstelle für Wohnpflegegemeinschaften bei der Stattdau). Mentioned as elements of the course of action for the next five years advertisement for the new form and particularly for new volunteer attendants their supervision and qualification, as well as the quality development and formation offers in general.³³

The most important providers of information and counselling on financial issues and possible support, and assistance in case management are the care support points (Pflegestützpunkte). They opened up in 2009. They are thought to replace the old counselling offer of boroughs and to complement existing structures from a neutral side. Eight of them are distributed equally throughout the boroughs. Additionally eight specialized information centres work in Hamburg, including one on technical support and living space adjustment, the one on flat-sharing communities for care recipients, two on hospices and palliative care and the Alzheimer Society. Finally the providers of care, the insurers and the social services of the hospitals provide also advice.

Reconstruction of the governance network

On the state-level the **department for social affairs, family, health and consumer protection** (Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, BGS) is directly concerned with home based long-term care. In 2010, it published the second 5-year-plan.³⁴ It is thought to serve as a common base of discussion for everybody involved in care delivery in Hamburg. It analyses the current offers, forecasts future needs of care and assistance concerning each type of service and on the local level (Hamburg-wide or borough-wide). It also analyses the current and future requirements care needs to meet, proposes corresponding actions and evaluates their success. As a result of new developments, newly emphasized topics were introduced to the structure of the 2010 report: For the first time, migration background is included and quantified. The development and maintenance of the quality of care is now the topic of analysis in a separate chapter, focussing on the newly introduced changes in the legal basis. More space is also attributed to hospice work and care

³¹ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 22f.

³² Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 24f.

³³ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 26f.

³⁴ In the aftermath of the latest elections in early 2011, the Department of Social Affairs, Family, Health and Consumer Protection was split in two agencies. The competence for seniors, care and legal /judicial assistance was overtaken by the newly tailored Ministry of Health and Consumer Protection.

services for people with disabilities.³⁵ One of the major goals of this framework policy plan of the BGS was the strengthening and supporting of home-based care. The document evokes autonomy and the free choice (where to live) of the people in need of care as main values.³⁶ The argument is evoked that the care-providing relatives need to be supported to create a sustainable situation for the caring at one hand and for the cared-for on the other hand, by preventing excessive demands and hence contributing to the quality of the care.

Within the city of Hamburg in a process of decentralization more and more competences and tasks performed with immediate contact with the citizens have been transferred to the local level, in the case of care to the **health offices of the boroughs**. Since around 2009 the work with seniors, the supervision of care providers, counselling is mostly coordinated and also funded out of the budget of the borough office, with the land-level health office (BGS) as coordinator between the boroughs and money source (GAH, 19 08 2011).

Care conferences: In the aftermath of the federal law setting up the insurance system on long-term care in 1995, the various Länder of the Federal Republic had to decide on specific laws on care in order to organize their share of the implementation of the law and to re-organize the functions they already had beforehand. In Hamburg, the care conferences were introduced in the first Hamburger law on care of 1996 (Hamburger Landespflegegesetz 1996). They aimed primarily at improving the coordination of local actors in the domain of domiciliary care. (For more details cf. the analytical section of this report.) The care conferences were meant to complement the care commission of the Land (Landespflegeausschuss) on a grass-root level.

The foundation of the **care commission** in the mid-nineties fulfilled a requirement of the law on care of 1995. Its function is to discuss the questions of funding and is composed out of representatives of associations of the private for-profit, as well as the private non-profit care providers, a representative of the HPG, representatives of different care insurances, a representative of the medical service of the health insurances, a representative of the administration in charge of care at land- as well as borough-level, a representative of the political representation of senior citizens at city-level, the working group of people with disabilities and finally somebody representing the local health- and care conferences. The commission can give recommendations on the regional and functional development of the care system. It also prepares and coordinates actions to improve the care supply.

The HPG is Hamburgs most important **care provider representation agency**. Its crucial task is to negotiate the prices of care services with the care financiers for all of Hamburg. It unites all types of providers: non-for profit, for-profit, private and public, outpatient, stationary, different sizes, as well as other provider agencies. Its formation was initialized by two big providers, the protestant church-owned Diakonie and an - at that time city-owned - provider "Pflegen und Wohnen (Care & Housing)". It was founded in 1997 to counterbalance on the provider's side the newly formed joint negotiation-power of the care-financiers, introduced by the federal law on care.

The most important discussion at the moment: At the end of 2012 the remuneration agreement expires. The old one was valid since 1997. Two models are being discussed: The first would consist in a general lift in prices. In that version the logic of the current system would not be changed. In the second one, the prices would be linked to the prime costs, which would reintroduce an element of the system before the introduction of the care insurance in

³⁵ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 3.

³⁶ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 16.

1995/1996. The majority of the HPG members favour this solution and the HPG plans to propose an cost accounting pattern (BAPP1 22 11 2011).

The HPG also runs programs targeting provider issues, like an advertisement campaign against the general lack of qualified personnel. It also runs a central complaint-phone for care clients and proposed to participate in a cross-sectoral initiative for the prevention of decubitus – an initiative considered in the city’s 5-year-framework-planning on care.³⁷

2. Analytical Section

2.1. Description of the innovative ltc-model for the elderly (today)

The care conferences are organized by administrative actors (the Gesundheitsämter, Health offices) at the infra-communal level of a borough (Bezirk). Care conferences are an instrument of governance that can be used for various purposes. Precisely, in the case of Hamburg, it seems that the goals attributed to this instrument have evolved over time. In the first period, care conferences were aimed at balancing the influence of the law introducing an insurance scheme for long-term care. This from the mid-nineties implemented law had introduced the market norm as a key principle governing the provision of long-term care for the aged. It was by then perceived as a very important threat to the traditional balance of power at local level. In the system prevailing until the introduction of the 1995 reform, local authorities were a key actor both in the planning, organizing, and financing of long-term care providers. German municipalities had integrated their key role in this precise domain of long-term care in various complementary services such as transport or leisure for instance. German local authorities, mostly in the Western part of the country³⁸, had developed ancient and strong relations with various welfare associations (Wohlfahrtsverbände) that traditionally benefited from very delegation of public task in that domain. Those associations are clearly related to the Protestant Church (Diakonie), the Catholic Church (Caritas) and the labour movement (Arbeiter Wohlfahrt) (further: German Red Cross (DRK); also: Arbeiter-Samariter-Bund (ASB) - also with labour movement background; perhaps with no own ltc-services: Zentrale Wohlfahrtsstelle der Juden). Some cities had as well developed strong own social services. In most cases, there was a mix of those traditions. Those established networks have had developed clear and tight ties with the local hospitals and other institutions such as day care centres, etc. The introduction of the market was seen as a threat inasmuch as it would destroy the traditional relations, would introduce competition and mistrust in the network and could trigger disorganization and chaos in the delivery.

The content of the care conference principally concerns itself with the **governance structure** of the long-term care domain. It is supposed to improve the coordination of the care providers. It is not supposed to implement concrete action but it should mainly foster mutual understanding and a common view on the local situation of as many local actors as possible. It can be interpreted as a cognitive policy instrument aiming at triggering change by persuasion, mobilisation and coordination of actors. From this betterment in coordination are expected as well positive outcomes on specific issues such as care management, planning, quality, etc.

As a primarily governance instrument, the care conferences target in the first place organized actors. All groups, organizations, providers, companies, associations, professionals of the health sector, etc. who are active in that domain of long-term care are invited to take part in

³⁷ Behörde für Soziales, Familie, Gesundheit und Verbraucherschutz, Hamburg (2010), p. 21.

³⁸ As the law on long-term care insurance was introduced in 1995, the reunification was still very recent.

the care conferences. In Hamburg, care conferences are organized at the level of boroughs, which are rather big units in this big city-state: for example Eimsbüttel has almost 260 000 inhabitants and Altona, more than 240 000.

In Hamburg, the care conferences were introduced as an experiment through an agreement between the “administration for labour, health and social affairs” (Land of Hamburg) and in the Bezirk of Harburg in Mai 1998. As the mission and the competencies of the care conferences are not defined in further details, the leaders or the heads of this micro-local instances might do the most various things with those. The following activities are for instance provided by various Hamburger care conferences attached to various boroughs:

- common reflexion in the network of providers about a specific issue (such as nutrition, leisure or sports activities, palliative or terminal care, etc.);
- provision of information about the neighbourhood (addresses, contacts, statistics, needs, epidemiology, etc.);
- information of beneficiaries and families about the themes and issues of reflexion (dementia, health care and personal care, quality issues in care, etc.).

Both the two first types of activities are dedicated to professionals of long-term care delivery. But, the third one should be opened to the public. Those information sessions should indeed play a part as an activity of public health, mostly concerning itself with prevention or the promotion of health maintenance.

2.2 Historic-analytical description and evaluation of the change

Addressed problem

This definition of the “addressed problem” in the case of care conferences should be tackled in various ways. In the first place, and one could say, at a meso-level, the model of the care conference deals with **the issue of governance in the networks** of providers of long-term care. Primarily aim of the care conferences is to **improve the co-ordination** of local actors in the domain of domiciliary care. It should address the high level of segmentation typical of the German system of domiciliary care delivery that is very frequently associated in the debate about this national system with the market principle. Care conferences should enable local actors coming from the most various professional and non-professional spheres (health, nursing care, personal care, voluntary sector and charity, market actors, etc.) to develop projects improving the well-being of the concerned population. It does not aim at providing in itself any direct service to beneficiaries. However in some cases, the care conferences set up a collective job of analysis, or of information gathering that then develops and comes up with results that can be of interest not only for the professionals of the sector, but as well for the beneficiaries.

Secondly, precisely at a smaller scale, the various local (at borough level in the case of Hamburg) care conferences can freely define their agenda. Some of them (see examples later on in this chapter) develop information systems, some other focus on prevention campaigns, or some other stick to the initial goals of the model, i.e. the coordination of the various types of actors of the domain. At this lower level, it is though difficult to analyse the impact of specific local problems to the agenda of the care conference itself. It might be that the choices made at this level rather depend on the specialities and priorities made by the local leaders of the conferences. In most cases however, the themes are chosen locally on the basis of what the individuals who are concretely involved in the care conference perceive from their own activity as being an urgent issue to discuss or even to address.

Explaining the process of change

In the case of Hamburg, the change process is a two-step one. The first step concerns itself with the adoption, at the level of the Hamburg-wide administration, of the instrument of care conferences as such. The first part of this section precisely deals with the history and the context of this policy instrument, in a long-term perspective. The second one is focused on the way the instrument has been implemented in one specific borough of the city-state of Hamburg, i.e. the borough of Eimsbüttel.

Political and intellectual origins of the concept

Care conferences are the replication in the domain of care, of the health conferences. Those instruments, primarily “invented” in the West-German context of North Rhine Westphalia, Land of Social-democrat tradition, close to the one in Hamburg, had been developed in this region in the context of the social city (Sozialgemeinde).

The initial project of this model of Sozialgemeinde was to create a network welcoming all the actors, not only of the long-term care domain, but also of the old age policy. This policy instruments might be related with one of the oldest models of local level welfare provision in Germany, the Eberfelder System, that was based on a tight cooperation between the religious organizations and the public provision by the local authorities own services in the mid 19th century (Wollmann 2008, p.140). More recently, and probably more certainly, the context in which the Sozialgemeinde has developed was marked by the quest of the West-German social democracy a very encompassing and ambitious model of democratization of the society. Conceptualized around the SPD manifesto of the 1950's – Sozialplan für Deutschland (SPD, 1957)-, the concept of social city was modernized in the aftermath of the Willy Brandt mandate, and in the context of “Sozialplan für Deutschland” particularly in the SPD fortress of North Rhine Westphalia. By then, the ‘social city’ was a model that aimed to build the widest possible consensus about the goals of specific social policies implemented at local level. The achievement of this program has specifically been important in the domain of old age policy. Consensus building, participation, direct democracy, proximity to the citizens, networks of providers, experimental forms of coordination etc. were in that context of the 70's and 80's political forms of innovations, advocated for and carried out by the SPD. Innovation for a very praised value, for its own sake, as was the concept of Gerechtigkeit (social justice), that was a central reference point of the whole framework (SPD, 1998).

This very concept of Sozialgemeinde was adapted in the early 1990's, as it fitted very well with the by then rather new and fast developing thinking in terms of network. As an attempt to connect all providers active in the domain of health and social care in order to improve the performance of the policies, it was understood as a pragmatic and proactive way to address the raising criticism social expenses were subject to. Strengthening on the same time the fight against social exclusion, the risk of poverty and isolation in old age, targeting the raising challenges of population aging, the social city was seen as a both solidaristic and democratic way to respond to the liberal attacks of the time.

Care conferences in the context of the law on long-term care insurance: the replication in Hamburg of the North-Rhine Westphalia model

As the federal law on long-term care insurance was introduced and as it foresaw the opening of a market for service providers, a rather common political reaction was to fear that

the market would threaten coordination, networks, solidarity, and all the values associated with the social city. The effect of this reaction was to re-launch this initiative and even to make it more consistent and more goal-centred in the domain of long-term care. The care conferences were founded in North-Rhine Westphalia precisely in this context. A rather detailed list of concrete objectives is attached to this concept of care conference (Rosendhal, 1998). They deal with the planning of provision, infrastructures on the basis of needs, the integration of all providers, the consideration of the high variety of needs along the life course, the training of personal, the encompassing coordination of actions, the consideration of informal or unpaid carers and of minority cultural milieus, the connection with town planning services, the policy goal formulation at the most various scales, the support of gerontologists (Ibid: 113). In this context of multiple of targeted goals, various networks or committees have been founded in various social-cities. This multiplicity soon raised the problem of coordination of those networks and committees with another. In North-Rhine Westphalia, all districts (Kreise) and city councils (kreisfreie Städte) must build a care conference. This is not the case in Hamburg.

The law on long-term insurance precisely explicitly formulates the necessity of a tight cooperation between the basic institutions and actors of the domain: Länder, local authorities, long-term care providers and insurance funds. But the federal law let the various Länder of the German federal republic choose the way they organize the concrete fundament of this cooperation (Dapp, 2005). In the case of Hamburg, the decision to take over the model of care conferences was made in the aftermath of the reform of the legal framework organizing the public health policies at the level of the Land. This decision was consequently taken in the first place in the institutional arenas of the regular policy process. The second paragraph of the Hamburg Landespflegegesetz of 1996³⁹ (Law of the Land on long-term care) foresaw the possibility to set up care conferences. The initial idea was to complement the Landespflegeausschuss (care commission of the Land⁴⁰) by an instance that would be closer to the grass-root level. In the first version of the law, the autonomy of the Landespflegekonferenz was presented as very high. The legal definition of the care conferences “even gave the impression that the boroughs would be able to set-up the repartition of competences about many aspects of long-term care regulation between the boroughs and the level of the city-state” (GAH, 19 08 2011). As a matter of fact, as the borough administration was still very weak in the domain of public health in general and long-term care particularly this legal anomaly has not had any concrete consequence. In the last version of the Hamburger law on care however (Landespflegegesetz 2007⁴¹), the official aim of the care conference is formulated in a very restricted and precise way. The 4th paragraph of the law merely says: “health and care conferences can be set up in order to improve the matching at low scale level of the long-term care providers⁴²”. In the words of the officer in charge at the level of Hamburg city-state health administration of this issue of health and care conferences: “the idea was and is still to create a forum in which the local situation can be debated and in which the participating actors can formulate agreements that could lead to improvements of this local situation” (GAH, 19 08 2011).

39 Hamburgsches Landespflegegesetz (20.06.1996) : HmbLPG.

40 Represents of long-term care delivery services, of long-term care insurance funds, one officer of the medical service of the health insurance fund, one officer of the Land administration in charge of care are members of the care commission.

<http://www.landesrecht.hamburg.de/jportal/portal/page/bshaprod.psml?showdoccase=1&doc.id=jlr-SGB11PflegeAusschVHArahmen&doc.part=X&doc.origin=bs&st=lr>

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<http://landesrecht.hamburg.de/jportal/portal/page/bshaprod.psml;jsessionid=B3484A20349C0E612341A867A574E9C4.jp94?showdoccase=1&doc.id=jlr-PflegeGHA2007rahmen&doc.part=X&doc.origin=bs&st=lr>

42 (4) Zur besseren kleinräumigen Abstimmung der pflegerischen Versorgungsangebote können in den Bezirken Pflegekonferenzen eingerichtet werden.

The Boroughs can decide to set up one care conference or not do to it. According to the law, the aim of the care conferences is to “maintain and further develop the provision of long-term care”. The both boroughs, which have in the first place developed a care conference, as soon as from 1998 onwards, are Harburg in the Southern part of the city-state and Hamburg North, on the opposite side of the city’s territory. Both these cases were so called experimental models. The goal of the Harburg care conference was to go on with a psychosocial network that had been started in 1996. In the case of Hamburg North, the aim was to develop a system of long-term care oriented towards community care and the specificities of the local milieus and have developed specific issues, questioning, ways to proceed and to create coordination, etc.

These various care conferences have been developed on the basis of their local peculiarities, but, it seems that the identity, the domain of interests of the leaders of the care conferences explain most of the choice in favour of one or another orientation for each local care conference.

The care conference of the Eimsbüttel borough

The care conference of Eimsbüttel⁴³ has been initiated via the institutional channel of the Bezirksversammlung (assembly of the borough) at the beginning of 2003. This elected assembly is a decentralized, grass roots institution. The decision to call for the set up of a ‘health and care conference’ was made by the commission for Work, social affairs and voluntary work. The motivation for this foundation was to improve the borough level coordination in the network of domiciliary as well as partly residential care providers and to foster the possibility for the aged population to engage in sport and leisure activities and finally to improve the health promotion, the prevention, and the rehabilitation via the strengthening of the geriatric infrastructure (Dapp, 2004 : 25). The inaugural session of the conference took place on the 23 September 2003 and was attended by about 30 persons: borough administration, political parties, academics, senior citizens organisations, domiciliary and residential long-term care providers, geriatric hospital (Ibid:31).

During this session, many supplementary issues and possible goals for the Eimsbüttel borough care conference have been discussed: development of an encompassing view of long-term care in the borough, provision of a grounded analysis of the locally available provision, foundation of a forum for the mutual acquaintanceship of the various local providers, foundation of a forum dedicated to the preparation or the comment of relevant sociopolitical decisions, development of professional standards, improvement of the image of long-term care and aging and lobby activity (Ibid: 32).

All those items that have been initially discussed did not develop into a working group or were not subject to focus work in the care conference. However, they are very representative of the variety of problems and issues that could possibly be addressed via care conferences at the most operational level. Even before the foundation of the care conference itself, two key actors had made an alliance that was coherent with the governance model they wanted to adopt for the conference. The chosen model was not a model of « delegation », according to which the political instance delegates its entire prerogatives to the leading group of the conference, but was a model of «consensus» according to which the power structure is joint between the institutional power and the leading group of the conference. In the case of the Eimsbüttel borough, a high-ranking member of the borough health-division administration

43 The borough of Eimsbüttel has been picked for this detailed analysis for the quality and the intensity of the activities of the local health and care conference. Exploratory interviews had been run in five (out of seven) boroughs of Hamburg.

(Bezirksgesundheitsamt) is the director of the conference. This person stands for the coordination between both the borough administration and the care conference. The other historical co-founder of the local care conference is a high-ranking member of a research institute in gerontology in the most important hospital of the borough. This person represents the “civil society” part of the governing body of the care conference. She is a member of the direction committee (Lenkungsgruppe), as a matter of fact, the most influential member of the committee.

Both these persons are doing, in consensus with each other, the work of running the care conference since its foundation in 2003. This operative committee has developed a specific strategy that could be summed up around three main actions.

The first one has been to launch a very far-reaching and detailed system of information about provision of services analysed in a geographical dimension. The information concerning GP's, nurses, associations, long-term care providers, services of help, public services, etc. were centralized and put on a digital map of the borough that is accessible online (FGBE 15 06 2011). Aim of this information system is not only to provide information to the families or directly to potential beneficiaries, it is as well to elaborate an analysis of the relationship between the available services and the type and the structure of need, at a micro level. Other epidemiological analyses run at the research centre to which the quasi co-director of the health and care conference complement very nicely this information system. It is possible to check the micro-local dimension of the fits and misfits between supply in services and to have a picture, as well in a more dynamic and patient-centred perspective, of pathways, complementarities in services, and specifically to think of the shortcomings in both those dimensions (RGS 15 06 2011).

The second type of activities initiated by the Eimsbüttel health and care conference are working groups. These working groups are specialized on various issues such as prevention and health maintenance, terminal and palliative care, or aging in the borough. Those working groups organize an issue network. The aim of both coordinators is to mobilize as many actors as possible and to try to build a consensus on the various items at stake. It is important to mention that the various working groups at stake are very autonomous within the general structure of the health and care conference. In the present situation of the health and care conference of Eimsbüttel, there seems to be a difference between the working groups run by the «co-directors» of the care conference itself and which seem to be more integrated to the general structure of the care conference itself, and seem, for obvious reasons, to be closely related to the organisations those co-ordinators belong to.

This for instance clearly the case working group AG Best. This group is dedicated to a very concrete goal i.e. the improvement and maintenance of the health situation of senior citizens that would be followers of the group via three main means: the improvement of the involvement in physical activity, a betterment in nutrition and a reinforced involvement in social life. Run by the coordinator working at the geriatric research centre of the hospital, the activity of this working group is clearly related to the action agenda of this structure.

Another working group is run by the head of one of the biggest long-term care private providers not only in the borough of Eimsbüttel, but in the context of Hamburg. This person who is engaged in one very active association representing private business in the city-state of Hamburg has a rather ambivalent position about the instrument of health and care conferences. On the one hand, she has a very negative appraisal of the instrument of the health and care conference in itself. The concrete results of the endeavour being in her view very poor, so that the conclusion should be that the « initial goals of the instrument were not clear in the first place ». On the other hand, this person has a very positive image of the direction style of the Eimsbüttel care conference and had herself directed for 5 years a working group on the issue of terminal care (PCP1 21 11 2011).

Finally, two questions happen to matter and to be viewed as pitfalls of the system of the care conference. In the first place, the lack of concrete consequences and decisions following the thinking or the elaboration of a consensus is seen as a problem by various actors. For many people who have been active for months or sometimes for years in a specific working group, the absence of clear outcome, or even decision or recommendation to the political or the operational level of the long-term policy-making is clearly a failure of the coordination system (PCP1 21 11 2011 / SPCP1 24 11 2011 / PCP2 22 11 2011⁴⁴). This criticism might appear to be inappropriate as it clearly does not belong to the original attributions of the care conferences, at least in their Hamburger version, to be a place of concrete policy-making. However, the strength of the impression that the care conference makes no difference what so ever on the policy process demonstrates the ambivalence of the instrument. On the one hand, it is clearly an instrument that primarily should enable actors to develop a common view over specific problems. This mechanism can be understood as being enough to trigger the coordination of actors that is the very *raison d'être* of the instrument. On the other hand, the absence of any concrete outcome for the developed and probably sometimes hardly constructed consensus, is a limit to the logic itself of the instrument. The elaboration of a consensus appears to be the logical preparation to a decision. The absence of such a possibility washes out the coordination performance of the instrument.

The second point that remains difficult is the performance of the care conference regarding the constitution of a well functioning network. The goal of coordination of the as many actors providing any kind of concrete service in the domain of long-term care raises many questions among the concerned actors. In the first place, the role of the coordination ambition of the care conference toward already existing networks is not always very clear. For instance, the responsible of Semi-private care provider (SPCP2 24 11 2011), who has been for some years the coordinator of a working group within the care conference, had started this activity about 17 years before the implementation of the care conference in the context of an informal working circle (Aktionskreis). This Aktionskreis Alter in Eimsbüttel that had gathered for years specialists, professionals, lobbyists and activists, administrative staff, researchers, GP's, etc. had in fact, on a very informal and open way, achieved the bulk of the key objectives of the care conference to come. It had created a very encompassing network of stakeholders and representatives of the beneficiaries and had tackled, over the years, many relevant issues in the domain of local old age policies. This network has progressively lost its relevance, in the aftermath of the introduction of the law on long-term care insurance, which means of the market of long-term care providers. The founder of this network has then joined the instrument of the care conference in order to make use of the status, and of the network of an « official » instance. This strategy has however not been successful.

This episode demonstrates the dilemma and maybe the impossibility of the construction of an encompassing network in a situation of reinforced competition such as the German one since the introduction of the 1996 on long-term insurance. Other interviews conducted for the sake of this case study have demonstrated the harshness, the tensions, the deadlocks created in the local welfare mix appear very complicated to overcome. The referral of patients for instance (PCP1 21 11 2011, PCP2 22 11 2011, BAPP1 22 11 2011, FGBE2 23 11 2011) is the occasion of a very strong competition between providers and types of providers. Mutual accusations of bribery, set up, success and development of private firms organizing and dealing the discharges from the hospital and the referrals of patients to long-term care providers are an indication of these strong tensions. Maybe this situation should / could be

44 The criticism formulated by this second private care provider, who was for many years a regular member in the Eimsbüttel care conference is even more radical as he complains about the lack of «professionalism» and «competence» in the management of the conference. This opinion appears however to be rather isolated within the local network of long-term care.

understood as an indication of the failure of the care conferences. As a matter of fact they might be the last instances where private, public, corporatist types of care providers (the traditional German Wohlfahrtsverbände) have an opportunity to meet in spite of the very difficult climate of cooperation in the domain of long-term care provision.

Type of change

There are in fact various forms of change in this case. In the first place, there are different types of institutional innovation along the all process. There is the rather long-term process of change that has started in North Rhine Westphalia along the process of innovation and development of the social city and then of the health and care conference. This process of institutional innovation (political / institutional arenas) has been continued at the level of the city-state of Hamburg at the occasion of the integration of the North Rhine Westphalian model of the care conference in the Hamburg repertoire of governance instruments in the domain of long-term care delivery. In Hamburg as in North Rhine Westphalia, the political orientation of the social city was the principal motivation for the adoption of the instrument. In 1998, as the instrument was integrated into the Hamburger repertoire of governance of the long-term care provision, the government of the Hamburger Senate was SPD dominated. The agreement between the North Rhine Westphalian tradition in the matter of social policy implementation was very strong by then. The project of coordination based on the double idea of an improvement of the quality of the service delivery (among other things via coordination itself and via an improvement of the information about needs and pitfalls) and on the idea of a fair (gerecht) way to address the needs is at heart of the interest for the social-city and the care conference. This political project has benefited from a renewed interest in the aftermath of the introduction of a competitive market in long-term care.

After these both clear steps of institutional innovation in both North Rhine Westphalia and Hamburg, at a relative high level of institutional power, there are other processes of change taking place at the level of the Hamburg boroughs, in the context of a more grass-roots institution. The various boroughs that have developed their care conference have done it on a voluntary basis and not in the context of a mandatory and completely administrative procedure. The adoption of the instrument at the level of a borough is always initiated by local actors, mostly from non institutionalized actors, who have close contacts to administrative employees, as they themselves are active in official commissions for instance. In the case of Eimsbüttel, we have to do of an alliance between an official of the borough health administration with a researcher belonging to the local civil society. Then finally, there is the last step of the dynamic around the instrument of the care conference, which is the running of a working group. Those structures are in almost all the cases managed by executives of private or semi-public long-term care providers, or by managers of associations. This last step of the implementation of the care conference instrument is really uneasy to consider according to our analytical grid which distinguishes institutionalized from non institutionalized process; the idea being that both those dynamics are typical of specific types of change. Institutionalised forms of change are supposed to make sense in a politicized and institutional universe. Institutionalized forms of change are supposed to be articulated with political projects and integrated in encompassing strategies. The last step, the running of a working group, is at some extent integrated in such a strategy, but it is as well initiated by individual actors who are not aware and do not share the whole program attached more or less explicitly to the instrument. As a matter of fact, the instrument of the care conference diffused by way of the law by the Land of Hamburg on the implementation of the federal long-term care insurance is precisely interesting as it opens up various opportunities to the actors to initiate small scale, and more or less guided (which means less spontaneous) processes of social learning.

Explanation of the process of change (regarding the national and the regional level)

Regarding the national level, the type of change analysed in the case of Hamburg is not a very original one as it makes use of a rather classical instrument of coordination and of improvement of welfare delivery. However, this instrument benefits from a renewed interest in the context of the long-term care insurance reform that has introduced a highly competitive private market at the point of delivery. The importation of this instrument is clearly explained by a political choice making sense in the context of the federal politics. The dominance of the Christian-Democrat / Liberal coalition, very well manifested by the choice of the marketization of long-term care delivery, was resisted by the Social-Democrat policy orientation of the care conference supposed to organize the coordination of the various care providers in spite of the competition norm.

The second level of change, from a scalar perspective, is the one of the infra-regional (infra Hamburg city-state level). As we have seen it, the various boroughs making up the city-state were not compelled to adopt the instrument of care conference. Some early adopters have done so as soon as 1998 (Harburg). Others such as Hamburg Nord, Altona or Eimsbüttel have launched their own care conference as late as the mid 2000s. Considered from a horizontal perspective, which means, across boroughs, there is a rather high level of differentiation among the modes of utilization of the instruments. The resources that might explain those discrepancies are made relevant by the very low level of constraint attached to the instrument of the care conference. The resources at stake are essentially the potential coordinators, be it for the care conferences directly or for their various working groups. Skilled, knowledgeable, but more importantly best connected, both in the network of providers of long-term care services or of other social actors of the policy domain, but as well in the network of the more institutionalized actors of the domain, most importantly in the health administration.

Evaluation of the result of change: continuity or discontinuity regarding our four dimensions

The problem addressed by the policy instrument of the care conference is a problem of **governance**. Following a process of institutional innovation, the care conferences were introduced in Hamburg in the context of the implementation of the federal law on long-term insurance. The SPD led Land government wanted to balance the influence of the market norm that would, according to the new federal law, become the most important principle regulating the service provision in this domain of long-term care. The perception that social coordination was threatened by the market principle was thus a very common view in the policy domain. In the previous situation marked by a public regulation and the existence of a limited pool of service providers (public ones and the Wohlfahrtsverbände), there had already been various initiatives to increase social coordination and to develop common views or common expertise over the issues of population aging or more specifically of long-term care (see for example the case of the Arbeitskreis Alter in Eimsbüttel).

The policy instrument was introduced by the an agreement between the Land of Hamburg and a specific borough (Harburg) to then be put at the disposal of the actors intervening at local level, in fact, at the level of the boroughs. This operational level, and the even more micro level of the working groups formed within the various local care conferences was open to different types of actors: institutional actors (health-division of the borough administration), associative, executives or experts working for private providers of long-term care services.

The type of institutional change at stake in the case of the Hamburger care conferences concerns the implementation stage of the policy cycle. Care conferences should improve the **coordination** of the various actors tackling the delivery of services and the concrete modes of addressing needs in the domain of age policies. Moreover, care conferences are cognitive instruments. They are as well based on the idea that the local actors of implementation, within specific, specialized and operational networks should be able to elaborate their own views over the problems they have to deal with. This instrument should consequently not only enable local actors to develop consensus about the policies they implement, but in fact to develop a real autonomy in the way they can steer the process of implementation.

According to the typology in terms of mechanism of change, the introduction of the care conference is clearly a process of layering. The introduction of this specific policy instrument does not replace a former one, nor is it the reinterpretation or the reframing by local actors of specific agreements or institutional rules.

The expected effects of the instruments on the policy domain were potentially important. Being **clearly an instrument of governance**, the explicit effect (defined in the various versions of the Land of Hamburg law on the implementation of the federal law on long-term care-insurance) of the care conference, was to improve the quality in service delivery. As regarding the other items we focus on in this study, the issue of diversity in the network of service provision is as well concerned as this instrument might be a useful mean to detect shortcomings and lacks in the network. Moreover, as a typical grass-root instrument, it could / should ease the participation of the (potential) beneficiaries of age or long-term care policies and of their families.

On those various issues, the concrete effects of the care conference appear to be rather weak. The non public health actors participants to the networks predominantly express their frustration about the lack of concrete decisions or effects of the coordination, expertise, discussions, etc. which is year in year out done in the various care conferences and working groups. Public health actors (the various actions and working groups undertaken by those actors in the case of Eimsbüttel) may reach their objectives in a more satisfactory way as they benefit from the support of public or quasi public structures that help them to use the public character of the instrument care conference.

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PCP2 22 11 2011 : Private Care Provider

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Local cases of social learning and/ or institutional/policy innovation in home based long-term care for the aged (HBLTC)

The Re-ablement Strategy of the City of Edinburgh Council

I. INTRODUCTION

The reform selected in the case of Edinburgh is called the “Home care Re-ablement service”. This service consists in providing a six weeks long intensive care principally to people leaving the hospital or simply referred by General Practitioners or by other instances. Explicit aim of the program is to "empower" the beneficiaries and to help them to "*gain autonomy*" at a further stage of their life at home. This service is in fact a new type of patient's journey implying a specific type of coordination of various services of care providers and is part of a much more ambitious program of reorganization of the health and care provision system for the aged in Scotland. The re-ablement model implies a strong co-ordination of various services representing an important break with the traditional organization of care delivery in the context of the Scottish Free Personal Care scheme. One of the most difficult issues intensively discussed in the British health system, specifically about the frail older population, lays in the coordination between the National Health Service and the *social care* which refers to the whole of the home-based long term care. The “Home care Re-ablement service” tackles this structural issue and addresses the intricate matter of the coordination of various types of care providers. The introduction of this instrument is part of a broader reorganization strategy of service delivery at the level of the Edinburgh City Council aiming at a far reaching privatisation. Only the re-ablement service should be kept by the City Council’s own services. The rest of the delivery is attributed via a tender, benefiting most of the time to private companies.

II. DESCRIPTIVE SECTION

1) General contextual information on the local case

Second city of Scotland after Glasgow, Edinburgh has been the capital of Scotland for centuries. The total population of the local authority¹ is 477,660 (30 June 2009). The territory of the Council is not only a very dense urban area, as it covers a rather large rural one: 259 km².

Local economy and labour market

Edinburgh's economy is said to be robust and competitive. With a per head gross value added of 34,562£ a year (City of Edinburgh Council, 2011a: 10), the output capacity of Scotland capitals' economy ranks second in all of the UK after London, but is almost 75 % higher than other big

1 The are 32 local authorities in Scotland.

UK cities such as Birmingham or as well almost 75% higher than the UK or the British average. In terms of economic output, the service sector and, specifically finance services, is the most important industry in the city. In 2000, the industry employed around 7% of the labour force and the service sector, close to 80%². Concentrating 9,2 % of the Scottish population, 15,7 % of its gross value added, Edinburgh makes 21,5 % of the private R&D expenditure of all Scotland (City of Edinburgh Council, 2011a: 11). The three biggest employers of the city are all public : the City Council (19,600), the NHS Lothian (18,800), the University of Edinburgh (10,400). They are immediately followed by three important private employers, all in the financial services: Lloyds Banking Group (8,750), Royal Bank of Scotland Group (8,200) and Standard Life (6,250).

The Scottish unemployment rate - 7,5 % - is below the UK-level - 7,9 % - (Government of Scotland, 2011). The local unemployment rates are calculated in a specific way and can not be compared with the national data. According to this Scottish data however, Edinburgh's unemployment rate is supposed to be slightly below the national average.

Wealth and migration

The average wealth of Edinburgh's population is only very slightly above the Scottish average (Scottish Government, 2010: 8) and the percentage of households "in relative poverty" is in Edinburgh precisely situated at national³ (Scottish) level with 19 % (Ibid: 10). With respectively 23% and 24%, other important urban areas, such as Glasgow city and Dundee city, are more concerned by relative poverty.

The city of Edinburgh is the second Scottish local authority with the highest rate of overseas immigrants with almost 40% of all new comers to Scotland for the years 2008-2009. The "ethnic composition" of the population was the following the years 2007/2008: White Scottish 71%, Other White British 12%, Other White 10%, Other 2%, African 1%, Indian 1%, Chinese 1%, White Irish 1% (City of Edinburgh Council, 2011: 4). During the period 1999-2009, the population of Edinburgh grew by more than 6 %, (Register Office of Scotland, 2010, 11) which is twice higher than the national population growth rate (Ibid).

Demographics and population aging

According to the last available data of 2009 (Register Office of Scotland, 2010: 17), 68,964 inhabitants were 65 years old and over (14,44 % of the entire population⁴), 35,035 persons were 75 years and above (7,33 %) and 20,753 were 80 years old and above (4,35 %). This rate makes of Edinburgh the Scottish local authority with the third lowest rate of 65 plus. National average of the age group 65 + is 20 %.

Politics

The last national election for the Scottish parliament took place in May 2011. The current state of the parties at Scottish Parliament is as follows.

2 http://www.visionofbritain.org.uk/data_rate_page.jsp?u_id=10211104&c_id=10090283&data_theme=T_IND&id=0
(University of Portsmouth).

3 The term national always means "Scottish". United-Kingdom or Britain will be used to refer to the meant territories.

4 In 2001 448,624 inhabitants.

Scottish Parliament: Current state of the Parties (2011)

Party	Seats
Scottish National Party (SNP)	68
Scottish Labour (Labour)	37
Scottish Conservative and Unionist Party (Cons.)	15
Scottish Liberal Democrats (Lib.Dems.)	5
Scottish Green Party (Green)	2
Independent	1
No party affiliation	1
Total	129

The denomination of the Conservative Party in Scotland gives a rather explicit clue on the dominant structuring logic of the Scottish party system. The Conservative Party is in Scotland both “conservative” and “unionist”. This is a clear positioning of the right wing party within the dominant logic created by the National Scottish Party, which is both separatist and rather left wing concerning social and economic issues. We have then to do in the Scottish case with a specific framing of both traditional axes. In the first place, the usual “authoritarian vs libertarian” axe becomes “Scottish nationalist vs unionist”. But, the second axe “plan vs market” seems to be the same as in other countries. The positioning of the Labour Party is more ambiguous. This is specially the case towards the axe Scottish nationalism versus unionism. The uneasiness of the Scottish Labour Party about the issue of autonomy and now of independence has much contributed to the end of this party's supremacy in Scotland. Scottish Labour had dominated and framed the political identity of Scotland for years (Hassan, 2004). It has for a long time kept more a “old labour” type of policy orientations than the English labour. The Scottish Labour is now in a better place to take distances to the failure of the New Labour orientation.

At Edinburgh's level, the results of this May 2011 Scottish Parliament election are the following:

Edinburgh's results for the 2011 Scottish Parliament election (in %) / elected MP in bold

	SNP	Labour	Cons.	Lib.Dems.
Edinburgh Central	32,7	31,9	15	20,5
Edinburgh Northern and Leith	39,7	41,6	9,5	9,2
Edinburgh Eastern	47,4	40,1	8,6	4
Edinburgh Pentlands	37,3	26,6	31,4	4,5
Edinburgh Southern	29,4	27,4	24,6	18,6
Edinburgh Western	35,8	21,4	15,1	27,7

The political orientation of the City Council of Edinburgh itself is even more important for our study. The present Lord Provost of Edinburgh (equivalent to a Mayor) is George Grubb. He is a

member of the Scottish Liberal Democrat Party that turned out to be the strongest party in the City Council election of 2007. The Liberal Democrats built a coalition with the Scottish National Party, third party with most votes.

Seats by party - City Council election 2007

Scottish Liberal Democrats	17
Scottish Labour Party	15
Scottish National Party	12
Scottish Conservative and Unionist	11
Scottish Green Party	3

The 2007 election interrupted a 23 years period of continuous majority control by the Labour party on the City Council. The victory of the Lib Dems in Edinburgh city has been very significant for the Labour which had been since the 70's the prevailing party at City Council level, with only a few exceptions.

The tradition of the Labour party in Edinburgh is however slightly different from the rather leftist position prevailing in the more industrial and working-class centred Eastern part of Scotland, for instance in Glasgow (Irvine, 2004). Nevertheless, the predominant patterns of local policies (strong development of public utilities, strong social work services, etc.) reflects the core of the rather traditional Labour policy in all of Scotland.

2) Historical description of the development of the local system of HBLTC for the elderly

General trend

The development of domiciliary care in Edinburgh has been for many decades rather similar to the characteristics of the Scottish and the British situations. As soon as 1968, Scotland benefited from a specific piece of legislation in the matter of social care for the older population. The Social Work Act of 1968 was on the one hand decided by Westminster (United-Kingdom central state level) in order to counter the early development of Scottish nationalism. On the other hand, it was inspired by surveys conducted in the 50's and 60's showing the harshness of the living conditions of the poorer older people. Health maintenance and housing conditions were often pointed in the literature as being both most important shortcomings of the Scottish social situation. The fostering and development of domiciliary care service delivery has been identified as a possible answer to those specific problems. The Scottish Social Work Act was meant to radically improve the living conditions of both disabled and frail older people⁵ (Black, 2008: 270). The Scottish Social Work Act of 1968 set, or more precisely, up-dated some of the basic features of the domiciliary organization of service delivery for the older population that are still important pillars in the present Free Personal Care framework of the early 2000's. The most important of those lays in the differentiation between the central state level financing and the local government delivery. The Social Work Act has as well had an important influence on the stabilization and strengthening of social work as an activity, as a profession, and even as a social

5 The most explicit aims of this piece of legislation were however directed towards the children. Specific dispositions tackled the issue of the reinsertion of ex-inmates.

status, anchored at the level of Local Authorities in the Scottish context. As a consequence, during the 70's, most of Scotland's City Councils, as a matter of fact, the most important Councils, have developed social work departments and have professionalized their action to the older population. The negative impact of the economic crisis of the 70's has certainly hindered this trend, but it did not stop it completely. The domiciliary provision has indeed improved in most cases in Scotland during this period.

In 1980, there were already more than 60'700 senior citizens receiving home help in all of Scotland for a total number of 83'616 in 1997 (Ibid: 276). In the early 80's, the bulk of the provision was clearly public. In 1980, almost 60% of the total delivery (for both domiciliary and residential care) was carried out by public services. The rest was implemented by the voluntary sector.

The Calvinist influence in the Scottish public culture is said to account for the high level of voluntary provision in the country. As soon as 1990 however, the share of the public had been reduced to 40%, the one of the voluntary sector had shrunk to around 20% and the during the 80's emerged market actors, had already won almost 40% of the whole provision market (Ibid: 278).

In 1990, a new regulation of care was introduced at UK level : the NHS and Community Care Act. This regulation changed the role of the Local Authorities. From direct providers of care, they had to become facilitators of the market development (Mc Farlane et al, 2008). In the rest of the United-Kingdom, the Local Authorities had to purchase 85 percent of the locally requested services. This part of the law did not apply to Scotland. Scotland was the last region of the UK, where it was still possible for Local Authorities to be direct providers of domiciliary social care.

Evolution of demographics

It is rather obvious on the chart 1 that the movement of population aging in the City of Edinburgh is not very specific and does not differ a lot from the UK average. The decrease of the aged population rate from the 1980's is accounted for by the important growth of the students' and young white collars' population in the city. However, in absolute terms, the number of senior citizens has reached an important figure with 94 172 people over 60 and 35 385 over 75.

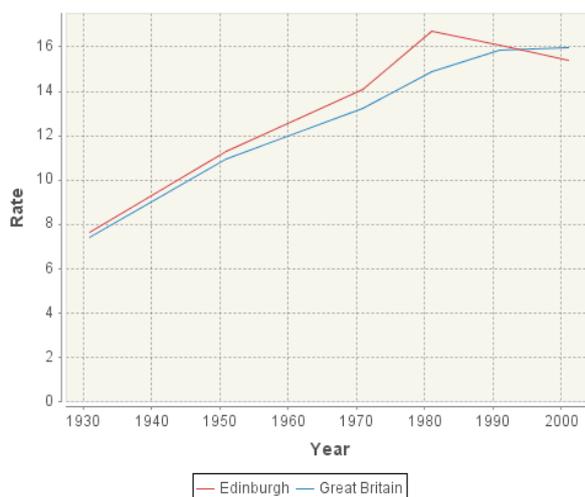


Chart 1: rate of 65 + in general population

Reference : http://www.visionofbritain.org.uk/data_rate_page.jsp?u_id=10211104&c_id=10090283&data_theme=T_POP&id=4 (university of Portsmouth)

Amount of the aged population in 2008 and projected aged population

	65 – 74	75 +	All 65 +
<i>2008</i>	33'838	34'772	68'610
<i>2013</i>	36'972	36'649	73'621
<i>2018</i>	41'701	38'634	80'335
<i>2023</i>	44'706	44'022	88'728
<i>2028</i>	49'891	50'062	99'953
<i>2033</i>	54'449	56'737	111'186

Reference: Register Office of Scotland (2011). National Records of Scotland - City of Edinburgh Council Area. Demographic Factsheet. Edinburgh, p.6.

The projected growth of the aged population is both strong and steady. The most striking fact in this projection is the important progression of the age group of the people over 75. Both age groups, the 65 to 74 and the 75 and above are expected to grow of about 60% in the 25 years to come. In Edinburgh like in the rest of the Western world, the most aged, over 85, will become a very numerous group in a close future. This age group is precisely the most prone to need both health and social care.

Care needs and care provision

Local Authority	Number of clients receiving a service					Total hours of service provided or purchased by LA		
	2007	2008	2009	2010	2011	2007	2008	2009
Edinburgh, City of	4 944	4 664	4 571	4 596	4 379	41 440	41 307	38 512
Fife	7 265	6 489	6 002	4 834	4 439	68 913	76 025	72 859
Glasgow City	8 586	8 264	8 284	7 899	7 253	83 724	81 971	80 050
SCOTLAND	70 710	68 759	68 331	66 224	63 458	645 041	651 014	645 727

Network of social care providers

The care market on the territory of the Edinburgh's City Council is rather important. According to the recently installed Care Inspectorate, there are 108 care providers approved by the Scottish official regulator. For the time being, most of the inspection work has been accomplished by the previous organizations that were merged in April 2011: the Care Commission and the SWIA (Social Work Inspection Agency). Many of the 108 providers in Edinburgh provide specific services to disabled adults. However, it seems rather plausible that about two thirds of those 108 actors provide as well domiciliary care services for the older population.

Apart from the remaining provision by the social work department of Edinburgh's City Council, the bulk of the providers are nowadays private, and in most cases, for profit actors.

There has been a very important change in the structure of the market providers since the far reaching transformation of the City Councils delivery of social care and the shift from direct provision to a commissioning strategy.

We will dedicate much more comments to this transformation as we actually consider this is a big part of the key innovation - the re-ablement program - we want to focus on. Those analysis are provided in the next section about “governance”. We will here only briefly sum up the general dynamics of the situation.

Before the 2007 election, the Labour dominated City Council had only partly opened the market of social care provision for the older population. 75% of the total provision the Council was responsible for, i.e. the one taking place in the context of the Free Personal Care program, was directly provided by the City Council's own services (Social Work Department). There was naturally already an open market and the services directly bought by the population, independently from the Free Personal Care program, or in the context of direct payment was of course already open to private providers. The Social Work services of the City Council decided by then to allocate the various needs to a group of 30 to 40 providers on a 'preferred providers' basis (Hazel et al. 2008). This logic of informal, tradition and relation-based network has been replaced by a logic of organized marketplace via a procedure of tender that will be explained in the governance section.

Market Structure

The analysis of the market structure is not a focus of our research project, however, we think that this is useful to indicate a few hints. As we haven't done an original research of the users' reactions towards the supply of services, we haven't got any reliable information about market segmentation from the users' side. However, the market segmentation appears very from the qualitative in-depth interviews we have done with social care providers. We have met six managers of very different private business and one working for the delivery service of the City Council Social Work Department. From these interviews with managing staff, we have understood that there is a very clear segmentation of the market, at least, from the providers' side. There are at least three market segments following the instruments organizing the market intermediation in social care services. It might however well be the case, that the following market segmentation is not a consequence of the instruments set up by the Edinburgh City Council, but rather that the institutionalized market segmentation unveils the market segmentation itself.

In the first place, we might think that the market share still hold by the City Council's own social Work Department services still corresponds to a clear market segment⁶. It still provides about 50 percent of all of the care delivery. The internal organization mode, the human resource managements (wage levels, types of contract, skills of the staff, etc.), the way the jobs are selected, the preserved control over the issue of re-ablement, the historical presence as a key provider in the city, etc. make of this provider a very special one (ECC 4: 07.03.2011). Secondly, there are big private providers, often belonging to big business chains organized at UK-level. Those private actors benefit from the professional support of the business they are affiliated, from their fame, from the national marketing campaigns they are providing, etc. (SCPp 2: 08.03.2011). The development of this kind of actor is still recent. This type of business has however already influenced the local market and some of the private companies of this type have already won tenders for specific areas. The business model of these providers is based on a mix of clients acquired via the Council organized mediation and of self-financing clients. In the former case, the price paid are set during the tender process organized in the context of care delivery for the Free Personal Care program. In the latter case, the price paid is set by the company itself. According to an interviewed manager working for such a company,

⁶ In one area of the City, the Social Work Department has won the tender and provides regular delivery.

the private financed clients can make up for the very low prices paid by the City Council. In spite of this arrangement, the economic situation of this kind of private companies is very fragile. The situation of the employees is specially tensed. The low prices paid by the Council and the non consideration of travelling time between clients or to get to a client, the very short periods of time granted to the clients (for instance 20 minutes for the diner⁷ delivery) seem to lead the companies to pay very low wages to their employees. As a result, these companies have very high turn over rates. In the case of business interviewed, this turn over rate is as high as 400% a year. This situation is however compatible with a very positive evaluation by the Scottish Care Commission (SCPrP 2: 08.03.2011).

Thirdly, there are much smaller private businesses. Those are settled at a very low scale, i.e. they are specifically working at the level of a neighbourhood and would not go beyond such a scale. These businesses are mostly working via the day-to-day procedure of the Service Matching Unit. This procedure is an internet based allocation method of care packages. Every incoming care package is in the first place offered to the companies that have won the tender. But they can always refuse those incoming packages. As a consequence, there must be a way for those care jobs to be taken by other companies. Those jobs are consequently published and made available on the internet by the City Council services and a simplified and short term bid is organized about each of those. Those jobs seem to be the speciality of those little companies. Their business model is rather modest and clearly centred on the local. They are very small units. These companies are looking for jobs that do not require important travelling, as the travelling costs are not refunded by the Free Personal Care scheme in Edinburgh. They recruit personal and look for jobs that are located at immediate proximity of their staff (SCPrP 3: 08.03.2011). Those small businesses are tightly tied to the local areas the various staff-member are covering. They have to deal with extremely high turn over rates but manage to stabilize some staff that can live (or even that appreciate) to work on irregular basis and in the immediate vicinity to their homes.

Governance

The governance framework of domiciliary care provision for the aged has been clearly transformed by the introduction of the tendering procedure. Since the introduction of the market principle in domiciliary social care for the aged at UK level in the 90's, the governance mode is an important and as well as delicate matter.

The previous governance system was a mix of direct provision by the City Council's own social work services and of commissioning. The commissioning procedure was not very sophisticated. The rating of the various private providers available on the market by the Care Commission was a first filter. For the rest, the concrete allocation of care jobs to providers was a discretionary activity by the Council's Social Work Department. A pool of 30 to 40 providers had been progressively constituted. It is difficult to know exactly on which basis the care packages were concretely allocated to the various firms. We however know from the literature that this allocation of publicly financed care activities into a market is a complicated and tensed matter. The introduction of a market raises the competition level among actors and tends to isolate the actors from another.

After the political change resulting from the 2007 election, the Lib-Dem dominated City Council decided to transfer the bulk of the personal care to the private sector. A tender was organized in

7 The diner is called in Scotland "High Tea".

2007. The goal of this reorganization is to reach a transfer of 75% of the total provision financed by the City Council to the private sector (ECC 1:07.03.2011). The idea was to retain only the activity of re-ablement and only 10 percent of the regular provision:

"We wanted to retain a decent size in the market place. Our experience in other markets within social care is that when the council pulled out completely and you are entirely dependent upon the private sector we have got mixed experiences of what happens in the medium to long term from doing that. So we still wanted to keep not a very large foothold but a significant foothold within the market place in order that we were trying to influence the market and market pricing so that if it needs to be, we could scale up or down again subsequently"

(ECC 3:09.03.2011)

After a first selection process (expression of interest, screening, etc.), the tender was organized via the internet, and 16 competitors were invited. 8 providers were chosen to take charge of 6 specific areas and 2 for the whole city area. The basic principle here is that all new patients in need of personal care should be taken care of by the companies, which has won the tender. There are matching procedures for new patients the local companies would not accept to take care of. To tackle this kind of situation, an internet system has been introduced: Carenap (Care Needs Assessment Package)⁸. Information about a new in-coming care-package are completed in the electronic system and are in the first place transmitted to the providers holding the tender in the various areas. If the tender companies do not want or has no capacity to take charge of the care-package, it will be passed to all competitors registered in Carenap.

According to first analysis of these renewed steering principles for social care provision in Edinburgh, the price component of this tender competition was central in the selection process of the providers (Hazel, 2008:6). The selection on an electronic basis was often seen as a form of "negative auction" triggering a race to the lowest prices that have as well lowered the wages paid to the carer to an amount of 2 to 3 £ an hour. The reduction of costs was a clear objective of the City Council (ECC 1: 07.03.2011) even though the Council invokes the European Union principle of "Best Value & Procurement Regulation"⁹ and has started a large Commission Strategy consultation¹⁰.

Edinburgh's Free Personal Care provision guiding principles have been reformulated and are now clear market principles. This transformation raises the question of the organization of the providers as a network. From our interviews with various types of providers (for instance: SCPrP 1: 07.03.2011; SCPrP 1: 08.03.2011; SCPrP 3: 08.03.2011), we concluded that there is a high level of competition and a very low level of co-operation and even of mutual knowledge among the providers. Answering a remark by "several" social care providers participating to the consultation process about the reform of the present tendering process and the problems in terms of transparency of information about each other situations and co-operation among another it had already triggered, the City Council answered:

We believe that the conditions have existed for a long time where organisations might perceive they are in competition with each other whether services are competitively tendered or not. Regardless of the funding regime, it is everyone's responsibility to work together to ensure that competition does not harm service users or partnerships. However we do acknowledge that when a tender submission is under way, it will be difficult for organisations to share certain aspects of their information with each other.

(City of Edinburgh Council, 2011b: 13)

8 This instrument has been introduced with the Free Personal Care reform. It is supposed to be an important part of the Single Share Assessment process.

9 www.edinburgh.gov.uk/%2Fdownload%2Fdownloads%2Fid%2F2929%2Fappendix_4_procurement_regulations&ei=oS3uTpLjJozhAffk5G_CA&usg=AFQjCNFVwdTvLnFsqs5j1olTwLyk86_teyg&sig2=s2vyQCu1a1kdtObAGa_Yog&cad=rja

10 <http://www.edinburgh.gov.uk/commissioningstrategy>

However, the voluntary organisations and the smaller businesses have the impression that they are excluded from the market by the largest private competitors: *"Not-for-profit voluntary sector organisations expressed concern in relation to the presence of profit making organisations in the marketplace. Furthermore, disparity in infrastructure and resources to participate effectively in tendering processes fuelled these underlying tensions"* (Hazel, 2008: 4).

The City Council is well aware that the high level of competition among actors has an impact on the relations within the network of social care providers. However, this awareness will not change the choice of the Local Authority for a market structure.

The resolution of the Council to opt for a provision via an organised market is very firm and lays on the idea that a new form of division of tasks should be introduced: the City Council should define the policy principles and watch the market, but the market should enforce the policy decisions. For the future, there is even a further step to be done in the direction of more decentralization and more autonomy for the care receivers. This will be the development of the self-directed care.

(...) the intention is for the whole Council and it's partners (...) is to set out it's principles so this is how we gonna go about things when we are commissioning with the things this is how we gonna do it so some information in there about the volume of demand and the projections and all of that but this is how we operate and then very explicitly what services (...) must come up with our procurement plans for each area or service. So there will be a procurement plan for children services for example and within that quite specifically for buying foster care services or residential care for children and so on and the same for adults in terms of mental health learning disabilities and so on so each will have it's own plan that we operationalize as you say and you know for the next five years or whatever this is what we intend to buy or this is how much we intend to give people for them to buy or whatever else (...). So there will be much more detail in there but (...) I would want it to be much more focused on the direction of travel. So to say much more about personalization and putting that up front and say you know the intention for us in the longer term is actually to have a system of very much personalized budget. So that anybody who has any level of need will according to our eligibility criteria whatever those might be will be allocated an amount of money and that they then can that they have a choice because you know the reality is that some people can not make those choices because their disability is so great or their need is so complex that they can't do that (...). I want to spend the money and I might want to buy it from the council or I might to just say to the council just deliver it to me cause I don't want to be involved or they might say well thank you very much I might actually gonna buy it from my neighbour or a small voluntary organization or whatever else it might be and we have to be really clear that everybody has that level of choice so and that's what the commissioning strategy needs to say. Not least because we have big organizations out there who are currently providing big bureaucratized and not very personalized services and we need to help them we need to give them a statement of our intention so that they can start to change their business models.

(ECC 1:07.03.2011)

The granting of personal budgets to the individuals makes a further retreat of the City Council from its basic functions of service provision and organisation possible. The Scottish government has a leading position on this part of the transformation strategy of the care delivery (Scottish Government, 2010). The City Council of Edinburgh watches however with much attention this evolution.

Complementarity and coordination

The network of providers of social care for the elderly is both well developed and diversified. There are not only sufficient actors of all kind of status - public, private, voluntary -, but they are as well diversified in the services they provide. The usual specialization of the various sectors is as well present in Edinburgh. There are about 60 providers of long-term care services across the territory Edinburgh' s City Council.

The City Council social work department provides not only all basic services of personal care (meals on wheels, social activities, etc.), it provides as well services outside the homes (day care centres) that might improve the living conditions of the isolated senior citizens.

The private providers are covering the more "classical" domiciliary care activities, the most commonly included in the classical care-packages resulting from the assessment processes. Some of those private companies targeting the most exclusive segments of the market would as well propose tailored services.

Lastly, in the voluntary sectors, there are in Edinburgh City various providers offering services resulting from a specific social mobilisation. There are providers specialized in people suffering from specific troubles (dementia for instance), or belonging to minorities (ethnic groups). Those organisations benefit from an active support from the City Council (SCPPrP 1: 07.03.2011).

Quality Insurance

The quality insurance is in Scotland an issue which is supervised by national institutions (see national report on Scotland). At the level of the City Council, there are no specific instruments or procedure aiming at improving or complementing the national framework for quality insurance. On the contrary, the transformation of the commissioning strategy is, in spite of rhetorical argumentation, clearly oriented toward the reduction of cost. The new commissioning strategy has been introduced along with the redefinition of time allocations for specific tasks (for instance, the time allocated for a meal preparation has been reduced from one hour to 30 minutes). "Pop ins" visits of 15 minutes have as well been introduced. This reorganization does not speak for an improvement of quality in the delivery of domiciliary care and worries lots of care providers and of other stakeholders of the policy domain (Hazel et al. 2008: 5).

Beneficiaries participation

Beneficiaries participation is not a big issue in the Local Authority of Edinburgh. For a few years however, commissions called "checkpoint groups". This type of consultancy is new and was introduced during the process of reorganization of the care delivery by the City Council.

When we were modernising the whole care service we felt that, because we were designing a service that we had to consult and engage with a range of stakeholders, so we actually developed that model fast when we developed the new strategy. (...) We developed a checkpoint strategy and that model was so successful that we now have a checkpoint group in any back consultation or service you design exercise which we undertake. So for the whole care modernization the checkpoint group comprises older people, people from the voluntary sector, people from the private sector and people who provide home care services in other settings, and other people. So this is a lot of interested parties (...) The role of that group is to comment on (...) the development of our strategies and action plans.

(EEC 2:09.03.2011)

The composition of the group varies with the issues discussed, so that the Checkpoint Group might bring together users or representatives of the users and professionals or experts from the issues at stake. For instance, in the case of issues concerning the reorganization of personal care delivery, the Checkpoint Group both invites staff of private care providers and members of the health board (NHS). In spite of this rather sophisticated and democratic design, the concrete impact of the Checkpoint Groups on the reform process is not very clear. On the other hand, it

can be stated that the introduction of a form of participation and of consultation is one by-product of the reform process of personal care delivery by the City Council of Edinburgh.

Financing

Among the 3800 persons over 65 receiving domiciliary care in 2009-2010, 3440 benefited from the FNPC program and had not to pay for this delivery for a weekly amount of 23 800 hours paid by the local authority of Edinburgh. This represents a total yearly spending of 30,36 millions of £ (Scotland National Statistics, 2011). For the sake of comparison, the situation is as follows in the local authority of Glasgow city: there are 6850 domiciliary care recipients in Glasgow, 5890 of those get personal care for free. This corresponds to 50 500 weekly hours paid for a total expense of 82,4 millions of £.

In Edinburgh, the weekly average of home care services received is 6,26 hours (all recipients). This average is of 7,37 hours in Glasgow. The estimated ratio price / hour of service delivery is in Edinburgh of 24,53 and 301,38 in Glasgow. This own calculation confirms the estimations according to which Edinburgh is already one of the Scottish local authorities that spends the least on long-term care for the aged in all of Scotland (Hazel et al. 2008). The prices paid by Edinburgh for each hour of commissioned service revolves around 2 to 3£.

II. ANALYTICAL SECTION

1) Description of the innovative ltc-model for the elderly (today)

The City of Edinburgh has progressively introduced from 2008 an important reform that changes the way domiciliary social care is organized, the way the relations between health and social care are arranged, and the way care tasks are allocated to the providers.

This program is called "Re-ablement". It is based on a special client's journey. Patients are to be referred either by the hospital or by the community. The idea is to provide, right at the beginning of care delivery, a higher amount of care, using in most cases the services of a occupational therapists. Aim of this scheme is to improve the condition of the beneficiaries, to raise and stimulate their autonomy. There are many ideas, discourses, values, as well as concrete objectives and expectations attached to this concept and policy scheme of re-ablement. We will discuss most of them here, but will consider successively the issue of care delivery organization (i), of the relations between health and long term care (ii), and the transformation of care tasks allocation (iii).

care delivery and organisation.

Re-ablement is the notion used in the contemporary policy and research language to describe an activity that is sometimes called "restorative approach" (Ryburn et al. 2009) or that used to be labelled "rehabilitation" in the previous decades. This idea of an intensive care, incorporating elements of cure, is thus not at all new.

In the case of Edinburgh, there is a period of six weeks during which the care provided to the persons in need is supposed to be intensive. Personal care is least at stake than the involvement

of Occupational Therapists (OTs) who are supposed to play a key role in the re-habilitation process of the beneficiaries.

Relation between health and long term care

Key to the program is the idea that people should be referred to the re-ablement program after an accident, or an hospitalization. A crucial issue in the debate about long term care of the aged in the British system - this is not a specific issue in Scotland - is the relation and coordination between the National Health Service, i.e. the hospital, and the various forms of long term care. There is a very big issue in all of Britain about "Bed blocking" which is a rather ancient and famous problem in the country¹¹. This expression stands for the fact that lots of, mostly older, patients have to remain at the hospital for very long periods of time as the system of domiciliary care is not capable of taking the responsibility of people who however might be well enough to be sent home. This issue of delayed discharges raises several problems. One of them is the organizational coordination between the NHS and the system of domiciliary care. Another is the issue of financial coordination between both systems. The relations between those both institutions is complex and the discourses both sides develop about each other is almost symmetrically accusatory.

The organisational coordination is often attributed to the lack of care capacity in local systems of both domiciliary and residential care. The development of nursing and care homes has been a priority of the City Council from the late 90's and early 2000's in order to radically reduce the delayed discharges¹² and to prevent the NHS from pursuing its policy of long term continuous care at the hospital.

In Edinburgh City as in most of the United-Kingdom, the need for financial coordination is apprehended as a request of taken from the budget of the NHS and given to the activity of social care delivery. For 2011, 6 million £ have been transferred from the NHS budget to the domiciliary care budget of the City Council in order to reduce the amount of delayed discharges (EEC 3:10.03.2011). In Edinburgh, the director of the Health and Social Care Department since 2005, Mr Peter Gabbitas¹³, is simultaneously the Head of the local Health Board (NHS Lothian). This holding of several positions concurrently aimed precisely at reaching a better coordination between both social care and the NHS. The results of this difficult endeavour seem to be paying off:

(...) to put it in context, when I started as the director, there were meetings between the leader of the council and the chief executive of the council with managers of the NHS and the chief executive of the NHS and those meetings were very very very difficult. They were just awful. You could cut the atmosphere with a knife and they were full of blame and incrimination and at that point 450 beds were blocked in Edinburg alone. It's the equivalent with the district general hospital in Edinburgh. There's only three of those anyway [in the whole City of Edinburgh] (...). Now the average delay is about fifty [percent]. The average length of delay is massively reduced. There has been

11 See for instance the following newspaper articles:

- <http://www.telegraph.co.uk/health/elderhealth/8929747/Rise-in-bed-blocking-is-costing-the-NHS-500000-every-day.html>

- <http://www.guardian.co.uk/society/2011/jan/04/bed-blocking-care-cuts>

- http://www.scotsman.com/news/bed_blocking_traps_hundreds_in_hospital_1_807971

12 http://www.scotsman.com/news/163_5m_care_home_plan_to_tackle_bed_blocking_1_1298435

13 http://www.edinburgh.gov.uk/info/690/council_departments/868/health_and_social_care_department/2

a ninety-six percent improvement in performance during that five year period. So now, my NHS colleagues talk positively about partnership and what has been achieved. And you know, but (...) you know this very well [those things] don't happen over night. You have got to work for those for a long time.

(EEC 3:10.03.2011)

In spite of this betterment at Edinburgh level, the situation of bed-blocking is still a very important problem, in Scotland as well and is one of the key priority of the new elected government¹⁴.

As for the City of Edinburgh, this shift in the balance of financing between the NHS and long term care is a part of the program of shifting the balance of care. The improvement of the long term care capacities, both of residential and domiciliary care, are a crucial part of this strategy that is supposed to reduce global costs of frail people's health maintenance. The re-ablement program, has an important role to play in the improvement of the coordination between acute treatment in hospital and long term care, be it domiciliary or residential.

Transformation of care tasks allocation

Finally, the introduction of the re-ablement program is related to a change in the procedure of care tasks allocation. This change has already been mentioned earlier. But the relation between both decisions was confirmed by the head of the Health and Social Care Department of the City Council of Edinburgh :

They [the introduction of the re-ablement program and the privatization of care delivery] are kind of related and separated. I kept saying when I was looking at the review of home care services what is the value of having any internal service at all and for 18 months. I would say to the manager what is the value ? [Be]cause there isn't an economic value, because the unique costs are much more expensive to have it internal than external. But I was convinced once we discovered the re-ablement model, that there is something generally that we could do better internally because it's an incentive for us to do that. And I think it's difficult to incentive the private sector to adopt a similar model. There was a previous occasion : we put out a contract to an external provider that somebody had said to us. Six weeks afterwards they would know that the twenty-week-hour contract could now become twelve hour because the person is stabilized. So there is no financial incentive to do that for the private sector. So I felt it was generally something were we add value as an internal service and then once we had re-enabled someone to the maximum, we could pass that work out to the private sector so that's the linkage in the relationship

(EEC 3:10.03.2011)

The link acknowledged by the Head of Health and Social Care Department is strongly based on market management issues. The idea of the system is to allocate specific tasks to each type of

14 <http://www.dailyrecord.co.uk/news/health-news/2011/10/21/bed-blocking-in-scots-hospitals-to-be-reduced-as-health-secretary-revises-targets-86908-23504687/>

market actors. Private firms are not supposed to be efficient at improving the condition of patients, as they are supposed to be willing to keep their patients. On the other hand, public services are not supposed to be efficient at long term delivery.

2) Historic-analytical description and evaluation of the change (institutional innovation and/ or local social learning process)

Problem addressed

The process of change analysed in the case of the City of Edinburgh is clearly an institutional innovation as it was introduced by the City Council's own services and decided in a political arena. This innovation introduces a new journey for the patients entering the long term care system in differentiating between two phases:

- a first phase of intensive care, which is not only based on personal care, but implies the intervention of more occupational therapists who are supposed to foster the rehabilitation process;
- a second phase of long term care, more based on personal care provision.

This two-steps journey has been introduced in Edinburgh as a very important piece of a much bigger and more ambitious reform program of the whole care system at the level of the Local Authority. This program of improvement of the local domiciliary care system consists in three main elements. The first one is an improvement of the discharges from the hospital. In order to reduce bed-blocking and delayed discharges, the Local Authority of Edinburgh has agreed with the local Health Board, to re-allocate a significant part of the NHS budget dedicated to older patients blocking beds at hospitals to the implementation of personal care. The second one is the introduction of the re-ablement program that should smoothen and accelerate the transitions from the hospital to the long-term care at home. The third one is the partial privatisation and the re-allocation of care tasks within the local system of care provision. This last step has been achieved by a transformation of the procedure of care tasks allocation within the local framework of care provision. The introduction of tendering procedure on the one hand, and of a service matching unit (day-to-day service of care tasks allocation on the internet) on the other was set up as for the allocation of the long term care jobs. The City Council's own Social Work services have kept a small amount of the long term care delivery but are in charge of the whole of the re-ablement program. The re-ablement program is then a part of a process of privatisation of the long term care delivery in Edinburgh.

Various *phases of the policy process* are concerned with this innovation.

Firstly, there is a change in the formulation of the policy problems concretely related to the delivery of long term care in the Scottish system. The issue of financing and the sustainability of the system are very often cited as being important causes (ECC 1:07.03.2011; ECC 2:0ç.03.2011) that triggered the changing process. The raising costs faced by Edinburgh City Council, and the pressure put by the Scottish government on all Scottish Local Authorities in order to make them control the costs, are two important factors explaining the focus of the local actors on financing issues. Then the issue of the organisation of the service delivery itself is a very important issue. The Council Social Work Services are described as a “*bureaucracy*”, that needs to “*dismantled*”. The resources and the provision are to be organised in a much more “*personalised way*” (ECC 1:07.03.2011). This second issue of service delivery is on the one hand a problem in terms problem definition, but it is as well a problem of implementation. The

renewed commissioning strategy via the tender, the privatisation of a very important share of the service delivery, the introduction of a new patient's journey via the re-ablement services, those are changes affecting the concrete implementation of the Free Personal Care delivery in the City Council of Edinburgh.

Those transformations in both policy problem formulation and implementation are related by the definition of policy instruments. This is a very key step along the policy process as it is at this stage that the debates, the ideas, the views about the public problem and the people at stake are transformed in concrete measures changing the reality of the policy process. This phase of the instruments design is clearly localized at the intersection of politics and administration. Both proposals about instrument design or expertise about scenarios of possible developments could be formulated as well by politicians than by administrative staff.

According to the *typology of forms of institutional change*, the process at stake in the case of domiciliary home care delivery in Edinburgh is clearly a process of “Displacement” (Streeck, Thelen, 2005). Old rules are removed. New rules are introduced. The configuration at stake in the case of Edinburgh is clearly a case in which there is a high capacity of control of the institutional power over implementation and the veto possibilities of other actors are weak (Mahoney, Thelen, 2009: 18). Both the City Council's Social Work department and the market of social care providers are at the disposal of the City Council itself and this institution could impose on those institutions the transformations at stake.

The most difficult part of the changing process for the City Council has been to transform completely the relation to the care providers and to install a real care market at the level of the local authority. In this case, the political change in the political majority explains largely the process of the change. And the process at stake is clearly a process of institutional innovation. All policy arenas that have triggered the change are clearly institutional and politicised policy arenas.

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(EEC 3:10.03.2011) : Edinburgh City Council, Social Work Department / Executive Officer.

(ECC 4: 07.03.2011) : Edinburgh City Council, Social Work Department / Manager in a local service delivery point, in charge of domiciliary care for the aged.

(SCPrP 1: 07.03.2011): Social Care Private Provider / Managing Staff.

(SCPrP 2: 08.03.2011): Social Care Private Provider / Managing Staff.

(SCPrP 3: 08.03.2011): Social Care Private Provider / Managing Staff.

The Fife Users Panels: a tick-box exercise?

Participation of frail elderly people in community care

I. Introduction

In this particular case study, we focus on the introduction of User Panels in Fife, Scotland. In general, « the purpose of the User Panels is to provide a meeting place for elderly people, encouraging a free flow of information between elderly people and key care workers to put forward views and experiences of maintaining themselves in the community. The User Panels meet regularly to discuss and review a range of services and any potential development, evaluate services considered to be effective and to propose amendments or the cessation of services that do not add value to the lives of older people. The panels invite key service planners and decision makers, social workers and health visitors to attend their meetings and listen and respond to the experiences of user groups »¹. Today there are 6 User Panels spread throughout Fife, with 8 to 10 panel members for each. Although the panels deal with all types of community care services, a condition for joining the panels must be that the older person still resides at home, and that due to his/her frailty he/she is a major consumer of home-based long-term care services.

Often highlighted by both policy-makers and researchers as best practice examples², the Fife User Panels are a result of top-down encouragement (through legislation that was passed at national level, encouraging the participation of users in community care) and bottom-up initiative (set up by voluntary organisation). Initiated in 1992 by the Scottish branch of a UK wide voluntary organisation dealing with older people (Age Concern Scotland), the panels have been operating for almost 20 years, providing a platform for dialogue and with the aim to provide an opportunity for panel members to influence service planning and provision of community care for older people.

In this case, the study of the process of change is threefold: first we will seek to explain how the change developed in stable institutional settings through a bottom-up initiative. The User Panels began to operate informally, with external funding from the voluntary sector. The change in this case implied a process of social learning that began at the level of the voluntary sector actors and later on spread to actors in social and health agencies. The introduction of the panels implied new ways of working and engaging with frail older people that were living at home and were users of community care services, by working for instance as focus groups

¹ <http://www.scotland.gov.uk/Publications/2003/03/16899/21094>

² <http://www.scotland.gov.uk/resource/doc/96459/0023337.pdf>

(cf. analytical section, part 1). For the first time in Fife, and in Scotland, there were frail and elderly people meeting in order to share their views regarding the services they were using.

Second we seek to understand how this process of social learning led to a change, albeit slow, in the working culture of social and health agencies. Gradually, the work of the panels went from discussion between panel members to inviting health and social services representatives to participate in discussion. Social and health representatives began consulting with the panels regarding the services they were providing and concerning future service provision. With the increase of the credibility of the User Panels, once the initial funding of three years had run out, the Fife council and the NHS decided to continue funding and consulting with the panels. Funding implied that a contract was drawn between these actors, formalising to some extent their respective functions. In 2007, the objective of effectively using the Fife User Panels as a means of consulting and engaging with older people was added to the general framework of policies for older people, furthering the formalisation of the panels.

Third, we explain how this process of social learning has not necessarily led to institutional change. Interviews revealed that although the panels are consulted, this is not done in a systematic way and does not always necessarily lead to concrete results. Consulting and involving the panels is more of an encouragement than a requirement. Although interviewees from social and health authorities welcomed the work of the panels and their responses showed a change in the credibility and usefulness accorded to the panels³, the influence that panel members have on service provision seems to largely depend on the saliency of issues. When the issues raised by panel members resonate with issues that have also been identified by local social and health authorities as being important, then it is more likely that the concerns and ideas raised by the panels will be reflected. In addition, It should however be noted that at this stage of the research it is still too soon to provide a solid basis for this assertion and thus it will be further explored.

Innovative nature in relation to the national case

The Fife User Panels project was developed because Age Concern Scotland became aware that although the 1990 NHS Community Care Act required social services departments to listen to the voice of users of services in planning and providing community care services, this was not the reality when it came to very frail older people. Consequently, Fife's User Panels were specifically set-up to provide an opportunity for house-bound physically frail and isolated older people to, on the one hand, be able to speak out regarding issues that concern their daily lives and on the other hand, to influence local community services. Today the Fife User Panels continue to be quoted as a best practice example and are quite unique in nature, in the sense that in Scotland and throughout the UK "there are few examples of the involvement

³ When comparing responses to the conclusions drawn by Barnes.

of frail older people as opposed to active older people who were participants in pensioner's action groups and elderly forums" (at least this was the case in 2003)⁴.

Care problems addressed by the innovative model

The User Panels were set-up because of a preoccupation with the fact that although local authorities had the requirement to consult with users in service planning and service delivery, they were not doing enough when it came to elderly frail people who were house-bound and unable to get out. Thus the main problem addressed by this innovative model is a problem of insufficient and even inexistent (at the time of setting up the panels in 1992) user participation. It is also linked to a preoccupation from the part of social and health authorities with quality assurance and quality development, in the sense that it is linked to a larger preoccupation with consulting with older people in order to make services as efficient and responsive to their needs. Although the User Panels address all sorts of social and health services provided for older people, in the sense that panel members can provide input into any type of service that concerns them, the fact that a condition to becoming a panel member is that they have to be over 65 and living at home, makes them major consumer of services provided by the home-based long-term care network. This is why the study of the panels proves interesting when focusing on home-based long-term care network for the elderly.

II. Descriptive section

Socio-, geographic, demographic and economic characteristics

Located in east central Scotland and part of what is known as the Scottish Lowlands, Fife Council covers an area of 1,325 km²⁵. Forming a peninsula, Fife is surrounded by coastline to the east, the River Tay to the north and the River Forth to the south. The larger urban areas are situated in the south and west of the council which are characterised by an industrial economy.

The north and east are predominantly agricultural (SWIA 2006:7). Although it does not constitute a large council area in terms of surface, Fife ranks 3rd in population, with a total of 365,020 inhabitants in 2010, accounting for 7% of Scotland's total population⁶. The share of people aged 60+ is 24.3%, which is slightly higher than the 23.1% Scottish national average. More specifically, 8% of the population is aged over 75 years old (7.8% for Scotland). As is the case in most western societies, Fife has been characterized by a fall in the birth rate and a rise in the total number of older people. In recent years, and partly because of the mix of rural

⁴ <http://www.scotland.gov.uk/Publications/2003/03/16899/21094>

⁵ <http://www.scotland.gov.uk/publications/2003/03/16899/21094>

⁶ <http://gro-scotland.gov.uk/files2/stats/council-area-data-sheets/fife-factsheet.pdf>

and urban communities in Fife, there has been a general trend in the population to move from larger towns to rural areas (SWIA 2006:7). For the years 2007-2008, the percentage of Fife Council's single pensioners living in "accessible rural areas" (17%) is higher than both the number of Fife's single pensioners living in urban areas (16%) and Scotland's total share of single pensioners living in accessible rural areas (13%). Yet, 17% of all single pensioners in Scotland live in "remote rural areas", there was none registered in Fife local authorities' tables.

The three major cities are Kirkcaldy, Dunfermline and Glenrothes, where the regional headquarters of the council are located. Over the past few decades, Fife's economy has experienced a shift from heavy engineering and mining towards a large service sector (SWIA 2006:7). Thus, most of Fife's industry is concentrated on the tertiary sector (81.2%), with most service-related jobs found in public administration, education and health. This is followed by the secondary sector, which accounts for 18.7% of employee jobs. Despite the fact that Fife is constituted of large rural areas, the primary sector only represents 0.08%. At the time of the 2010 Census, "there were 3,073 people working in agriculture in Fife, of which 1,878 were employees and 1,195 occupiers or spouses. In comparison to other regions, Fife has the second highest proportion of casual and seasonal staff in Scotland, at 22% [...]. Tayside represents the highest proportion at 34%. This reflects the seasonal demand for harvesting fruit and vegetables⁷."

Key competitive economic sectors in Fife today are renewable energy manufacturing and clean technologies (with the current development of Scotland's flagship Energy Park based in Fife), tourism (in 2009 tourism generated approximately £184 million to the Fife economy, and supported around 11,000 full-time and part-time tourist-related jobs⁸), financial and business services, construction, creative industries and IT and technology. Finally the unemployment rate is above the national average: 8.6% between January and December 2010.

Politics

Fife is one of 32 council areas in Scotland and has a mainly Protestant tradition. Before the Local Government etc. Act 1994, Fife was a county divided into three districts. In 1996 the region reverted to a single tier system of administration and was set up as unitary local authority. Today, there are 78 councillors in Fife, usually serving for a period of four years. Each councillor represents a specific area or "ward". After the May 2007 elections, Fife's 78 wards were reduced to 23 with 3 or 4 councillors per ward.

Various political parties are represented on the council, as well as independent councillors. The breakdown by percentage of seats is: Labour Party (30.77%), Scottish National Party (29.49%), Liberal Democrats (26.92%), Scottish Conservative and Unionist Party (6.41%), Independent (3.85%) and left Alliance (2.56%). Since 2007 control of the administration has been shared between the Scottish National Party (centre left) and the Liberal Democrats

⁷ <http://www.fife.gov.uk/uploadfiles/publications/c64%5FTheEconomicReportonScottishAgric%2Epdf>

⁸ <http://www.fife.gov.uk/topics/index.cfm?fuseaction=page.display&p2sid=D0C8E2C8-1CC4-E06A-52BC1864AB5FF70F&themeid=727AF7D3-2D44-4D14-8C1B-D1B0E10EEA6B>

(radical centre to centre left), furthering the change from a long-standing Labour tradition (the Labour Party lost seats in both 2003 and 2007 elections).

The 2011 election results to the Scottish Parliament for Fife were clearly favourable to the SNP as they took seats from the Liberal-Democrats in Fife North East and Dunfermline and from the Labour Party in Kirkcaldy while holding their majority in mid-Fife & Glenrothes. Only one of the 5 relevant constituencies, Cowdenbeath, was won by another political party, namely the Scottish Labour Party and the Co-Operative Party.

As far as general election maps are concerned, Glenrothes and Kirkcaldy & Cowdenbeath were still deemed “safe” Labour Seats prior to the 2010 ballot with Labour unbeaten since 1950 and 1935 respectively⁹: results confirmed this trend as with the exception of Fife North East where Liberal Democrats came in first (followed by the Conservatives) the Labour Party won all of the other three Fife constituencies.

Civil engagement structure

Historically, Fife had a large mining community which led to the development of trade unions, contributing to a tradition of active participation. As one User Panels facilitator explained:

“a lot of the original people who were in the development of the forums had actually all been trade union members throughout their working lives and that kind of thing, you know, they had had a voice there and they felt that as older people they still wanted to have a voice, and I think that's the way the forums actually developed.” (S-F-NA-04)

In addition, there towns such as Glenrothes which was created in the 1950's and had an influx of migration from the West of Scotland which traditionally has been known for its activism and thus contributed to the development of a participatory culture in Fife.

Today there are several means for civic participation in Fife. This includes attending Fife Council committee meetings which are open to the public or regular “surgeries” where individuals can meet councillors face-to-face in order to provide them with feedback or raise issues; open consultations on particular issues; trade unions; the media...

In addition there are 105 community councils in Fife, although only 87 are active¹⁰. Community councils constitute one of the main mechanisms of public participation in

⁹ http://www.electoral-reform.org.uk/safe-seats/#Safe_seats_in_2010

¹⁰ <http://www.fifedirect.org.uk/topics/index.cfm?fuseaction=service.display&p2sid=ABA5B599-0AE2-4337-836B-71162E5E1BB0>

Scottish Local government. They are constituted by groups of volunteers that are elected every four years and allow local people with the opportunity to express their views in relation to decisions taken by local authorities and other public bodies. “Their primary purpose is to ascertain and express the views of the community to the local authority and other public bodies. Many community councils also involve themselves in a wide range of other activities including fundraising, organising community events, undertaking environmental and educational projects and much more”¹¹. Community councils and their areas of responsibility are defined by local authorities which fund them.

Fife has also a large voluntary sector. “There are over 1200 voluntary organisations in Fife ranging from small purely voluntary groups to Fife-wide organisations helping disadvantaged groups and individuals who employ staff and manage large budgets.”¹²

More specifically, older people also have the opportunity to participate through 8 elderly forums that are run throughout Fife and which provide individual and peer-group advocacy for the elderly. They engage in consultation with councillors and with representatives of council services in matters related to older people. However, these elderly forums are different to the User Panels in that they are active and more able bodied and are not necessarily users of community care services. Each forum has its own committee and they tend to deal with issues on their own. If they feel they are getting nowhere they will come together as the Fife elderly forum Executive. Each local forum appoints two members and they meet together once a month (S-F-NA-05).

Demographics, aging, migration

As with the rest of Scotland, there has been a steady increase of population since the 1950’s. Improvement in health conditions and decrease in the birth rate has led to an increase of older people, in particular the 80+ fraction of the population. It should be mentioned that there is very little migrant population, mostly migration within Scotland coming from the West during the 1950s¹³. A 1994 Age Concern Scotland Publication focusing on Fife states that “there was considerable immigration of miners from the west of Scotland both prior and post the Second World War. This has meant, for some older people, a separation from close family members. In some parts of the region, there are communities originating from Poland and other parts of eastern Europe. There are very few black people living in Fife”¹⁴.

Fife local authority tables published in *Scotland’s People* annual report for the years 2007/2008 seem to confirm this description:

¹¹ <http://www.scotland.gov.uk/Topics/Government/local-government/CommunityCouncils>

¹² <http://www.cvsfife.org/general/index.htm>

¹³ One of the earliest study of this demographical trend is to be found in Watson, W An., “British and foreign immigrant miners in Fife”, *Manchester School of Economic and Social Studies*:1952 Vol.:20, p. 203 -212.

¹⁴ *New Ways of Working. Age Concern Scotland’s First Report to Charity Projects, October 1992-September 1993.*

Table 2.2: Characteristics of adults - Ethnicity

Fife	
White	99
Scottish	88
Other British	8
Irish	0
Any other White background	2
Any mixed background	1
Asian	1
Indian	0
Pakistani	0
Bangladeshi	-
Chinese	0
Any other Asian background	-
Black	0
Caribbean	0
African	0
Any other Black background	-
Any other background	0
All	100
Base	1,683

Development of perceived problems of care

For centuries care for the elderly in Fife and Scotland was ensured by family, in particular women, and community groups such as churches. “Social and economic arrangements between individuals were based on Calvinist concepts such as social responsibility and self-help” (Blach 2008).

From the 1960s till the late 1980s, home-based care provided by Fife Social Work for older people was known as “Home Help” service. Until the early 70s there was no emphasis in terms of personal care, such as assistance with personal hygiene, eating and drinking, immobility problems, management of medication and personal safety. As various interviewees explained, Home Help at the time was primarily based on domestic support. “Home helpers”, as they were known back then, would provide services such as cleaning the house, vacuuming, dusting, polishing, lighting coal fires, shopping and preparing food, to name a few. Although the personal care side to the service began to appear from the late 70s onwards, it remained rather minimal until the 1990s. This emphasis on domestic chores rather than on personal care was mainly due to the fact that there was a tendency of transferring older people to an institutionalised setting once their health deteriorated past the point of being able to stay at home. The following assertion by a social work official is a good example of the evolution of community care towards the conception that older people should be kept at home:

"Yeah well, going back 20, 30 years I think that umm there was less people, people ummm there was less of a voice umm from umm service users about wanting to stay at home and I think people assumed as they got older that if they could not manage at home in their own home that they would go into some form of care home some kind of residential or nursing home but

over the last 10 or 15 years survey after survey shows that people actually want to stay in their own home umm and as and as people have seen that there are services such as home care yeah? Such as telecare umm meals on wheels umm you know private home care that can be purchased if people have the money I think that people see that more and more services can be brought to their own house they they have an even stronger desire to stay at home because there are now alternatives that did not exist ummm 20-30 years ago". (S-F-NA-01)

The 1990s brought many changes in Fife. Fife witnessed the same demographic changes characterising Scotland and the UK resulting in growing pressure put on services. In particular services witnessed a progressive shift from a producer- to a consumer-led perspective focusing on outcomes and individual needs. Free personal care also meant that demand for services rose and costs increased. There was a shift from £4 per week paid for services in the 90s to £11 an hour (S-F-NA-N1, S-F-NA-05). This rise is one of the most commonly alleged reasons for SNP's Alex Salmond's much unexpected defeat in Glenrothes 2008 by-election for an MP seat in the House of Commons. Victorious Labour candidate and Kirkcaldy High School rector Lindsay Roy focused heavily on rising home care charges. Former Prime Minister Gordon Brown, who holds a seat for the neighbouring Kirkcaldy and Cowdenbeath constituency, visited Glenrothes several times during the by-election campaign.

There were also shifts in public culture (S-F-NA-01) in the sense that it took some time for the public to accept that the Social Work would offer less and less home help (domestic chores). Nowadays, domestic chores are provided for the most intensive cases.

Development of the care market

From the late 1960s till the beginning of the 1990s, the network of actors involved in the provision of domiciliary care was not largely diversified. There were two major actors that provided services for older people living at home: Social Work and NHS Fife. Most support services were provided in-house by Social Work, while the NHS was mainly responsible for the provision of health and personal care services. Unpaid carers also played a large role in care giving. Although there was a large voluntary sector in Fife, its role in providing home-based long-term care services was rather limited, and focused mostly on providing some day care centres. The role of the private sector was also limited, and some interviewees went as far as saying that it was almost inexistent. When asked for reasons behind a mainly in-house provision of services, one public official replied:

“In Fife we had a very strong Labour administration here who did not want to go to privatising services. They wanted to maintain council workers doing council jobs, so for many years that's why it was nearly 95% of employees of the council who were doing the work.” (S-F-NA-01)

This situation, however, was not specific to Fife. Throughout Scotland “local government remained dominated by the Labour party, still hostile to neo-liberal policies, and where the ethos of state responsibility and provision was embedded in the foundations of the social work profession” (Bordie et al. 2008:705).

This however progressively changed as demands for services grew with the demographic rise of older people. In 2002, the Scottish Executive implemented Free Personal and Nursing Care for people aged 65 and over and Free Nursing Care in care homes for people of all ages. It should be mentioned the Fife Council was already providing free personal care for older people, so in this sense this did not imply a big change for Fife. What did change was that from then on personal care was a right for people aged over 65 and thus demand for services increased. Progressively Social Work started tendering out to private companies.

Historical development

Governance

Since the 1940s and as a result of British Welfare State legislation, Fife and all local authorities became responsible for the provision of social welfare to older people. More precisely, the National Assistance Act (1948) foresaw the provision, by either local authorities or through voluntary organisations, of residential accommodation, helps at home, meals on wheels and recreation for older people. Despite this fact, domiciliary services and housing for older people remained largely inadequate (Black, 2008:266). Comparatively, the situation at the time was worse in Scotland, due in particular to disparities at the regional level. During the 1960s the UK witnessed fundamental changes in the area of social work. Reasons behind these changes were namely due to a progressive “formalisation of social work as a professional activity within the community” (Black, 2008:267). Originating from the discontent of social work interest groups with government policy, these changes translated into a shift from a conception of services as being fragmented and focusing on specialised demands to a generic profession. Social problems were seen by social work reformers as being interconnected and complex in nature, thus requiring a set of core skills allowing social workers to deal with a variety of situations. In Scotland, this shift had broader implications than the realisation of the need for change in organisational structuring: there was a shared belief “that social work could be a positive and radical force for social change” (Brodie et al, 2008:699). In what is deemed to be a landmark piece of legislation, the Social Work (Scotland) Act 1968 laid down the duty for local authorities to provide services for vulnerable groups in society, among which older people were included. In order to do so, parliament established Social Work, limiting as a consequence the role of central government in the implementation of welfare state services. Local authorities were now in charge of establishing as well as managing social work service structures, and encouraged to be more inventive about the type of services they delivered.

Today objective and strategy setting is complex in Fife. Many interviewees cited funding as one of the main issue:

“finances is a worry and I think if everybody had a wish it would be to know what the budget

would be form the next ten year probably so that they could just strategically plan forward, but obviously we don't know and I think most of the agencies, even like NHS Fife and Fife Council are the same so, I think everybody's really willing and eager to go forward and provide a good service but at the same time there's a weariness about money, and what will happen in the future." (S-F-NA-06)

Quality Insurance

A shift to outputs and evidence based quality assurance (**need to contact Louise Weynes in Planning and Service Development**). Quality assurance and development is mostly done at national level, with inspection of services done by the Care Commission (now called the Care Inspectorate).

Complementarity and coordination

In the 1990's there was little joint-working and coordination between the different actors involved in the network. There were very few conferences and forums where different actors would meet. Most home care services were provided in-house by Social Work. As demands for services grew, there was more tendering or contracting out to external providers (mostly private). Also coordination problems between NHS Fife and Fife Council led to the realisation that more joint working was necessary. There were tensions in relation to budgets and to the provision of equipment, but also delayed discharge.

Delayed discharge is indeed still a major issue. Notes from the December 2011 meeting of the NHS Fife board made it clear that "NHS Fife was meeting virtually all of its waiting time targets, a better performance than national targets for diagnostics, an improving position on the national target for waits in A&E but a challenge remains in meeting the delayed discharge standards."¹⁵ After figures for 2010 were revealed, Health Secretary Nicola Sturgeon voiced renewed concerns about the "unacceptably high" level of delayed discharge in Fife.

From the very late 1990s till today, there has progressively been more joint-working from different actors. Community Health Partnerships (CHPs) were created for instance (although the impulsion for creation came from the national level), where Social Work, NHS Fife, voluntary organisations and private service providers meet on a regular basis to discuss common goals. Fife's Health and Social Care Partnership¹⁶ was also created in order to improve joint working through its remit in policy strategy and resource issues.

¹⁵ <http://www.nhsfife.org/nhs/index.cfm?fuseaction=nhs.newsdisplay&objectid=66312AE0-FB04-D30C-19EF5A32CEC5792E>

¹⁶ <http://www.fifedirect.org.uk/news/index.cfm?fuseaction=committee.detail&servid=95E72793-EE29-F9BA-78EDEE99E0E8C106>

Beneficiary participation

As one local health official explained:

“I would say the 90s were the start of that building and developing of opportunities for older people to stay at home and people were starting to voice their desire to be at home”. (S-F-NA-02)

Until the early 1990s there was no participation of users in service planning and service delivery, however this was a situation that not only characterised elderly users, but all users of community care services. As one social work official explained:

“[G]oing back many years I don’t think the users themselves were consulted in terms of how they saw the service developing over the years to come, I don’t think there was much of that” (S-F-NA-01)

The local network of HBLTC for older people today

In order to get a better idea of the demand and offer of domiciliary care for the elderly in Fife today, it should be noted that in 2010 there was a total of 3614 home care clients aged over 65 years old, representing approximately 74.7% of all home care clients¹⁷. This means that older people are the largest receiving group of home care. Out of these older home care clients, 87.4% were in receipt of community alarm or other telecare service. Between 2008/2009, there was a total of 2130 of +65 supported in care homes, showing a 7% increase since 2003/2004 (SWIA 2010:134). In 2010, Fife Council provided or purchased a total of 64’939 hours of care. National statistic reports show that since 2006 there has been a decrease in the number of clients receiving a home care service and that the total of hours of service provided or purchased by the local authority has also dropped since 2008¹⁸. Nevertheless, it should be borne in mind that this is mostly due to issues of inaccuracy of data received from Fife¹⁹. In reality, the number of home care clients has increased, in particular older clients.

¹⁷ See <http://www.scotland.uk/publications/2010/11/30092349/21>

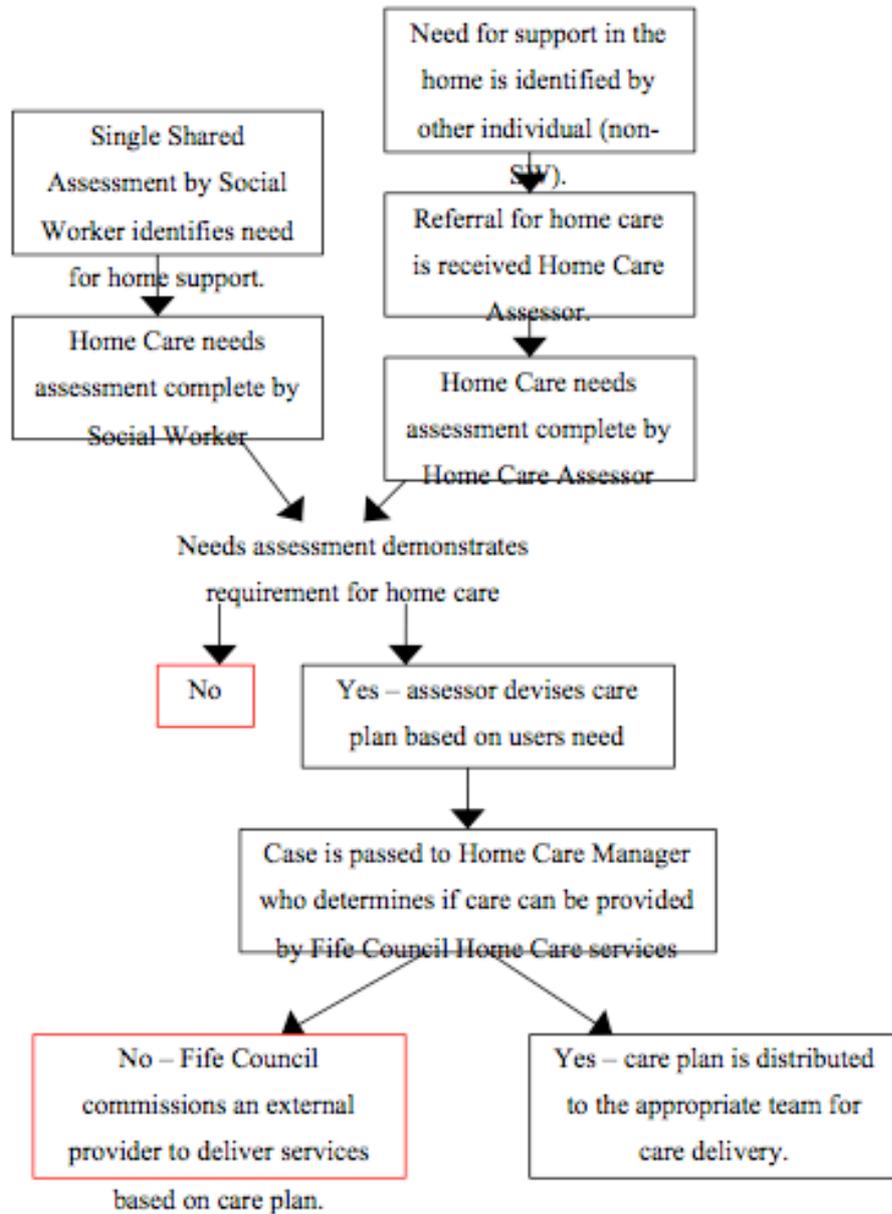
¹⁸

¹⁹ <http://www.scotland.gov.uk/resource/doc/332697/0108278.pdf>

Available services and providers

Several questions arise when seeking to describe Fife's present system of provision of home-based long-term care for the elderly: how is the process of home care service delivery organised? Which actors are involved? And what benefits are available for which groups? Figure 1 illustrates the different existing steps allowing an older person to become a recipient of care at home in Fife. A person can either apply for home care themselves or be referred by another individual. A needs assessment will then be conducted by staff members of Fife's Social Work Service (cf. national context). In general, needs assessments are free of charge, however in Fife there may be a charge depending on the assessed person's income²⁰. If the assessment determines that the older person is indeed in need of care at home, then a care plan will be devised depending on the user's specific needs. Under the Community Care and Health (Scotland) Act 2002, all local authorities in Scotland are required to proceed in a similar manner.

²⁰ <http://newsite.1fife.org.uk/topics/index.cfm?fuseaction=service.display&themeid=98A56687-9A344494-A43C-68E07CCA64E&p2sid=E677BE69-07EV-451F-B62A-EA346237D444>



Source: Ellis, B. (2009 HOME CARE: Research into Best and Innovative Practices. Brief Review of the Literature)

As we can see from Figure 1, Fife Council is not the sole provider of home-based elderly care services. The provision of home care and support is divided between various providers including Fife Council, NHS Fife, private sector agencies, the voluntary sector and last but not least, informal carers. Fife Council Home Care and Support Services will commission external providers if they are not able to cope with demand.

Fife Council – Social Work

Care at home at the local authority level is provided by the Social Work Service. In Fife Council, home-based care comes under the management of Older People's Services (SWIA 2006:80). Home care and Support Services, which is divided into 3 geographical areas -West, East and Central- consequently falls under the management of this department. It must be noted that these three subdivisions act as branches and are consequently registered separately. This means that they have been subject to separate inspections from the Care Commission (at least till April 2011, afterwards the Social Care and Social Work Improvement Scotland (SCSWIS) has taken over). "Each of these three geographical areas is managed by a Team Manager who has responsibility for a team of Home Care Managers, Home Care Coordinators and Home Carers" (Care Commission 2010:11). Despite the fact that Home Care and Support Services is managed by Older People's Services, it provides a generic home care service (Ellis 2009:4). As such, this is the only service responsible for providing home care to a wide range of individuals with a multitude of needs. This arrangement is opposed to specialist services which "serve a targeted population based commonly on age or condition" (Ellis 2009:10). Home Care and Support Services in Fife is thus not differentiated on the basis of age and diagnosis. For this reason, Home Care workers are required to have a vast knowledge of care provision for a broad audience and follow a two-week training programme provided by Fife Council in order to reinforce this knowledge²¹.

Examples of free personal care services in Fife include (Fife Council 2011:1): personal hygiene – washing and toileting; dressing and/or undressing; getting up from and to bed; assistance with eating and meal preparation; simple medical treatments; surgical appliances; use of manual or mechanical aids; psychological support. As has already been explained in the national chapter, there's a set of services that are nonetheless charged for. In Fife, these include: bed making, housework, laundry (with the exception of incontinence laundry), housing support (assistance with finances, paying bills, cleaning and laundry, attending appointments), Meals on Wheels (delivery of meals to older people in their own homes) and Community Alarms Services. There are however exceptions, and if a person's assessed income is less than £160.01 or less for individuals and £244.30 or less for couples, the person will not be charged for any care and support services (Fife Council 2011:2).

In addition, respite care services are provided by Fife Council, but also by private and voluntary sector organisations. In 2008, there were 14 facilities providing a total of 1124 day respite places per week. There were also 8 overnight respite care facilities with 57

²¹ "Home Carers provide services for people who are elderly, children within families, children who have special needs or those who have a physical disability, people suffering from mental illness or dementia, people who have a terminal illness, people who have learning disabilities, alcohol problems, HIV/aids, drug related illnesses and people who have difficulties maintaining their tenancy » (Care Commission 2010 : 11).

beds available for older people. The main identified challenges to respite care provision in Fife have been linked to the mixture of urban and rural areas in the council. The main goal of Fife Council respite care has been to support the role of carers²². Usually these services run on weekdays during normal office hours, although there are some that operate over the weekends as well. As of 2009, there were no dementia-specific day care units for 65+ adults in Fife, staff estimated that approximately 65% of older people receiving respite care have a form of diagnosed or non-diagnosed dementia.

Self-directed support/direct payments: SWIA inspections have shown that Fife is performing well in this area, offering significantly more direct payments than any other council in Scotland²³. However, interviews with local authority and health officials revealed that there are very few older people that actually opt for this option. The reason behind it is that they tend to see it as being rather complicated. In total there might be approximately 25 older people receiving direct payments. It is a service that is mostly centred on disabled people.

Fife Council also provides its own range of day care services. This is done mainly through the Fife Day Care Services Ltd registered charity which is funded by Fife Council. The day care groups are for people over the age of 65 and are aimed to “relieve social isolation and/or to provide a respite for carers²⁴.” There are currently seven groups per week which operate in the communities of Benarty, Lochgelly, Kelty, Blairhall.

NHS Fife

Another actor that is involved in providing health services to older people in NHS Fife, which is the health board for all of Fife. According to an NHS Fife official, “although this organisation is not directly involved in the long-term home-based care for the elderly (which is a service provided mostly by Fife Council) there are points of overlap when an elderly person is discharged from an episode of hospital treatment. NHS Fife works with local authorities by means of partnerships. It also works with voluntary organisations and private service providers.” (email correspondence). NHS Fife works with local authorities by means of partnerships. It also works with voluntary organisations and private service providers.

Fife Health and Social Care Partnership

²² http://www.socialwork.fife.gov.uk/fds/file.php/1/publications/Literature_Briefs/Respite_Care_Literature_Brief-Final_Draft.pdf

²³ <http://www.scotland.gov.uk/resource/doc/96459/0023337.pdf>

²⁴ http://www.google.com/url?sa=t&ret=j&q=&esrc=s&source=web&cd=1&ved=0CCkQFjAA&url=http%3A%2F%2Fwww.fifedaycareservices.org.uk%2FIndex.asp%3FMainID%3D9873&ei=wmxvT96QKMqa0QWP_qGOAg&usg=AFQjCNFFled eMCYHIyX1F9ZJFs0QHIAVbA

“Fife Health and Social Care Partnership is a joint Fife Council and NHS Fife group which is responsible for the management and strategic development of health and social care services²⁵”. The partnership is responsible for drawing a plan setting Fife-wide priorities for different care groups, including older people, in the area of health and social care services provided in the community. The Partnership has “delegated authority from both Fife Council and NHS Fife”. However, the two partners “come together through different arrangements at both strategic and operational level to agree priorities and joint working arrangements. However, each remains individually accountable for the use made of public funds under their control”.

Community Health Partnerships (CHPs)

“CHPs were established in April 2005 and are responsible for the delivery of health services in local communities. CHPs are partnerships made up of health, local authority, voluntary sector organisations and members of the public.”²⁶ There are three within the Fife area – Glenrothes & North East Fife, Kirkcaldy & Levenmouth and Dunfermline & West Fife.

Voluntary organisations and private service providers

As is shown in figure 1, in cases where Fife Council is unable to provide a particular service, it may purchase it from voluntary organisations or from private service providers. Services from voluntary organisations and private service providers can also be purchased directly by service users. As one voluntary organisation manager explained:

What happens is at the moment, individuals pay for some areas of their care themselves but that is direct with the Council, we don't play any part in that at all. Any support that we give is costed out, we're paid for that, that's paid for by the Social Work department, generally, although we can get payment through the National Health Service as well, it just depends where people are coming from, which branch of funding they tend to use, or somebody can pay for it themselves, you may find that somebody has got substantial amounts of money and they'll come to us and say “right I want you to come and support me”, no problem, we'll give them an hourly rate then we would invoice them and that would be it.”

In relation to home care, there was a total of 19 registered organisations that provided a variety of 32 care at home services (Ellis 2009:2).

²⁵ <http://www.fife.gov.uk/publications/index.cfm?fuseaction=publication.pop&pubid=098DA2D3-C326-8221-C37D3EA571DC7B21>

²⁶ <http://www.scotland.gov.uk/Publications/2010/05/06171600/4>

It should be mentioned that in Fife, social work services in general are provided in-house instead of being commissioned externally. It seems that “this agenda has been driven by elected members” (SWIA 2006:209). However, at the time of the 2006 SWIA inspection, 46% of the social services’ total budget was destined to the purchasing of services from the voluntary and independent sector. Despite this fact, decisions pertaining to the balance between in-house and purchased services were not based on established processes related to quality, customer choice and best value.

In the past, and due to this in-house trend, Fife Council has been a major provider of home care services for older people. The Council has also been the major provider of care homes in Fife. However, it is important to mention that recently (August 2011) there has been a change in policy and the LibDem/SNP administration has decided to privatise all of Fife’s 10 care homes. Reasons behind the highly criticised move were linked to estimated losses of 100m in capital over the next 10 years and revenue reductions of £120m over the next four years. The Labour opposition has criticised the administration’s failure to take into account the voluntary sector’s ability to provide for care home services.

Informal carers

“The estimate is that 13% of the population are carers, the numbers rise to 47,253. By 2012 it will have risen again to 47,831.”²⁷ In view of this trend, the Scottish Government issued a report entitled *The Future of Unpaid Care in Scotland* in 2006 whose aim was to fully recognise “the contribution of carers to society” as well as “the economic impact of their contribution. [...] As such [carers] will be wholly included in a society which will provide adequate support to carers.”²⁸ According to one interviewee from the voluntary sector:

“There’s been a progression from that piece of work. And again that was really an important piece of work in terms of flagging up to Scottish government that particularly the key partnership role that carers play in you know delivering health and social care services.” (S-F-NA-07)

Informal carers might be eligible to have respite care which may be provided by Fife Council or voluntary or private service providers. Locally, the “first Fife carers support project began in June 1995 with Mhairi Lochhead being employed part time to develop recognition and support for carers within Fife”²⁹. It is now an independent charity representing carers’ interests and engaging in advocacy work. They receive funding from Fife Council, NHS Fife

²⁷ http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&ved=0CDEQFjAB&url=http%3A%2F%2Fadmin.1fife.org.uk%2Fweborgs%2Fnhs%2Fuploadfiles%2Fpublications%2Fc64_fifecarersstrategy2012-15complete%5B1%5D.pdf&ei=RG1vT6-HOcPB0QXBnKiNag&usq=AFQjCNEvfb5YXF_bWJ_5t9AoY_j-VPWBOg

²⁸ <http://www.scotland.gov.uk/Publications/2006/02/28094157/1>

²⁹ <http://www.fifecarerscentre.org.uk/history.php>

and the Big Lottery Fund among others. Yet the rising number of unpaid carers and their recognition remain an issue. As one voluntary organisation manager puts it:

“they don’t get any payments, they get not thanks, they get no respite, these are the people that our country relies upon. [...] There’s not a voice for unpaid carers out there so we don’t hear them, we don’t know how many there are because there are so many of them, and I think it’s actually quite frightening for the government to think about how many people are unpaid carers because if these people weren’t caring, who would do that job for them.” (Sharon Stuart)

Identified care problems

Today, the main identified problems in Fife in relation to home based long term care seem to be a reflection of what is happening in the rest of Scotland. There is a major concern with demographic trends which show that there is an ageing population and a lowering of birth rates. This has led to an increase of older people needing services in particular in the +80 portion of the group. An increase in older people has translated into an increase in the demand on social work services which have difficulties to cope. All interviewed actors seemed to view demographics as a sort of ticking bomb, in particular due to the expansion of services that it entails. On the basis of population projections, it has been calculated that there will be a 2.5% increase in demand each year on social and health services. This concern seems to be additionally aggravated by the financial climate in Scotland. Thus on the basis of this, there is an identified “need to re-focus budgets and effectively manage risk e.g. the ability to meet often very complex and demanding social care needs of older people and other community care groups” (Fife Council and NHS Fife joint community care plan 2004-2007³⁰). “The resources of local people and communities will be at the centre of care provision”³¹. The issue is thus ensuring the delivery of quality care at the least cost possible, hence the need to come up with innovative ideas that can reduce the costs all the while maintaining efficiency.

Other problems that were put forward during interviews with local authority and health officials were linked to the issue of carer recruitment. There is a preoccupation that because of low birth rates, in the future there will be less and less younger people who could become carers. In addition, the challenge that the Social Work Service is particularly faced with is the fact that home care is no longer a large in-house enterprise as it was in the past. There has been a diversification of actors, in particular private companies, coming into the picture. The

³⁰<http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCgQFjAA&url=http%3A%2F%2Fwww.cvsfife.org%2Fpublications%2FJCCPMain.pdf&ei=oG1vT8z7LMbOhAfr9uyxBw&usg=AFQjCNGttH13GfrVMwqh-dIIR50FXXf8yQ>

³¹http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCoQFjAA&url=http%3A%2F%2Fadmin.fife.org.uk%2Fweborgs%2Fnhs%2Fuploadfiles%2Fpublications%2Fc64_Final-Summary.pdf&ei=um1vT6OjMaHhQeywoicBw&usg=AFQjCNGbVrOyTCqNKi6ZslrUiLIQZH8Qkg

balance of care provision is approximately 65% in-house and 35% private. Recruiting carers has thus become more difficult than in the past. As one local authority official explains:

“One of the challenges is recruitment it is difficult to recruit people to work in the home care service in some parts of Fife (...) because you are competing. Remember I said that 30 years ago there was one big in-house home care service, yeah? which means that if you wanted to become a home helper there was only one employer. Today we have 20 different home care agencies in Fife when we are trying to employ people they are also trying to employ the same people, so we are competing for the same small number of home carers yeah?” (S-F-NA-01)

Fife Council has long stated that its aim is to “enable people and their carers to live in their own homes for as long as possible. This is done by providing reliable, high quality, flexible care and/or support in the community for people and those who care for them. The care offered will be the minimum needed to best help people to be independent.” (Care Commission 2010:11). This focus on independence –at least at the level of discourse- is closely linked to a general shift of healthcare from institutional to domestic settings. The idea of remaining at home for as long as possible rather than entering a care home has been a key priority of Scottish social care policy for quite some time (McFarlane et al. 2008:2) and this has also been the case for Fife. As Glasby (2007:40) points out, it is no longer an issue of adding years to life, rather it is about adding life to years by maintaining independence and increasing quality of life.

Other identified needs for older people include: “being involved and listened to; having increased control and participation; the opportunity to stay at home as long as possible; and to have better information about services and resources”.³² The partnership group between Fife Council and NHS Fife has recognised that there is not enough advocacy provision for older people in Fife. In the action plan for Fife’s Framework for older people 2007, one action point is to “make effective use of Fife elderly Forum and Age Concern Scotland, Fife Use Panels as a means of consulting and engaging with older people.”³³

Among solutions mentioned by interviewees to deal with problems we find: technology (the use of telecare), the need to develop joint-working, to listen to users and carers, but also Single Shared Assessments and the development of people-centred planning techniques in order to develop independence. Reablement is also a big thing at the moment in Fife and will soon be launched not only at the level of services at home but also in day care centres.

In general, the main identified problems for health care and social services in general in Fife are that people find it difficult to access information about or physically access services. Processes to arrange and provide care can be long and complicated. There will always be

³² Fife Health and Social Care Partnership Draft Service Delivery Plan 2012-2015

³³ http://www.google.com/url?sa=t&rt=j&q=&esrc=s&source=web&cd=1&ved=0CCgQFjAA&url=http%3A%2F%2Fadmin.1fife.org.uk%2Fuploadfiles%2Fpublications%2Fc64_FifeFrameworkforOlderPeople2007.pdf&ei=82lvT6u_BoLMhAej7OCQBw&usg=AFQjCNF4VmcV6wG-5WbouxIKErY0q10WfQ

more requests for services than there are resources available. More support is required to enable people with long-term conditions or disabilities to fully participate in the community. Resources need to be rebalanced to both help people to avoid illness where this is possible, and provide support earlier to prevent crises. When people move from services designed for children to adults or from adult services to services for older people they often find it hard to find out about or access services and find the change itself difficult.

In general, carers are also recognised as a vital part of health and social care and Fife Council and NHS Fife thus need to further engage with carers in order to support them. In addition, policy documents also recognise that “carers from minority ethnic groups have specific needs and these should be addressed”³⁴. Demographics are also a cause for worry when dealing with carers-related issues: “the balance of population is also changing, with the number of older people increasing most. It has been estimated that the highest increase is in those over 90 years of age. Many of the people who care for the very oldest population will themselves have reached retirement age”³⁵.

Dementia is now also one key issue in Fife today. Fife Council and NHS Fife completed the Fife Dementia Strategy 2010-2020 following *Scotland's National Dementia Strategy* (June 2010). Dementia is becoming a cause for concern among Fife health officials, for both demographical and financial reasons. Indeed, according to the 2010 publication of the Fife strategy, “The number of people living with dementia in Fife is set to increase dramatically over the next 20 years. This is due in part to an aging population, improved techniques to identify and diagnose dementia earlier than before, and lifestyle factors. Currently in Fife there is an estimated 5700 people with dementia. Approximately 63.5% of these people live in their own home in the community, while the remaining 36.5% live in long term care. [...] Based on demographic predictions, by 2030 the number of people with dementia in Fife will nearly double and be an estimated 11000 people. Services must begin to adapt now to the increasing number of people with dementia and the shifting culture of care centred on the home and community. The current cost of health, social care and accommodation for people living in Fife with dementia is an estimated £88.6 million per year; by 2030 this will have increased to over £178.7 million per year at today’s prices. [...] It has been estimated that the care and support carers provide is worth over £49.8 million per year in Fife alone.” This is meant to find solutions to current problems as identified in the 2006 SWIA inspection which revealed that “the range of provision to meet the needs of people with dementia appears to be mixed and uneven” (SWIA 2006:50). Issues that were raised included uneven geographical coverage, gaps in the provision of intensive services for dementia sufferers and their carers

³⁴ http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCgQFjAA&url=http%3A%2F%2Fadmin.1fife.org.uk%2Fweborgs%2Fnhfs%2Fuploadfiles%2Fpublications%2FCIStrategy%2520updated%2520July%252008.pdf&ei=W29vT6_pO6eu0QWtvLiNAg&usg=AFQjCNH8AN8sSP77jyQFYZ19aSfMscy3Wg

³⁵ http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCUQFjAA&url=http%3A%2F%2Fadmin.1fife.org.uk%2Fuploadfiles%2Fpublications%2Fc64_Item14-CarersStrategy.pdf&ei=im9vT9W3Oew0QW0zb2OAg&usg=AFQjCNEEDPaYboX8WtMPKml14KNUSQkwSQ

and gaps in the provision for people with early stage dementia.

Prior to this dementia strategy, Age Concern Scotland (the nationwide voluntary organisation responsible for setting up the User Panels) had also started working on complex cases by setting up “dementia forums” around Fife in the 1990s. Though people suffering from dementia were deliberately excluded from the User Panels, one former development officer for Age Concern Scotland in the 1990s explains:

“When I started working for ACS I was asked to do an investigation into day care, and that was day care with the private sector, the voluntary sector, Social Work and health, [...] and what came out of that was that if you had dementia you could fall off the edge because there was no coherence, and I knew that work was being done in the north of England, that there were attempts to bring people together, [...] and so I set up what I called dementia teams and dementia forums. The dementia teams were general psychiatrists, psychologists, social workers coming together and discussing the whole issue of dementia on a care policy base but then from there we had what we called forums and they would meet regularly, so say somebody was a senior social worker, or somebody who organised home help would say “well, you know, Mrs So and So, we think she’s not managing too well and then that was the way in which the other agencies could come in without having to go this way and that way and that way. They just sat and talk and went right “I’ll go and see her next week and I’ll do whatever”.” (Joyce)

These forums no longer exist as such but the Fife Dementia Strategy now includes a “Dementia Learning Forum” which “is a joint initiative between Fife Council Social Work Service and NHS Fife, launched in its current form in February 2008. Previously funded by Kirkcaldy & Levenmouth and Glenrothes & North East Fife Local Management Units (LMUs), however funding this year [2010] has been secured from the Carers Information Strategy fund.”³⁶ The forum is held 6 times a year “over lunchtime and each forum commences with a presentation by a keynote speaker on a dementia related topic usually recommended by forum delegates via evaluation forums. An opportunity to network is made available over lunch followed by small conversational learning groups, facilitated by DLF members.”³⁷ Since 2008, the forum has gathered an average of 68 delegates including people from community social work, community health, acute and primary care ward staff, voluntary agencies, independent sector, carers and people living with dementia.

III. Analytical section

³⁶ <http://socialwork.fife.gov.uk/fds/mod/resource/view.php?id=353>

³⁷ *Ibidem.*

Description of the innovative long term care model

The User Panels were created in 1992 by the Scottish Branch of Age Concern, a UK wide voluntary organisation representing the interests of older people to policy makers. The organisation ran the panels from 1992 till 2009. In the beginning of the 1990s the organisation had begun to change its views with regards to the forms that elderly participation could take. It began recognising the importance of ensuring that older people, in particular frail elderly people, have the possibility to speak out rather than having staff decide what they think their views are. With this in mind the project was set-up for an initial period of three years and with funding coming from the charity sector. After those three years, Fife Council and NHS Fife began funding the panel. From 1999 until 2009 there were 7 panels operating and spread out throughout Fife and composed of 8 to 10 frail elderly people living at home and large consumers of community care services: “we seek to have as Panel members older people who are users, or potential users, of community services – be these statutory or voluntary. We are particularly looking for those living on their own although we do have one or two where there is one other person in the household. We aim to have people over 75 years of age. [...] The people identified, because of the constraints through their various disabilities, are not part of pensioners clubs, elderly forum or similar such organisations and hence there are no obvious channels for their views to be expressed. (We do, however, have one panel member who makes great use of the local press to voice his opinions. We do not have older people with dementia. We feel that their inclusion would involve us working in different ways. Their ability to sustain a contribution over the three year period of the Project could prove difficult.” Although panel members were not necessarily chosen so as to ensure representativeness, the panels were spread out geographically across Fife in order to include people in both rural and urban localities, as well as from different socio-economic groups (Barnes, 1998:203). During the setting up process, local service providers at different levels were contacted by project workers in order to introduce them to the project and ask them to nominate potential panel members. Stakeholders included professionals such as home carers, health visitors, GPs, social workers and district nurses, to name a few. Several ground rules were established, in particular that project workers were not to deal with the individual problems of panel members, although they were allowed to provide general information. In 2009 Age Concern decided that the User Panels were no longer a priority and decided to stop running them. Later that year Age Concern and another UK wide organisation called Help the Aged decided to merge, becoming Age UK. As a result, Age Concern Scotland no longer exists and has closed its operations in Fife. Faced with this situation, Fife Council and NHS Fife agreed that the User Panels were useful in particular with regards to consultation for service planning and delivery. The requirement of the 1990 NHS and Community Care Act on social services departments to listen to users in service planning and delivery was also still in effect. They decided to continue with the panels and asked the Fife Elderly Forum if they could run the panels. Having agreed to do so and funded by Fife Council and NHS Fife, a User Panel coordinator was hired in 2009. It should be mentioned however that when Age Concern Scotland closed its operations it did not pass on its information or archives to the Fife Elderly Forum. The User Panel coordinator would then have to start from scratch. Age Concern did however provide a list of 20 former panel members that wanted to continue participating in the meetings.

Today there are 6 User Panels spread out throughout Fife. Each panel has between 8 and 10 panel members. The criteria for selection are still the same as when the panels were first established: older people over 65 who are frail and have mobility problems, meaning that they make considerable use of community care services and are not able to be active in other types of elderly fora.

In general terms the panels have been set up to “enable older people who were unable to leave their homes without assistance to meet together to develop a collective voice expressing the needs and experiences of older service users” (Barnes 1998:102). In order to reach this particular goal the panels have provided the opportunity for panel members to:

- develop their confidence and self-esteem in order to allow them to express their views in relation to their experiences of growing older and of using health and social care services;
- provide information and advice on a wide range of issues relating to the daily lives and care of frail older people;
- use the outcomes of discussions in order to influence local action by means of consultations with local authority and NHS departments, and service providers.

In doing so, and regardless of the actual impact that they have had, the aims of the User Panels address some underlying care problems that have been identified at national level, in particular:

- a preoccupation with a democratic deficit in the governance of public services;
- the need to involve users in the planning and delivery of services (Barnes 1998).
- a need for community health and social services to work with increasingly older people due to overall population ageing (John Glasby 2007:39). Namely, existing structures have rarely allowed frail elderly people to be able to speak out about services or about their overall needs.
- A need to improve quality and ensure responsiveness and accountability on the side of public services. Improve service design, delivery and cost effectiveness by shaping services to meet local and user needs.
- A need to improve public information structures.

Historic-analytical description and evaluation of the change

In the UK, the 1980s and beginning of the 1990s witnessed a policy shift from producer to consumer led interests in social services (Barnes 1999). This shift was materialized by the 1990 NHS and Community Care Act which required, among other things, the increased consultation of social care authorities with users, carers and voluntary organisations. User-led participation was seen as a means to ensure responsiveness and accountability on the side of public services. As Glasby (2007:129) explains, this contrasts largely with the situation forty years ago, where “most people did exactly what [their] doctor told them” to do. The policy shift was accompanied with a shift in attitudes, leading to increased expectations of patients and the public to be able to have a greater say in the provision of social care. As Barnes (1999:75) writes, “by the early 1990s user involvement had developed from something encouraged by the more innovative social services authorities to a statutory requirement”.

Listening to both users' and carers' views was one of the pillars of the NHS and Community Care Act of 1990. At the time, several vulnerable groups had started to organise themselves throughout Scotland in order to express their views (namely disabled and mentally ill people). Despite the fact that they represented the largest fraction of community and NHS service users, there was one particular group that continued to remain silent: frail elderly people. Shortly after the creation of the User Panels, the Age Concern Scotland team of workers involved in the project still noted that they were "taken aback at the degree of scepticism of some service providers as to the ability of older people, particularly these very old frail people we sought, to articulate their thoughts on the issues around their care."³⁸ It should be mentioned that today still, there are very few examples in Scotland of house-bound frail elderly people's involvement in the consultative process. This is not only due to the health and reduced mobility implications of their frailty, but also because opportunities to take part are rarely designed with house-bound people in mind.

Against this backdrop, Age Concern Scotland (ACS) initiated the Fife User Panels. The origins of Age Concern Scotland date as far back as the 1940s³⁹. According to the Fife deputy officer for Age Concern Scotland, the User Panels was very much the offspring of the work of the then Assistant Director for Training and Development at Age Concern Scotland. Averil Osborn (1944-1994) who died a sudden death at 50 now has a memorial fund in her name awarded by the British Society of Gerontology. In memory of her work with older people - including the Fife User Panels - the Averil Osborn fund is granted to "projects in which older people lead or directly participate" or "those following an agenda agreed with older people."⁴⁰ *Working with Older People* (J. Cormie and Lorna Warren, Bristol: The Policy Press, 2001), a publication meant to share Fife User Panels actors and members' good practices and experience was actually partly sponsored by this fund. A report to Charity Projects (1992-1995) by Age Concern Scotland is even dedicated to Averil Osborn "from whom came the concept of the Fife User Panels Project"⁴¹.

According to one of her former colleagues, Averil Osborn was indeed very much concerned about whether the Community Care Act would actually mean that older people would be involved in designing and planning home care services:

« In 1991-92 the government set up a scheme called Community Care. The idea was that people would stay at home. My colleague [Averil Osborn] was concerned about [...] who would determine what services would be put in for people [...] Her idea was « let's devise a way in which we can find out how the users of the services can actually determine what they're looking for. [...] When the Community care act came into being, people with disabilities got together, [...] they were quite good at having a voice [...] but she realised that the very old were the one group that did not have a voice.»

³⁸ *New Ways of Working. Age Concern Scotland's First Report to Charity Projects, October 1992-September 1993*, p. 7.

³⁹ *New Ways of Working. Age Concern Scotland's First Report to Charity Projects, October 1992-September 1993*, p. 7.

⁴⁰ <http://www.britishgerontology.org/about-bsg/averil-osborn.html>

⁴¹ Age Concern Scotland, *Voices of Experience. Reports to Charity Projects 1992-1995*.

Age Concern Scotland made it quite clear in their comments on the Community Care Plan 1992-1995 that though ‘the commitment to enabling elderly people to stay within their own homes and their own communities is to be applauded’, they strongly regretted that “very little attempt [had] been made to involve older people themselves in the discussions both prior to the first draft and as part of the current consultation process.”⁴² The User Panels were a way to answer these failings and to foster active participation of frail older people. As Averil Osborn knew and trusted the Fife deputy officer for Age Concern Scotland at the time, she thus turned to her to work on the project.

A proposal was submitted by an Advisory Group to Charity Projects (now known as Comic Relief), a fund raising charity, in order to set-up small groups of frail elderly people throughout Fife. Age Concern Scotland initially received around £125,000 from Charity Projects to cover all aspects of the work on User Panels (publishing, hiring a consultant, setting up and holding the meetings proper). The ethos behind the creation of the User Panels was made quite clear in a quotation chosen as an epigraph to one of Age Concern Scotland’s reports to Charity Projects 1992-1995: “Dignity. To give people help, while denying them a significant part in the action, contributes nothing to the development of the individual. In the deepest sense, it is not giving but taking – taking their dignity. Denial of the opportunity for participation is the denial of human dignity and democracy. It will not work”⁴³. With funding secured for three years, the setting-up process of the Fife User Panels began in October 1992. In order to truly take into account the views of the targeted group, there were three older people on the Advisory Group in charge of the project. They were the ones asking for monthly meeting rather than the initial proposition that consisting in holding a forum once every 6 weeks, for regularity’s sake. According to one member of the Advisory Group, they were also very useful in questioning and criticising the official terminology. One Age Concern Scotland former deputy officer explained during an interview how one of them refused to use the term “referral” as she thought it made it sound as if they were being done a favour.

That same deputy officer also staunchly refused to consider the User Panels as “focus groups”, as she deemed the notion and concept alien to what they were then trying to set up:

Do you have these things in France called “focus groups”? Well I think they’re dreadful things if you try to find out anything. Because you’ll say to somebody “we’re going to talk today about...”, you know it’s like that. To go back to the home health business, now I didn’t ask them what they thought about home helps, I always came up with a topic obliquely, so we’d sit and chat and I would say “how do you manage in the house”, and then they’d just come up with “oh you know, I can’t do this and I can’t do that and my home help says she’s not allowed to...” and you built up this picture and then you would share things with each other [...]. They were really into what they were discussing but they weren’t talking about “The Home Help”, they were talking about managing at home, how you manage at home when you’re supported, what

⁴² Age Concern Scotland, “Fife Regional Council / Social Work Department Community Care Plan 1992-1995. Comments”, *Occasional Papers on Development*, 1995, p. 1.

⁴³ “Rules of Radicals”, Saul D. Alinsky, 1971.

more support would you like and that was the way and then I would write it all up and then send it to the relevant department in either Health or Social Work.”

Once the panels had started operating, an independently funded evaluation of the initial three-year period was undertaken by Barnes (1997), who has also dedicated a series of subsequent research pieces to the panels. Her work provides us with a detailed account of the working methods of the panels and their nature during the initial three-year period. It is particularly insightful with regards to their functioning and impact at both personal and service provider level throughout the covered period. Through a series of semi-structured interviews with panel members, project workers and key stakeholders in social work and health, as well as the “tracking” of key issues which emerged during discussions, the evaluation sought mainly to understand whether panel members could influence service provision and whether members could benefit from the panels (Barnes 1998:105).

Results from the evaluation concluded that “the work of the User Panels was well received by local social work and health authorities and influenced local action in some areas” (Barnes 1998:102). From early on, the main issues that emerged were related to home care services, hospital discharge and complaints and information procedures. Most local health and social work interviewees put forward the innovative nature of the panels and their added value in seeking the views of older people. However, the evaluation revealed that individual responses to the panels depended largely on five factors:

- 1) The nature of the issue: there were some issues that were easier to respond to than others. “It was the issue of home care which generated most negative responses to the panels” (Barnes 1998:108).
- 2) Timeliness of needs of service agencies: for example, hospital discharge at the time was a salient issue for local authority and thus the contribution of panel members was well received.
- 3) The way issues were introduced and presented: in some cases the credibility of issues was reduced because of the uncertainty as to how issues presented by the panels were generated. Inadequate communication with social department was also at stake here. Officials were sometimes defensive as they perceive the panels suggestions as negative and hostile.
- 4) Personal and interpersonal factors: responses to panels were also dependent upon individuals’ openness to change. Individual responses were sometimes influenced by how much an organisation valued and supported a learning culture.
- 5) Perception of the role, composition and purpose of the panels: although publicised, some respondents were unclear about how panels worked. Respondents had doubts whether the panels were representative or not, which had an impact on the credibility of the views expressed.

At the level of panel members themselves, panel members agreed that they obtained information on services and learned how others dealt with their problems and about the expectations of others *vis-à-vis* services. Panels also enhanced members’ self-esteem and their belief in their capacity to influence change. Third and last, panels prove an efficient way of developing social contact and sharing experiences, particularly in the case of people at increasing risk of social isolation.

In the first years of the panels' existence, the meetings agenda was set by older people themselves. This was one of the main aims identified for the User Panels by Age Concern Scotland. They would also always receive a write-up of what had been discussed and said at meetings to be approved of by them during the meeting to follow. Consequently, Panel members would focus on their common experiences, lifestyles, expectations. As time went on, some key issues emerged during discussions. The first big issue to emerge was domiciliary care. Views on this issue were written up and presented to the head of the relevant department. Panel members then invited rather senior staff responsible for home care to participate in a panel meeting in order to pursue matters further. In addition, panel members were approached by a member of Fife Healthcare NHS Trust, when the project was at its starting out stage. They were asked to collaborate on a questionnaire destined to understand older people's knowledge of voluntary community services. Asked about what they thought of the questionnaire, the panel members answered they were dissatisfied with most of the questions and the way the issues were put forward. As a result, Fife Healthcare NHS Trust rethought the whole questionnaire. After redesigning it, Fife Healthcare NHS Trust sent it out to 1,000 older people aged 70+ living in Fife and got a 70% response rate. The changes suggested by the panel members included changing the front cover photograph which the members did not deem acceptable, redesigning the layout of boxes to tick for clarity's sake, explaining what would be done with the information so as to get answer to some potentially intrusive questions and even taking out some words (such as "routine").

The Panels were also attracting increasing curiosity and interest from other parts of the UK, and project workers were asked to come and speak about their experience across the country. As a result, they started publishing a newsletter that went out to universities, social work or health departments and anyone that showed an interest in the project.

Despite the panel's growing success, Age Concern decided to stop funding them. The reason one former Deputy Officer for Age Concern Scotland gave is that the new director of the voluntary organisation "found [project workers] all rather daunting people, because [...] to do the job you have to be able to address issues, you have to be able to challenge people". For a while they kept on funding one panel: "there was Only one left up in Tayside Dundee but that's because he [the person in charge of the panel] was a councillor as well [...] so he stayed on". They thus kept it going for a short time before ceasing all forms of funding for panels: "according to them it became too expensive, but according to everybody else they didn't want us to carry on". That same Deputy Officer explained that it was also due to a wider change within Age Concern Scotland, whose aims and values changes so that it was "no longer a proactive organisation as it used to be".

Since 2009, the Panels have been under the responsibility of the Fife Elderly Forum Executive, which has been running since 1990 and is the umbrella organisation for all elderly forums in Fife. Due to the merger of Age Concern and Help the Aged at the UK level and the constitution of New Age Scotland, Age Concern Scotland stopped operating in Fife in April 2009. Today, the Panels continue to be funded by Fife Council and NHS Fife. The eligibility criterion for panel members continues to be the same: older people with reduced mobility and a user of health or social care service. "Various local authority and NHS departments contact the User Panels as they have a responsibility to consult with representative groups as part of

assessing the impact their proposed changes to delivery may have. [...] Fife Council provides details of all of its consultation on the Council website: [the Panel facilitator provides] Panel members with this information and they can either participate as individuals or as part of a group response (regardless of whether or not [they] have been contacted directly by a particular service). [...] Panel members also participate in Scottish Government consultation exercises: information is sent to [the panel facilitator] in the form of e-mail alerts and members discuss and complete the questionnaires at the meeting before [the panel facilitator sends] off the collated response as appropriate” (email to facilitator, Aug. 29, 2011).

The introduction of the User Panels regards mostly the dimension of participation. If we were to link the User Panels to a model of participation of elderly in social services and research they would now mainly correspond to a consumerist approach, in the sense that at least from the part of Fife Council and NHS Fife (as was revealed by interviews) the User Panels and user participation in general are seen as means to enhance efficiency and reduce costs. Listening to the User Panels and users in general is seen as a means to an end: the end being making services more responsive to older people so that resources are well allocated and that money is not badly spent in particular in a financial climate dominated by austerity measures. In a way, this is not very different to what one voluntary organisation manager described as some councils’ reasoning behind the recent drive towards “self-directed support”:

“There is the big mental health hospital in Stratheden just outside Cupar they are discharging all their patients in the next 2 or 3 years, and they will all be coming out with self-directed support packages [...]. Self-directed support is something we do in other areas in Glasgow for instance, all the individuals on the Glasgow Council who’ve got learning disabilities now have self-directed support, unfortunately that wasn’t meant for the benefit of the individual, it was done because it was seen as being cheaper, and actually you know the ethos of self-directed support is wonderful, it’s about having control of your life and how you want to spend that money but unfortunately some councils are taking it as “then we can just give you less money”, which is a real shame because we are going to lose sight of what it’s really really about”

The focus in Fife is on welfare needs and not participatory rights. With the Free Personal Care demands for services exploded in Scotland and in Fife and there was also an important increase in spending. For all the interviewees financing and budget were deemed as the main issue affecting home based care for the elderly. The debate is how to reduce costs while maintaining a high level of quality. The User Panels and user participation in general are seen as means to do that. When looking at the degrees or levels of participation, it should be noted that the Fife User Panels are mostly partial, in the sense that although they might influence service planning, the final power rests with the Social Work department and NHS Fife. Both these agencies are the ones that decide to what extent the User Panels’ views and input will be taken into account. In relation to the scale of participation, the User Panels have been mostly used for consultation purposes. The User Panels are mainly involved in strategic planning for service provision and development.

In the early years of the panels, as Barnes’s research shows, there was reluctance to see the panels as being representative and they had to win their credibility. And still today, when asked for obstacles to listening to users’ views, one health professional replied:

“I think that that is the big one, it is that we genuinely believe, that professionals genuinely believe that often they do know better” (S-F-NA-02)

However, it should be mentioned that if we compare the content of the interviews today to what Barnes found in the first three years of the panels, there seems to be a difference in particular in the way interviewees view the panels. They welcome them as a positive source in service planning, so there does seem to have been a culture change in the way the User Panels are viewed and their utility. This in turn goes hand in hand with the decision to fund them that furthered their legitimacy:

“But we were also funding so I think each organisation was aware that we were investing so we were encouraged to use them, so I think the fact we were investing also gave them legitimacy” (S-F-NA-02)

The driving forces behind the development of participation approaches in social cares were both the legal and policy mandates for social services (with the 1990 NHS and Community Care Act paving the way for such changes) and user mandates (panel members themselves decided they wanted to invite key actors in social and health services to participate in their meetings in order to influence service planning and delivery).

Analysing and explaining the process of change

Facilitating factors for the change

Regarding the setting-up of the initial project by Age Concern Scotland, the 1990 NHS and Community Care Act provided a legal window of opportunity allowing the project to emerge. There was a shift in conceptions of care from producer- to consumer-led services at the national level, that added up to Fife’s own innovative culture and reputation for being progressive, as the early implementation of Free Personal Care had show. In addition, there was an incentive structure, in the sense that once the Panels had acquired sufficient credibility and that local health and Social Work authorities had been in incremental contact with the Panels, Fife Council and NHS Fife decided to fund the Panels once the funding from charity had run out in 1995. In 2007, using the User Panels as an effective means of engaging with older people was included in the action point of the older people’s strategy, thus officially recognising the importance of the Panels.

The Panels were also hailed as good practice by the *Scoping Study of Older People in Rural Scotland*, a study commissioned by the Scottish Executive's Environment and Rural Affairs Department in February 2002: “Recent reviews of NHS services and the delivery of community care have highlighted the need to involve older people in the decision making process (for example, the reports Better Government for Older People, Scottish Executive, 2001c and Adding Life to Years, Scottish Executive, 2002). A recent review of initiatives to involve older people in community care planning found few examples of the involvement of frail older people as opposed to active older people who were participants in pensioner's action groups and elderly forums (Thornton and Tozer, 1994). An innovative project, initiated

by Age Concern Scotland, has encouraged the involvement of frail older people in the decision making process. Age Concern Scotland Fife User Panels were intended to " enable older people who were unable to leave their homes without assistance to meet together to develop a collective voice expressing the needs and experiences of older service users" (Barnes and Bennett, 1998, p102). [...] There is a need to ensure that services for older people strike a balance between what professionals think older people should receive, and what older people themselves think that they need to help them remain independent (see, for example, Tanner, 2001) and the User Panels are one means of achieving such a balance."⁴⁴

Regarding the passing of the User Panels onto the Fife elderly forum, locally shared visions between different actors (in particular with Fife Council and NHS Fife) of the need to consult with older people and the representativeness and usefulness of older people allowed to continue with the groups. Funding was assured by the two organisations and a contract was drawn up with Fife elderly forum. At Scottish level and within the Free Personal Care Scheme, "client consultation is a central element of Scottish policy on service improvement"⁴⁵ in order to improve quality of services and service planning. Actors that had previously been social workers when they worked with the panels became heads and high managers at a later stage and thus knew the work and usefulness of the User Panels.

Hindering factors for the change

In the beginning it was difficult for the Panels to be taken seriously by health and Social Work officials, in particular due to the fact that they were not considered as being representative (Barnes 1997, 1998). User Panels (the development officer in particular) had to build a reputation before being taken seriously. She had to build trust and establish communication with network actors (in particular Social Work and the NHS). Network actors also had to get acquainted with the panels and their way of working. For example, over the course of an interview, one User Panel facilitator how she would ask actors coming to the Panels to not address the members condescendingly and to not use too much jargon so that they could actually exchange with the Panel.

Regarding the passing of the User Panels onto the Fife Elderly Forum, they had to restart from scratch with no information as to what Age Concern had previously done. As a result of the transition, many health and social work officials thought that the Panels were no longer operating. The coordinator of the User Panels had to inform network actors (Fife Council and NHS Fife) that the panels were being re-launched and that they would continue with their work.

⁴⁴ <http://www.scotland.gov.uk/Publications/2003/03/16899/21094>

⁴⁵ <http://www.scotland.gov.uk/Publications/2006/06/29093046/11>

As of today, it is still difficult to see the impact the Panels may have on policies and service planning and delivery provided that it is rather too early to tell, as was pointed out by the coordinator of panels. In addition, there is no real evaluation of the Panel's work being undertaken at the moment (S-F-NA-04).

Lunch in community for frail and isolated elderly **The project “Around the table” in Geneva**

INTRODUCTION

The city of Geneva is the capital of the canton of Geneva. It is one –the biggest - of its 45 municipalities. In Switzerland, this canton is a pionnier regarding the centralisation and the development of home based long term care for the elderly. Indeed, the canton of Geneva adopted its own legislation on home based care as soon as in 1992, while national shift can be traced back to 1995. Compared to the other cantons, the spitex organisation of Geneva is characterized by its early centralization, at cantonal level. Generally speaking, the health policy of the canton has been considered as an exemple that could inform reflexion at national level : the attempt to group health and social services as well as the idea to put the individual at the center of this devise are the two dimensions mentioned in this context (Achtermann, Berset 2006).

In such a strong cantonal context, how does the city of Geneva can contribute to social innovation in the specific field of long term care for the elderly ? Wich dimensions of the local innovations can be considered as meaningfull regarding both the cantonal and the federal level ? And, lastly, what are the factors that favor or impede innovative changes at local level ? In this case study, we adress these questions by focusing on the development of an innovative service of HBLTC called « Around a table».¹ This project illustrates a specific pattern of innovation of the swiss system: a strong potentiel for *social innovation* at local and cantonal level (due to the vitality and diversity of social actors, public-private mix, and direct democracy) that gets reduced and crumbled during the process of institutionalisation.

« Around the table » is a new service of HBLTC that has been first implemented in the City of Geneva since 2005 and gradually spread to other communes of the canton with the aim to prevent the isolation of the frail elderly and to promote healthy alimentation. In that perspective, the project gives the opportunity for people requiring meal-on-wheel service to take their lunch outside their home (in a restaurant) and in company. The project is build as a collaboration between the social service of the City of Geneva and the cantonal spitex organisation. It is inspired by a *communitary action model*, as part of a new attributions of the

¹ « Autour d'une table ».

social service of the City which is supposed to focus on communitary action while the canton is mainly responsible for individual care.

To organise lunch in community for frail and isolated elderly, as part of the HBLTC services, appears to be innovative in the context of the national home based long term care system. Obviously, the City of Geneva could develop some innovative project as part of communitary action. The Swiss national health system is focused on individual and medicalized treatment. The concern about social participation and specific needs is relatively low². By contrast, the project « Around the table » explicitly addresses the risk of social isolation of frail elderly, as it aims to enhance *their social inclusion*. Indeed, increasing isolation is identified at both local and cantonal level as a social consequence of the development of home based care services in Geneva. Interestingly, social isolation as well as the loss of mobility is considered as a consequence of psychic or social barriers more than a consequence of physical impairment or illness.

Moreover, the development of this project from the City social service perspective questions the dimension of the *quality* of HBLTC. In Switzerland, quality measure is progressively defined through a standardised individual assessment, specifically the instrument RAI-HC. Regarding the issue of alimentation, spitex services have developed specific dietetic norms and control procedures. Indeed, the project « Around the table » contributes to reframe this issue, by assuming that lunch time is about *conviviality* more than protein or glucides and that HBLTC can be considered as a community issue more than a professional one.

Lastly, the project appears as an interesting case of multi-level governance and coordination in the field of elderly care. In line with the *territorial dimension* of community care model, the project is part of an attempt to generate sub-local spaces of health and social intervention, in which a multiplicity of actors of different levels or statuses can answer in a coordinate and adapted way to particular social problematics of the neighbourhood. This appears to be innovant as the Swiss health policy is characterized by a tangled governance between federal, cantonal and local levels. In Geneva, the relationships between the city and the canton have been a recurrent political issue for years and coordination in the network of care is a weakness of the system.

² As far as is thematised, « participation » is mainly understood at national level as the client right to choose between services or providers.

II: CONTEXTUAL INFORMATIONS: GENEVA

Whenever referring to Geneva it is important to make a distinction between the canton of Geneva and the city of Geneva. Geographically, the canton of Geneva is a French speaking western most canton of Switzerland. The canton is situated in the southwest end of Lake Léman and its borders are almost entirely surrounded by France. In the beginning of 2012, the canton counts 466'574³ inhabitants.



The canton of Geneva consists of 45 municipalities or “communes” spread over a small and rather urbanised area of approximately 282 km². Locally known as « *ville internationale* », Geneva city is the capital of the canton. With a population of 191'816⁴ in the beginning of 2012, it is the second largest city in Switzerland.

a) Local economy and labour market

According to the 2008 census, both the canton and the city of Geneva rely heavily on the tertiary sector, representing 84.8 % and 93.7 % respectively⁵. The main industries are

³ http://www.ge.ch/statistique/tel/domaines/01/01_02_1/T_01_02_1_1_2012.xls

⁴ http://www.ge.ch/statistique/tel/domaines/01/01_02_1/T_01_02_1_1_2012.xls

⁵ http://www.ge.ch/statistique/tel/publications/2012/informations_statistiques/autres_themes/is_localisation_emplois_08_2012.pdf

banking, technology, tourism and inter- and non-governmental administration. While most financial activities and international organisations are found in the city of Geneva, the canton's tertiary activities concern mostly wholesale and the retail trade sector⁶. Highly urbanised, the city of Geneva has almost no primary sector activities. As we move away from the city, there is some agricultural exploitation in the peripheral areas of the canton. However, only 0.6 % of the canton's activities are located in the primary sector and 14.6 % on the secondary sector. This trend, although slightly lower (69.6% in 2008), is also reflected in the rest of Switzerland, which has progressively shifted towards a services oriented economy⁷. It should also be mentioned that the city of Geneva accounts for 51.9% of the total number of jobs in the canton⁸. Moreover, the canton has access to an educated workforce and is home to the University of Geneva with almost 15'000 students in 2011⁹.

b) Wealth and migration

The city of Geneva has time and again been ranked among the world's most expensive cities¹⁰, but also amongst the world's cities with the best living standards¹¹ according to city rankings such as the Mercer survey. The unemployment rate in the canton (5.5%)¹² stands slightly higher than for the rest of Switzerland (3.4%). Moreover, the cantonal GDP per capita in 2005 was 62'839 CHF, which is higher when compared to Switzerland (54'031 CHF)¹³. It is interesting to point out that 12.6% of the population receive some form of social aid, while 18% of those aged over 65 are on welfare. Most of social aid beneficiaries (45%) reside in the city of Geneva¹⁴.

The canton of Geneva, and in particular the city of Geneva, boast a significant presence of international organisations, contributing to their international character and to the multicultural nature of the population. Approximately 40% of the canton's population is constituted of foreigners¹⁵. This figure is much higher than the Swiss average, which in 2010

⁶http://www.ge.ch/statistique/tel/publications/2012/informations_statistiques/autres_themes/is_localisation_emploi_08_2012.pdf

⁷ <http://www.bfs.admin.ch/bfs/portal/fr/index/themen/00/01/blank/02.html>

⁸ http://www.ge.ch/statistique/tel/publications/2012/informations_statistiques/autres_themes/is_localisation_emploi_08_2012.pdf

⁹ <http://www.unige.ch/communication/communiqués/2011/CdP110916.html>

¹⁰ http://business.blogs.cnn.com/2012/02/15/worlds-most-expensive-place-to-live/?hpt=hp_c2

¹¹ <http://www.mercer.com/press-releases/quality-of-living-report-2011>

¹² http://www.ge.ch/statistique/tel/publications/2012/informations_statistiques/marche_travail/is_marchetravail_06_2012.pdf

¹³ <http://www.bfs.admin.ch/bfs/portal/fr/index/themen/04/02/05/key/pro-kopf-einkommen.html>

¹⁴ <http://www.bfs.admin.ch/bfs/portal/fr/index/themen/13/22/press.Document.145885.pdf>

¹⁵ Own calculation : http://www.ge.ch/statistique/tel/domaines/01/01_02_1/T_01_02_1_1_2012.xls

was approximately 22.5%¹⁶. This is particularly due to the strong and steady influx of foreigners and the emigration of Swiss citizens that have been recorded in the canton since the 1980s¹⁷. The five main nationalities present in both the canton and the city are: French, Italian, Portuguese, Spanish and the UK¹⁸. In addition, cantonal statistics recorded 190 foreign nationalities in 2011¹⁹. Although the canton has traditionally been a Protestant Christian stronghold since Calvin's Reformation, immigration from Southern Europe has resulted in a higher proportion of Catholics, largely outnumbering Protestants. Regardless of this fact, the canton's official religion continues to be Protestant.

c) A right-wing canton for a left-wing city

The Swiss federal system is organised in a three political levels: federal, cantonal and municipal or communal. At the cantonal level, Geneva has its own constitution, parliament, government and tribunals. Traditionally pluralist, the cantonal government ("Conseil d'Etat") is composed of seven members elected directly by the people of Geneva for a term of four years. The 2009 elections resulted in a left-wing majority²⁰ government, a first since the 1930s. The canton's legislative power ("Grand Conseil") is composed of 100 deputies, with the 2009 elections resulting in the following composition²¹: Liberal (20%), Green Party (17%), the Geneva Citizens Movement (MCG) (17%), Socialist (15%), Radical Party (11%), Christian-Democrats (11%), and the Swiss People's Party (9%). The canton's legislative has thus a right-wing majority.

With regards to the city of Geneva, the city's legislative ("Conseil municipal") is composed of 80 members elected for a term of 4 years. The left lost its absolute majority after 24 years of rule in the 2011 municipal elections, which witnessed more specifically the rise of the MCG (right-wing)²². The results in percentage of seats were as follows²³: "Ensemble à gauche" (14.4%), Socialist (18.9%), Green Party (12.83%), Christian-Democrats (8.7 %), Liberal-Radical Party (18.7%), Swiss People's Party (9.9%), and the MCG (13.4%). The city's executive ("Conseil administratif") is composed of five councillors elected every four

¹⁶ Own calculation:

<http://www.bfs.admin.ch/bfs/portal/fr/index/themen/01/02/blank/key/bevoelkerungsstand/02.Document.141990.xls>

¹⁷ http://www.ge.ch/statistique/tel/publications/2011/informations_statistiques/autres_themes/is_population_15_2_011.pdf

¹⁸ http://www.ge.ch/statistique/tel/communes/recensement/fiches_communes/Canton/Canton.pdf

¹⁹ http://www.ge.ch/statistique/domaines/01/01_02_1/apercu.asp

²⁰ http://www.ge.ch/conseil_etat/membres.asp

²¹ <http://www.ge.ch/grandconseil/grandconseil/electiongc.asp>

²² <http://archives.tdg.ch/geneve/actu-geneve/elections-municipales-suivez-resultats-direct-2011-03-13>

²³ <http://www.ge.ch/elections/20110313/global/>

years. The mayor of the city of Geneva is elected once a year, on a rotation basis among these councillors. As with the exception of one member, all other councillors belong to left-wing parties since the last elections in 2011.

Consequently, in terms of political orientation Geneva is a city that is mostly to the left, in a canton that is mostly to the right of the political spectrum. Nevertheless, its population is rather sensitive to social issues and the political culture is rather moderated and more oriented towards centre-left than liberal right. Finally, the Swiss direct democracy is functioning at cantonal level: the population has the right of popular initiative and the right of referendum (which was adopted by the cantonal parliament). As we shall see, the development of the HBLTC system of the canton was strongly linked to the use of these popular rights.

d) Demography and ageing

As with most European countries, Switzerland and the canton of Geneva have been faced with a steadily ageing population. The proportion of 65+ year olds has progressively been increasing since the 1950s, mainly due to improvements in health conditions and medical treatments. It is expected that the coming decades will be marked by an acceleration in the aging population due to the lengthening of life expectancy and a decrease in birth rates²⁴. By the end of 2010, the share of 65+ year olds in the canton of Geneva was 15.7%, and the share of 80+ was 4.5%, with an ever increasing proportion of women as we move towards and beyond the 80+ share. The city of Geneva recorded similar results with just a slightly higher 80+ share (5.2%). In addition, since the 1960s there has been also been a considerable increase in the number of people living alone in both the canton and the city of Geneva, and the number is expected to continue to rise over the next decades (OCSTAT, 2010: 52-57)²⁵. This trend is particularly important in the case of women over 65 years old. The share of elderly migrants over 65 years old is approximately 3.8%²⁶.

e) Care needs and social care provision

According to the latest available statistics dating back to 2009²⁷, there were 4'600 people residing in the 52 care homes or “établissements medico-sociaux” (EMS) available in the canton. One third of these residents were women. The cantonal rate of institutionalisation of

²⁴ <http://www.bfs.admin.ch/bfs/portal/fr/index/themen/01/01/new.Document.151678.pdf>

²⁵ OCSTAT (2010). *Annuaire statistique du canton de Genève*. Geneva.

²⁶ http://www.ge.ch/statistique/tel/domaines/01/01_02_1/T_01_02_1_3_1_01.xls

²⁷ http://www.ge.ch/statistique/tel/publications/2011/informations_statistiques/autres_themes/is_etablissements_s_ante_30_2011.pdf

elderly persons is particularly low when compared to the national average; 14% of 80+ year olds lived in care homes, whereas the number climbed to 47% for people over 95. The rate of available beds per 1'000 inhabitants at the time was the lowest in Switzerland: 7.8 in the canton versus a Swiss average of 11.9 beds. The average age of people residing in EMSs was 83.2 for men and 87 for women. In addition, at the end of 2009, EMSs employed 4'205 people, 80% of which were women. This shows the highly gendered nature of care-giving and the high feminisation of related professions. In addition, it reflects a situation that is also found in the private sphere, where women tend to assume the greater part of care-giving activities. In 2010 women in the canton of Geneva spent an average of 7.1 hours per week on family care giving for adults, whereas men spent an average of 3.2 hours. This does not take into account the number of hours per week spent on other domestic chores²⁸. Finally, regarding hospital needs, approximately half of all hospitalised persons in 2009 were aged over 65²⁹.

According to Association Alzheimer Suisse, in 2010 there were 104'736 people over 65 living with Alzheimer's or some form of dementia³⁰ in Switzerland. The number of such people living in the canton of Geneva is 5'800, most of which are over 65. Due to the lengthening of life expectancy, the proportion of degenerating diseases linked to old age is set to increase particularly in the case of cognitive disorders and dementia (FSASD, 2010)³¹.

In relation to home based long-term care, the vast majority of beneficiaries in both Switzerland and the canton of Geneva³² are 65+. In the canton and by extension in the city of Geneva, the number of such people receiving care at home has been steadily increasing each year (OCSTAT, 2010: 315)³³. According to the Cantonal Statistical Office (OCSTAT), about 60% of the population in the canton of Geneva aged 80 and over “live independently at home and/or benefit from other forms of support (activities in day care centres, residence in housing with social support, care by close ones)”³⁴. In 2010, there were 24'020 people over 65+ receiving care at home services at cantonal level, representing approximately 74% of the total

²⁸ <http://www.bfs.admin.ch/bfs/portal/fr/index/themen/20/04/blank/key/haus-und-familienarbeit/ueberblick.Document.21746.xls>

²⁹ http://www.ge.ch/statistique/tel/publications/2011/informations_statistiques/autres_themes/is_etablissements_s_ante_30_2011.pdf

³⁰ http://www.alz.ch/f/data/data_279.pdf

³¹ FSASD (2011). *Mobiliser les énergies et les compétences au bénéfice des clients. Rapport d'activité 2010*. Carouge.

³² http://www.ge.ch/statistique/tel/publications/2011/informations_statistiques/autres_themes/is_maintien_domicile_52_2011.pdf

³³ OCSTAT (2010). *Annuaire statistique du canton de Genève*. Geneva.

³⁴ Own translation.

number of home care beneficiaries³⁵. This is almost identical to the Swiss average (75%). In addition, 65+ year olds take up in average about 82% of the total number of hours dedicated to home based care, which is also the case in the rest of Switzerland (81%)³⁶. In 2010, the canton of Geneva spent a total of 196.32 million CHF on home care services.

2. HISTORICAL DEVELOPMENT OF THE LOCAL SYSTEM OF HBLTC IN GENEVA

The isolation of the elderly - the first aim of the project “Around the table”- is a recurrent issue with profound historical roots. Indeed, both the city and the canton of Geneva have a long tradition in elderly home-based long term care. The development of the home-based care policy in this canton follows the main steps of the swiss social policy history and is characterized by the importance of subsidiarity principle (Cattacin 1995, Butschi/Cattacin 1994). Up to the 1960, elderly care is framed in the context of a *liberal welfare policy*, wich focuses on public assistance (a). In line with a first dimension of subsidiarity principle, home-based care is mainly provided by private actors, namely the family and associations and the public assistance also favors home-care. Then, from the 1960 to 1990, with the development of *welfare State*, public actors get more directly involved in the field of elderly care (b). In line with a second dimension if subsidiary, the impulsion for a cantonal implication comes from civil society: both private organizations and direct democracy will the adoption of a cantonal legislation on home-based care policy in 1992. This law initiates a new period of *welfare mix governance* (c), in wich the cantonal State as well as the City cooperates with the privates organizations in the field of home-based care for the elderly. In this period, we assist to a revitalization of subsidiarity principle, in wich the States tries to activate informel carers, while the HBLTC is cantonalized while the City tries to develop and autonomises projects of the civil society.

a) A liberal policy: family care and public assistance (before 1960)

The city of Geneva historically played an important role in elderly care, in term of both assistance and medical care. The first caring institution, the General Hospital, is created in 1535 by the independant City of Geneva, during the Protestant Reform. Its aim is to assist

³⁵ Own calculation:

<http://www.bfs.admin.ch/bfs/portal/fr/index/themen/14/22/publ.html?publicationID=4587>

³⁶ Own calculation:

<http://www.bfs.admin.ch/bfs/portal/fr/index/themen/14/22/publ.html?publicationID=4587>

poor and sick people, but soon it includes refugees, orphans, beggars, disabled and elderly. This charity institution is inspired by a protestant morality. In 1815, Geneva joins the Swiss Confederation as the 22 canton. The time of the independent City had passed out and new borders of the canton of Geneva are drawn in the Congress of Vienna and Paris³⁷. In the middle of the XIX, the radical revolution will confirm the importance of the canton in the government of the poor. The revolution of 1846 in Geneva brings James Fazy and the « radicaux » to power. With the destruction of the wall surrounding the City, or the creation of the first system of pension for lower incomes, the transformation of the General Hospital is part of the big projects of the radicals to modernize the canton of Geneva. The Hospital becomes a cantonal institution and its activities of cure and care are separated. In 1856, medical assistance is left to the *Cantonal Hospital* and in 1869, the social assistance is attributed to the *General Hospice*³⁸.

Regarding elderly care, Geneva will long differ from other parts of Europe, where the end of XVIII and the beginning of the XIX is characterized by the development of specific institutions, the asylums. In Geneva, the oldest people are specially in need for help: around 1830, only 10% of the population are assisted but almost 25% of the elderly³⁹. But the elderly in need of assistance are mainly assisted *at home*. The alternative practice is to send them in pension in families, either in the rural part of the canton or –it is less expensive –in Savoie (Nussbaum 1989). Indeed, elderly may receive punctual or seasonal help (like money, bread, clothes or rent payment) from the Hospice but they are only admitted in the Hospital in case of illness.

Two asylums are opened in 1849 and 1879. As Nussbaum explains, the debates around the creation of these asylums reveals the opposition of two conceptions about the role and the limit of the State. For the conservative-liberals on one side, family and private saving are the basement of solidarity. The assistance must be left to voluntary, Christian charity. Otherwise, assistance may generate poverty. On the other side, the radical-socialist defend a new conception of assistance. For them, the conservative vision gives bread but doesn't help people to improve their life condition. They consider that the State has a role to play in prevention and in redistribution. Obviously, the radicals, who had to design this first policy, faced an

³⁷ In order for Geneva to become adjacent to the Confederation, the new canton includes Catholic communes.

³⁸ This was confirmed by the law on social assistance of 1901

³⁹ Nussbaum (1989) calculated that in 1827, the General Hospital was concerned by 66% of cases of assistance. The same year, 22% of the assisted were 70+, which represent 22.5% of the population of 70+.

issue which has contemporary resonance : how to make compatible a liberal ideology with the development of collective services ? How to reform the system of public assistance in order to avoid that it generates poverty ?

The result is a political compromise in elderly care. To assist elderly is considered as a State moral duty, but the elderly have no specific rights. Moreover, the State has to limit the amount of the assistance, in order to preserve the obligation of the family, and to avoid laziness and lack of *prévoyance*⁴⁰. This compromise is reflected both in the hospice practice and in the characteristic of the two asylums that were finally opened. Hence, the Hospice practice is inspired both by a philosophy of relief and by the aim to improve the condition of the poor, following the maxim « *The Lords helps those who help themselves* » (Nussbaum 1989 : 51). The two *asylums* for elderly also reflect these two conceptions of care. The first one, opened in 1849⁴¹ is a quite nice institution for middle class with no trace of discipline or coercion. The opportunity to access is linked to the cotisation to a Mutual Insurance Society. Its vocation is mainly pedagogical : it is supposed to illustrate the virtue of pension scheme and to frame the « good elderly ». The second asylum is created in 1879 for the poorest elderly in «a moment of generous sentimentality ». It is not supposed to be too attractive in order not to discourage the promotion of pensioning (*prévoyance*), and the regulation is strict in order to exclude bad elements⁴².

Hence, the first elderly policy in Geneva developed by the radical party members from the middle of the XIXth century is mainly based on the family care (including the extensive pension's practice) and complemented by the General Hospice assistance. Assistance is supposed to be limited as the principle of personal responsibility – through personal saving - spread in political discourse. In line with this liberal policy, private services to help families in their care task are developed after the WWII. From 1953, new protestant associations are created in some of the *paroisse* of the city of Geneva and then, at the turn of the 1960, in the rural part of the canton⁴³. But these associations are mainly dedicated to help or substitute the mother's of popular family. The only specific service for elderly is opened by the Fondation Pro Senectute, a national Fondation created in 1920 and financed –this is not the case of the

⁴⁰ Key concepts were « *prévoyance* », « *épargne* », « *work* », « *discipline* » and... « *productive spending* ».

⁴¹ Asile des vieillards du Petit Saconnex. The first asylum in Geneva is a private initiative in 1830, but there is no more historical traces from 1835.

⁴² Asile d'Anières. The decision is considered by the one who took as «a moment of generous sentimentality » « Dans un moment de généreuse sensiblerie, nous avons fondé un Hôtel des invalides », cité dans Nussbaum, 1989 : 52, note 20.

⁴³ In 1960, 18 of the 37 *paroisses* of the canton wants to develop such service (Frommel 1996)

other associations - by the Confederation⁴⁴. In 1955 in Geneva, a small service is dedicated to the home based care of the elderly. Its aim is to help elderly to come back home after an hospital stay and to stay at home. Their intervention also differs from the other associations. They provide daily care, for a short time (one hour) but a long period (until the death usually). Interestingly, isolation of this elderly is pointed as an important problem in the foundation report, as well their lack of resources (Frommel 1996). In 1956, all the associations are federated in the Fédération des services d'aides familiales de Genève.

b) Towards a cantonal home based care policy (1960-1992)

During this period, the canton (and the City) gets more directly involved in the field of elderly care. In line with the federal policy development, elderly care is getting more specialized and more medicalized. The canton develops hospital structures, that will later favor community care for elderly and geriatric home-based centred structures. Meanwhile, the canton and the city still favor the development of home-based care. Private organisations get increasingly financed and organized. In line with subsidiarity principle, the impulsion for a strongest state implication in the field will come from civil society: private organizations ask for more cantonal subsidies and it is a popular initiative that will impulse the adoption of a new cantonal law on home-based care.

A new period of problematisation of aging in Geneva can be traced back to the 1960 (Lalive d'Épinay and al. 1983). In the beginning of the 1960, Geneva is one of the Swiss cantons with the most important part of elderly. Most of the home-based care is still provided by the family, and particularly the women. With the growing urbanisation, the Federation is confronted to a new challenge: the importance of elderly care need is growing in the city compared to the family needs. In some urban area, there are no more family living there but many offices, and the only inhabitants are elderly, who live in very old and dilapidated buildings (Frommel 1996).

In 1963, the cantonal authorities impulse a reflexion on the problems related to ageing. They are concerned by this increasing number of elderly, living in an urban environment, with a nuclear family. In this new context, *isolation* appears a risk that should be considered and "cantonal commission on the problems related to aging" is appointed by the government in 1963⁴⁵. Published in 1965 – one year *before* the first federal report on aging - the report of

⁴⁴ Pro Senectute was first created in the perspective of the promotion of national pension insurance, that was adopted in 1947.

this cantonal Commission lays the foundations of the Geneva elderly care system. Three types of structures are developed at that time.

First, in line with the federal policy, the development of *private homes for elderly* is encouraged by the Confederation and in some cases financed through the federal subsidies for the building or renovation of homes, while these homes can also receive subsidies from the canton or the City. The cantonal control is increasing during this period and, from 1977, opening a home for elderly will require a cantonal authorisation and a specific gerontological formation.

Second, the *hospital structures* are developed by the canton and contribute to the specialisation and medicalization of elderly care from the 1970. Following the recommendation of the cantonal commission, the first geriatric hospital in Switzerland is created in Geneva in 1971. This pilot experience completed the treatment for elderly provided both in the Cantonal hospital and in the Psychiatric hospital. Hospital structures are opened to home-based care. In this period, the Day Care Hospitals are also created in the two institutions.

Lastly, the home-based care field development continues during this period. The private structures focus on elderly and get organised. In 1964 is created the first association specifically dedicated to the home-based care of elderly and disabled, called AMAF (Association Aide ménagère au foyer). It is addressed to the inhabitants of the canton and partly financed by the State. The second most important organization at that time is the cantonal section of the Red Cross, the SASCOM. Third, the SGAF (service genevois d'aide familiale) is created in 1979 and include many organisations, including the services of Pro Senectute. They focus on elderly and disabled.

The cantonal commission encourages *home based long term care*, and more particularly the creation of the Geriatric center in 1966 (it was first called "center for information and coordination for elderly"). This center offers ambulatory medical consultation as well as consultation at home. It will be at the heart of the development, in the 1990, of the community model. Some home-based care services are also provided during the 1960 through the Hospice General. From 1963 for example, the hospice develops social activities for the elderly in order to improve their life quality and to help them to stay at home (Seiz 1985). It also develops a service of meal-on-wheels in 1965 and will develop later the *telecontact service* (security alarm at home).

Apart from the Hospice, the first day care structures (foyers de jour) are opened (the first in 1969) and the first *immeubles à encadrement social* and *medico-social* are built (1963

and 1967). This last kind of intermediate structure will develop strongly in the 1980 (Cavalli 2008). Meanwhile, the *City social service* also get involved in home-based care. A small service of family care created by the Hospice is then taken under the auspice of City of Geneva. But the City of Geneva will also created its own service of home care (*aide ménagère*) dedicated to elderly that are taken in charge by the city and the social service of the city provides a laundry service.

In 1984, a popular initiative for a “real home-based care policy” is launched by progressists. In only one week end, 15'000 people sign in favor of such a new cantonal policy. The objectif is the development by the cantonal state of social and medical services, in the context of a general health policy and with the aim to help people to stay at home if they want to and to reduce hospital stays. The project includes elderly, but also sick people, disabled, and family in temporary troubles. More precisely, the issue is to include new principles of social policy in the legislation, but also –and mainly - to guarantee the financing of home-based long term care⁴⁶. The principle are not contested, but the financing part is highly disputed and restricted⁴⁷. Significantly, it is during this period between 1985 and 1991 that the financial situation of the canton of Geneva is completely reversed. After a time of benefit during the 1980, the cantonal deficit appears from 1989 as an important problem⁴⁸.

Nevertheless, the cantonal Parliement adopted a legislation on home-based care in 1991 (LADom K1 05). The law confirms the the State will provide annual subsidies to the private organisations but without precisions regarding the amount. The financement is grounded on a 4 year credit program and completed by an increase of taxation (“centime additionnel”). Right parties opposed the legislation (liberal, radicals and employers) for financial reasons but the population accepted it by 60% in february 1992. This popular legitimacy is an important dimension of the Geneva’s home-based care policy.

c) *Strucuration and rationalisation of a cantonal HBLTC network (1993-2012)*

From 1995, the new objectif of federal elderly policy is to reduce the number of institutionalised beds (hospital and nursing homes) and to promote home-based care. This swiss « ambulatory turn» follows the european movement of desinstitutionalisation started in the field of psychiatry in Italy in the 1960. In Geneva, the construction of nursing homes is

⁴⁶ 6 parlementary motions had been deposed between 1981 and 1984 in the same purpose.

⁴⁷ Extrait de l'arrêt de la Ire Cour de droit public du 7 juin 1989 dans la cause Comité d'initiative "soins à domicile", S., G. et T. contre Grand Conseil du canton de Genève (recours de droit public) <http://www.servat.unibe.ch/dfr/bge/a1115148.html>

⁴⁸ « Faut-il mettre Genève sous tutelle ? » *L'Hebdo*, 25 juin 1992

suspended for 8 years while the number of hospitals' bed drops significantly⁴⁹. Meanwhile, the structuration of HBLTC is characterized by a first period of organization of the private network by the canton, backed up by the development of a community care concept in the hospital. From the 2000, the priority is the coordination and rationalisation of the network.

The ambulatory turn : the structuration of a cantonal home-based care network

In 1992, Geneva appears as a pionnier in Switzerland regarding both the development of HBLTC services and the cantonalisation of the field. The law of 1992 defined and organised HBLTC in the canton. The article 1. states that both the canton and the communes encourage the development of home-based care in the context of a general health policy. Home-based care addresses all the people needing care, control or temporary help because of their physical or mental health situation. It includes: every treatment prescribed by a doctor, the nursing care, the body care (soins corporels); the *tâches ménagères* and actions of health information, prevention and education.

During the 1990, the home-based care policy of the canton of Geneva follows an experimental logic (Cavalli 2002). For a first legislative period (1993-1996), the development of home-based care as well as the moratoire on the nursing home are decided as an experimental measure (4 years credit). Then, the second program (1997-2000) confirms the options of 1993 and extend the moratoire. Nevertheless, this cantonal policy is characterized by a limited centralization: first, private actors are the one who provide services and second, this services provision is decentralised and organised on a territorial principle.

First, the canton relies on the private sector for the provision of services and push for a fusion of the organisations into one single unit in which the different professions of care will be included. Hence, as a result of successive fusions, the FSASD (Fédération des services d'aide et de soin à domicile) is created in 1999, when the FSASD absorbs the three main structures active in the field. First, the SASCOM (Service d'aide et de soin communautaire, Red Cross) which employs nurses, aides extra-hospitalières, ergothérapeutes, physiothérapeutes and pedicure (Cavalli 2002); second, the AGAD, created in 1994 by the fusion of the SAF (for needing family) and the AMAF (more focused on elderly). The AGAD supervises the activities of 200 *aides familiales* and 600 *aides ménagères* (Frommel 1996). Third, it includes the APADO (Association pour l'aide à domicile) created in 1993. This private organisation includes the ex Hospice services of tele-alarm and meal-on-wheel –that were privatised- and

⁴⁹ From 3000 to 2000 during the 1990 (Rapin and al 2004).

coordinates the activity of the social direction of the “immeubles à encadrement sociaux” for elderly.

Second, the centralisation of politics goes hand in hand with a confirmation of the proximity principle regarding elderly care. In 1997, the organisation of HBLTC is *decentralised* into 22 sectors of the canton, called CASS (Centre d’action sociale et de santé)⁵⁰. Among the 22, 9 CAAS are situated in the City of Geneva. The idea is to favour proximity intervention by covering the territory of the canton but also to provide a more integrated care by the physical regroupement of the different services of health and social care in the CAAS building. Hence, three types of actors share the CAAS building. First, the General Hospice, which is dedicated to social assistance. Second, the FSASD (Fondation des services d’aide et de soins à domicile) for HBLTC. Lastly, the social service of the municipalities.

At that time, the *social service of the City of Geneva* is quite involved in elderly care. Nurses, social workers and animators are dedicated to the ageing population of the area. As a social worker follows the individual cases, they work differently from the cantonal Hospice. First, they take care of the non-financial issues (like family problems, isolation, counselling) and second, they offer a punctual help. Hence, both the proximity and the flexibility of their structure allows for a flexible and personalised care. Moreover, the social service develops a specific program for people with mobility problems (elderly and disabled), called “accompanied animations”⁵¹. They also organised lunch in the neighbourhood (GE-4).

This first policy development, as well as the historical vivacity of private organizations in domestic economy impact the development of home based care services in Geneva. In 2002, the canton of Geneva is classified in the group that provides the most developed services of HBLTC in Switzerland, together with Vaud, Jura and Basel. This means that in these three cantons, both the number of clients and the number of hours are situated above the national average (Höpflinger/Hugentobler 2005). By contrast to its neighbour, the canton of Vaud, the services provided in Geneva are characterized by the importance of the domestic economy compared to medical care (Ruedin and al. 2006). This ambulatory turn is backed up at that time by the development of a community care model in the cantonal hospital - a concept that is progressively implemented in the geriatric sector.

The community turn : the hospital experience

⁵⁰ The law of 1992 is modified.

⁵¹ « Animations accompagnées »

The HUG (Universitary Hospitals of Geneva) are a public institution. They have been formally constituted in 1995 as a result of a general reform of the sector. Hence, their missions are threefold: treatment; teaching and research. From the 1990, the Geneva hospital structures start to implement the concept of « community care for the elderly ». This « community turn » is characterized by the development of « équipes mobiles » and of new kind of beds (reliefs), in order to increase the intervention capacity in the community. Moreover, some health promotion program are developed in cooperation with the association of elderly and with the whole network of community care. Following Rapin and al. (2004), the concept of Community care for Elderly⁵² developed in the Geneva' cantonal hospital is constituted by the articulation of four dimensions that should not be separated :

1. home-based care services
2. hospital beds for short stays (relief, observation and cure)
3. day care activities (social and therapeutic activities provided by a care team)
4. collaboration with other organizations concerned by elderly care and welfare

The development and implementation of this concept in Geneva is incremental. The first step was the creation of the Geriatric center at the end of the 1960. It is followed in the 1990 by the opening of different units of the Polyclinic of Geriatrics in different parts of the canton, including day care hospitals. The community care service, that used to be attached to the geriatric department, is included in 2003 in the Department of community medicine (médecine communautaire). The aim is to develop proximity care and home intervention and to enforce the Health network for community care for elderly. From 2004, the new types of beds (for crisis management) will be opened in the Polyclinic of Geriatrics.

The community care approach is grounded in an explicit ideology. For its promoters – Prof. Charles-Henri Rapin was one of the leaders of this approach in Geneva and in the Swiss French speaking area⁵³ - the application of this concept had to be understood in the context of the promotion of a society that will be sensitive to *equity, quality of life, care* and « *cost* » of *suffering*. As the authors wrote in their book of 2004, to implement such a four pillar concept is costly; and this cost is more difficult to calculate than a classical economist way, in which « after 65, the most economic patient is a dead patient ».⁵⁴

⁵² SCPA : Soins Communautaires pour les personnes âgées

⁵³ Prof. Rapin died in 2008.

⁵⁴ Rapin and al. 2004 : 7, our translation.

Three important programs of community action in elderly care have been developed in Geneva. First, a program was oriented towards the *quality of life* that started in 1994. It was called « years to savour ». In this context, the issue of alimentation, nutrition and hydration were raised up as well as alcoholism. Moreover, this program problematized the isolation of the elderly and promoted autonomy, mobility and social care. Second, a program dedicated to the *citizenship of the elderly* was launched the same year. Its aim was to support the rights of elderly and the development of the anticipated directives system (directives anticipées). Third, in 1999 started an important program focusing on the *reduction of the pain* in elderly care. This was dedicated to prevention and care in the case of chronic pain, promotion of palliative care and accompanied end of life. These programs were supposed to give philosophical orientation of the Community action service, as well as to orient its activities (research, teaching, development). (Rapin and al. 2004 : 260).

From 2002: the rationalization of HBLTC and revitalization of subsidiarity

Since 1985, the issue of the governance and the coordination of the HBLTC network has been very salient in Geneva. The focus of reforms was the repartition of tasks and roles between the different types of actors, as well as the concrete cooperation in the field. During this period the clarification of the task and responsibilities between the city and the canton is an important issue in the field of home-based care. The first object is the division of task and the cooperation in the context of the new CASS. The second is to clarify the financing of the private networks between the City of Geneva and the canton.

Let's start with *the redistribution of tasks and the attempt to improve coordination*. Up to 2006, the CASS is at the heart of the system of HBLTC. It has been the object of successive legislations, in 1992, in 1996 and in 2001. In 2001, a new direction of CASS is created in the Department of Health and Social action. For the City of Geneva, the reform of 2001⁵⁵ represents a turning point. The main objectives of the law are to organize both social work and HBLTC by sector and to clarify the division of task between the municipalities and the canton and between public and private services. Hence, home-based care is attributed to the FSASD ; individual social action is attributed to the General Hospice and proximity community social action is attributed to the municipalities. It was also decided that the municipalities had to provide the premises (locaux).

⁵⁵ Law K 107 on the center of social and health action.

The law had important implication for the socialservice of the City. At that time, the city of Geneva is already involved quite strongly in elderly care through its social service. First, for thirty years, there is a sector of the social service dedicated to elderly. It is concerned by the animation of the “clubs des aînés”. Women, animatrices, are in charge of this tasks. Moreover, there is a sensibility for the issue of isolation. This is concretized by a sector called “acompanied animation”. The idea is to help people with autonomy/mobility problems to participate to different activity. Lastly, the City of Geneva is proud to provide means-tested subsidies to elderly of the City (in addition to the one provided by the canton and the condeferation) –a competence that will be contested by the canton. With the new law of 2001, the social services of the City of Geneva actually gives up individual social help and focuses on communitary action. As we shall see, this important shif in the profession skills and official mission of municipal social workers will provide a strong impulsion for the the development of the innovative project « Around the table ». The elderly sector of the social service is included in the new communitary action program (GE-5).

Nevertheless, the results of this reform are not the one expected. In their evaluation report, Horper-Papapzian and al. (2004) observe importants problems. First, the competence division is still not clear and this situation generates tensions or even conflicts between the actors of the fied, specially actros from the Hospice and from the municipal social services. The FSASD is not involved in the controversies, partly because their employees are still focused on the quite recent fusion process and because the main problem for the FSASD is the lack of ressources.

Second the cooperation is not improved. They are too many places for coordination and the coordination is weak. Moreover, into the CAAS, the only cooperation observed is about premises issues. If everebody agree on the importance of strengthening cooperation between health and social work, concretly, professional network is largest and not focused on the CAAS partners. The law was also supposed to improve the local cooperation between the municipal social services and the CAAS units. This is not the case, except for the city of Geneva, where the municipal authority are involved in comun projects. Hence, the division bewteen individual social action and communitary action generated confusion and even contestations. How to get involved in proximity action without any knowledge of individual problematics ? Moreover, some municipalities refuses to give up their traditional task. In this context, the City of Geneva is the only one to take the division seriously and shifted completely its way of providing services, including for the elderly.

As a conclusion, the evaluation reports gives a quite negative feedback on this reform, wich is said to lack of vision and leaves the different CAAS with own interpretation of their missions. The objective to assure a proximity service is well deserved by the decentralisation and the 22 CAAS, *but* obviously, it is not sufficient. As the report states :

« If the objective is defined as « to reach the population needs, to define and implement prevention projects and to adapt to the emergence of new needs », then professionals of the field consider this objectif as only partially reached, because of a lack of ressources and a lack of common vision »⁵⁶

Apart from this reorganisation, a new law is adopted in 2005 in order to clarify the *repartition of the financing of the private actors between the City of Geneva and the canton*. This project is elaborated by both the cantonal department of social action and health (DASS), the City of Geneva (specially the social work department). The objective is to clarify and homogenize the financing of private network. The criteria a grounded on the same difference between individual social action and community action. Follows the 2001 law on the CASS, the individual social action becomes a cantonal priority, while the communitary action is a municipal priority. This instrument is recognised as a good mean to control the finance of public institution. 149 insitutions are concerned, including the one that provides services for elderly.

Nevertheless, the implementation of the law is contested a by some representant of socialist party and by associations for its by-side effects. The technocratic application of the law is denounced as many associations work both on individual and communitary base. As a consequence of the law, they explain that some private institutions loose their cantonal subsidies without getting enough from the City, that to get financed by only one public actors weaken the independence⁵⁷.

From 2005, the HBC policy is included in a general politics of rationalization framed by new principles : to « rediscover the liberty of innovation » and to « restore the trust ». Soon, the government announced his objective to restore the budget equilibrium, *without* increasing taxes and *without* reducing services provisions. This is the begining of a new public management period in Geneva (Millet/Durot 2007). The field of HBLTC is concerned as the departement of Social action and health is reorganised. There will be two departement, the Departement of economy and health, and the Departement of solidarity (social action) and

⁵⁶ Horber-Papazian and al. (2004). Résumé : IV Our translation

⁵⁷ Référence

labour (labour market). For many critics, this reform reflect a profound change in the understanding of health and social policy:

« Health is an economic issue, hence it becomes the Departement of economy and health. Labour is an issue of social assistance and disability : unemployed are, somewhere, disabled people ! Hence it becomes the the Department of solidarity and labour.» (GE-13).

Following the department restructuration, the CASS system is dismantled in 2006 by the gouvernement, even if the law stays untouched. This decision is justified by the weak number of common clients (4%) between the Hospice and the FSASD and the differences in the clients (75% of 65+ for the FSASD and 90% 65- for the hospice). (Millet/Ducrot 2007). Each of these structures is now governed by a different department. The premises – wich are municipal buildings – are distributed among the Hospice and the FSASD.

Meanwhile, the new objectif of the Department of economy and health is the reorganisation of HBLTC network. A new law is proposed in 2007 and accepted at the unanimity of the cantonal Parliement in 2008. This new law is clearly innovant. It clarifies the situation (the law of 2001 is *abrogée*) and organise and coordinate the whole network of HBLTC. Interestingly, this new law aim to preserve the « autonomy » of the dependant people and wants to answers the needs in an adapted way along the life course⁵⁸. Hence, this law confirm that the canton Geneva is developing a specific model of care compared with other canton. Gouvernement of care is comparatively more oriented towards participation and empowerment of the patients, even if the implementation reveals the lacks and the ambivalence of this model (Lucas 2011).

Moreover over, it is the first cantonal law in Switzzlerland that explicitly recognised the role of *informal carers*. The increased concern for informal carer in Geneva can be observed from 2005, in a context of budget restriction. The issue is part of the new attempt of the Health Departement to shift the burden of care, from nursing homes and hospitals towards home-based care. « Cost-containment » and « quality of care » are the main dimensions of this strategy. Id the first elderly policy developed from the 1990 was focus on two main actors (nursing homes and hbltc services), the new policy now formally include a thrid partner : informal carers.

⁵⁸ « Art. 1 But 1 La présente loi a pour but de préserver l'autonomie des personnes dont l'état de santé et/ou de dépendance exige de l'aide et/ou des soins ainsi que de répondre de manière coordonnée aux besoins de ces personnes dans leur trajectoire de vie.2 Elle entend ainsi mettre en place un réseau de soins qui favorise le maintien à domicile, encourage la participation des familles et des proches et leur apporte le soutien nécessaire ». (Loi sur le réseau de soin et le maintien à domcile K1 06, annexée).

As a consequence, the main policy instruments aims to support the informal carer in their now official role (Lucas, Giraud 2012). More precisely, the canton relies on two types of instruments : first, the canton wants to develop the services that could support informal carers (counseling, information, self help groups) but with no direct cantonal involvement (soe services are provided by the City and the associations). Second, the canton wants to develop intermediate structures, like the « foyers de jour et de nuits », « unités d'accueil temporaire » et immeuble avec encadrement pour personnes âgées. It mainly relies on the FSASD that now includes the management of « temporary stay structures. ».

3. DESCRIPTION OF THE INNOVATIVE LTC-MODEL FOR THE ELDERLY

The innovative service of home based long-term care called « Around a table »⁵⁹ is the result of a collaboration between the City of Geneva and the cantonal FSASD. The project was first implemented as a pilot project in a City borough in 2005. The experience then spreads to others area of the City and in 2011, the City of Geneva and the FSASD agreed on a convention that officialises their collaboration on this project. This new service provides the opportunity for people requiring a on-wheel-meal service to eat lunch outside their home, in a restaurant and in company of other people. The aims of this new service is twofolds. On one side, it aims to prevent the isolation of elderly receiving HBLTC and on the other side, it aims to prevent malnutrition, as both issues have been identified as crucial issues of HBLTC service delivery in Geneva.

The concept backing up the project “Around the table” is related to many discourses, values, objectives and expectations related to the implementation of a community care model. As such, it is an innovative project that questions both the national HBC care delivery system and the cantonal one, regarding quality and participation but also governance and coordination. Hence, we will first present the ongoing functioning and organisation of the project “Around the Table in Geneva” in the City of Geneva. Then, we will describe the way the project is related to these cantonal (and sometimes national) issues.

a) Care delivery and organisation of the project

The project “Around the table” is a new service provided by the FSASD in collaboration with the different UAC (Community Action Unit) of the City of Geneva or with other interested

⁵⁹ « Autour d'une table ».

municipalities. This collaboration has been formalised in a collaborative agreement signed in 2011⁶⁰. This document defines the two aims of the project.

- to favor the social relations between people of 65+ in their neighbourhood
- to promote a healthy alimentation of the elderly, in order for them to stay in good health.

The service is understood in the context of the promotion of health, social welfare and quality of life of the elderly. It is officially dedicated to every person of the neighbourhood of 65+ and in risk of isolation. Hence, even elderly that are not clients of the FSASD can benefit from this service. Indeed, they may become clients of the FSASD through this unique service.

On one side, the Social Service of the City of Geneva is the responsible service of the Municipality. It acts through its 8 community action units (UAC). On the other side, the Service of Meal and Dietetic is the competent service of the FSASD. The UAC look for a suitable and interested restaurant, find the volunteers and follow up the project at the sub-local level. They are also involved in the promotion of the project to the elderly that may be interested. Meanwhile, the FSASD checks the quality of the meal, negotiates price and is in charge of the registration of clients and of the facturation. It also promotes the project: both the *livreurs de repas* and the nurse are supposed to distribute the flyers to the elderly that may be interested or that may benefit from this service. They have to check if the elderly is sufficiently autonomous, does not suffer from too many psychic troubles or dementia and will be able to reach the restaurant on their own. This agreement is specific to the City of Geneva. In some other commune, the FSASD also promotes the project to the social services of the municipalities. They may also check the quality of food and the availability of the restaurant or even send a professional to share the lunch with the elderly.

The idea of the project is to offer a convivial moment for isolated elderly, around a table. The restaurants must fulfil some criteria regarding their localization (centrality is important), the accessibility, the meal quality and the capacity (tables, number of waiters). They get involved through an *oral contract*. The meals service is not included in the basic Health Insurance prestations in Switzerland. Nevertheless, the elderly do not pay the lunch directly in the restaurant. The lunch - be it taken in the restaurant or as a meal-on-wheels lunch - are charged by the FSASD. Included is lunch, water and bread. The invoices are then

⁶⁰ FSASD, Ville de Genève (2011). *Accord de collaboration portant sur la prestation « Autour d'une table »*.

send to the elderly. It can be reduced by cantonal subsidies, if the elderly income is above a specific level. Therefore, the price of the lunch varies from 15.80 CHF (13.20 euro) to 7.90 CHF (6.60 euros)⁶¹. The full price (15.80) is under the average price of a lunch in Geneva (wich is around 17.00 for the cheapest). The bill of the lunch of the volunteer is taken in charge by the FSASD. Definitive price is negotiated directly between the Meal and Dietetic service of the FSASD and the restaurant manager.

The service is functioning from Monday to Friday, from 12: 15 to 14:00. A partner's restaurant reserves a table and a there is an accompanying person (a volunteer) that welcomes people, share the lunch with the elderly and animates the group. The elderly have to be able to go by themselves to the restaurant as there is no service included to come with them from home. Before, they have to register to the FSASD center.

The geographical diffusion of the project in the City of Geneva is quite good. In 2011, the project is implemented in 6/8 of the UAC of the city and 8 others municipalities. There are two exceptions, namely areas of the city where the project never started or started and then stopped. The first is a popular area (Plainpalais), where the project could never be implemented. The second is a rich area (Champel). In this neighbourhood, the project was developed in 2008 and 2009 but then stopped.

If the geographical diffusion is good, the number of meals taken in the context of the project is still relatively low at cantonal level. In 2010, 5'652 lunches were provided though this new services (This represents only 1.4 % of the total number of meals that has been provided in the canton)⁶². We will discuss the point in the next sections.

Indeed, the project "Around the table" represents a new services of HBLTC, that does not impact on the other services provided by the network or by the FSASD but has implications in terms of governance, coordination and participation. For the FSASD, the main issue today is to promote the project in other municipalities of the canton, in order to cover a maximum of the cantonal territory. The 3 *dieteticiennes* of the institution (for 2,3 working posts) have taken one third of the cantonal area each. Another actual issue is to diffuse the information and reach the elderly concerned. By the way, no active strategies have been decided regarding that issue in the FSASD, except the sensibilisation of the professional team which is in direct contact with the elderly. If the extension of the project in some rural municipalities is considered as difficult sometimes, the project –at this stage of development – do not represent a real challenge in terms of management for the FSASD (GE-8; GE-11).

⁶¹ FSASD (2012). *Tarifs des prestations 2012*. Genève.

⁶² FSASD (2011). *Rapport d'activité 2010*. Genève.

b) Quality and participation: the social dimension of HBLTC

By addressing the issue of meal services, the project “Around the table” questioned the dimensions of quality and participation in HBLTC network in an innovative way. Let's start with the quality issue. Firstly, the project explicitly focused *on the isolation of frail elderly as a result* of HBLTC services development. This is not a new idea. We have seen how the preoccupation for social isolation of the elderly is a recurrent issue in the long history of the Geneva's care policy. Then, when the home-based care policy gets a strong impulsion, at the beginning of the 1990, actors of the field –at least in the social service – were soon aware of the problem. As an interviewee recall:

We immediately detected that looking after people at home, this perfect home-based care organisation, see: nurses, domestic help, meal-on-wheel, very nice indeed, but this was going to create a “ghettoisation” for people. Because once you bring everything at home, people don't get out any more. And we know that for 22 years ! And that quickly appears to be exact. (GE-4).

Indeed, the pilot project is grounded in a more general reflexion about the unintended consequences of HBLTC and about the limit of the medicalization of care. In 2003, the FSASD mandated the University in order to study the possible relationship between HBLTC and isolation. Then, a second report was mandated in order to a) study the socio-demographic profiles of the clients of the FSASD and their satisfaction or dissatisfaction regarding meal-on-wheel services and b) develop the concept of a concrete project. Indeed, the first concept of the project “Autour d'une table” was the result of such scientific expertise. In this context, the problematic of isolation related to HBLTC was clearly formulated:

“L'isolement des personnes âgées et leur confinement à domicile est aujourd'hui une préoccupation sociale, sanitaire et politique. La diminution de la mobilité risque d'augmenter jour après jour le déclin physique et psychique et par la même précipiter la dépendance des âgés. Les comportements et habitudes autour des repas pris à domicile et hors domicile sont souvent le reflet de cette capacité de *mobilité* et de *lien social*, qui en s'appauvrissant, sont causes d'hospitalisations ou d'entrée en institution. Identifier de nouvelles voies pour prévenir l'isolement et la perte d'autonomie et favoriser la socialisation de personnes dans et hors de leur domicile autour du repas a été le point de départ de ce travail” (Arzel/Struckelberger 2005: 5).

One striking result of this study was that physical barriers (like incapacity, illness, sensorial apparatus, etc) *did not* determinate mobility of the elderly. What was determinant was psychical and social barriers like depressive syndroms and weak socio-familial network (op.cit: 47). Indeed, first, an increasing isolation is identified -once again ! - at both local and cantonal level as a possible social consequence of the development of home based care services in Geneva; second, the barriers of mobility are reframed in a social – on not medical - perspective. As a consequences, HBLTC providers have to change their conception of care. This approach is not new in the canton of Geneva, and was in line with the development of ambulatory care – more particularly for elderly- that started at the end of the 1990. It was also the follow up of the 2001 law about the CASS. The ideat that time was to bring people *into the CASS* to reviece care instead of going into their homes. (GE-10)

Second, this issue of isolation *vs* social relation was clearly related to the moment of lunch and to the *importance of socialising lunch time for the frail elderly*. From 1998, the elderly community care program of the Policlinic of Geriatry “Years to enjoy”⁶³ had also advertised about the importance of isolation of elderly and of conviviality in the alimentation problematic. The “empty fridge” problem and the under-alimentation of some isolated eldery was pointed out, as well as the importance of the environmental factors (spcially the social) regarding the moment of lunch (Gorin-Gottraux/Nykius/Rapin 2004). Obsivously, the meal-on-wheel service of the FSASD was in question, both in its general concept and in its more operational dimension (how many Kcal, how do eldery actually use the meal thy receive at home ? a.s.o). In this context, the projet “Autour d’une table” was conceived to provide an community alternative to classisc meal-on-wheel services. Moerover, in its first design, the pilot project was supposed to spread first to the entire population of 65+ and then to the entire city.

Apart from quality issue, the projet “Around the table” can be understood in the context of the main objective of the City of Geneva, naimly developing the communitary action. Hence, it is a projet that directly concern the *participation dimension* of HBLTC. Since 2003, the City has developed the communitary action, with the first implementation of the UAC in some bouroughs, followed by the progressive diffusion in the 8 sectors of the service. From the beginning, the communitary action development was concieved as an experiment, a laboratory that offers possibility to test approaches and know-how in a still

⁶³ « Des années à savourer ».

unfix domain.⁶⁴ After three years of experimentation, the social service mandated an independent evaluation of the process, which pointed out the good but also the bad results of the experience⁶⁵. From this first assessment, an official “referential” for the city community action was elaborated.

In this context, the shift toward community action in the City specially concerned the elderly. The priority was the development by *projects*. Indeed, the project “Around the table” was part of the new projects developed by the city for the elderly. The other projects – as they were listed as an example in 2005⁶⁶ – were the creation of a cinema of proximity; the organisation of a preventive collective meeting against purse-snatching with the participation of a policeman and the facilitation of a joint theater evening for a volunteer and an elderly. Today, the social service confirms this option towards the development of projects, in a perspective that is focused more on the autonomisation of projects than on empowerment of groups or community. Indeed, participation in that case is part of a new mode of governance, the “reflexive subsidiarity” (Buttschi/Cattin 1994) in which the public actor actively created the conditions for associations to be created and get autonomous in some specific social field.

We claim to be representative of community action, but not only this “empowerment” project (...). You can have different approaches. Maybe today we would not use this terminology (...). We can be coordinator, there can be different positioning, even if we support strongly, centrally the project at the beginning, but we can aim to get out, to autonomise the project. This is slightly different with empowerment, because empowerment means immediately, creating the conditions in which groups or community can act (...). We have different approaches, they all aim at the autonomisation of projects. “Around the table”, we could aim to autonomise it. We are not in the empowerment anymore. But we can start projects, we can conceive them, we can bear them and we can aim at their autonomy. (GE-5)

The project “round the table” is, in this context, a top-down project that is strongly supported both by the professional of the FSASD and by the social service of the city. Nevertheless, it is considered by many of the field workers as strongly innovative, because it refers to *collective action* by contrast with individual care or with case management,

⁶⁴ Evaluanda (2008). *Document de référence de l'action communautaire du Service social de la Ville de Genève. Missions et modes d'intervention*. Genève, Service Social.

⁶⁵ Evaluanda (2007). *Bilan des unités d'action communautaires*. Genève.

⁶⁶ Ville de Genève (2005). *La réforme du service social et l'action sociale communautaire. Présentation des « Unités d'action communautaires » (UAC), de leurs nouveaux sites extranet et internet et des huit plaquettes d'information par quartier*. Dossier de presse. Genève.

specifically in the context of a problematic of isolation of elderly. As some of our interviewers point out about “Around a table”:

“We take an individual problem et we offer a community solution. That’s innovant! The is what I have discover: I think it is the *last collective thing we can offer to this population.*” (GE-2)

Finally, participation was a result of the individual change that the frail elderly were reported to experienced. As different interviewees told us, the project goes to show the radical change of some elderly that were about to leave themselves dying and who recover through their implication in these convivial lunch. One of the first participation act that is reported is the *claiming activities* (something that sound quite familiar in the swiss imagery of the typical Geneva’s inhabitant that always loudly complaint). First the complaint about the restaurant lunch quality, followed by the group dynamic towards autonomy: a group of elderly wanted to organise the lunch by themselves. Finally that had to give up this idea for they have not the physical resources to do it and they continue into the UAC structures. There is no systematic evaluation of this kind result that links convivial lunch and health recovery, autonomy recovery, social relation recovery - but this may be an interesting point to explore further.

c) Governance and coordination: the territorial dimension of HBLTC

The project “Around the table” is interesting regarding both governance and coordination of the Geneva’ elderly care network. Regarding governance, the project is a case of multi-level governance which mixes cantonal, local and sub-local levels with aim of preventing social isolation of elderly and promoting health. More specifically, in Geneva, the relationship between the city and the canton has been a recurrent political issue for years and generates tensions and deadlocks in the network (see section 2).

In that context, the project appears innovative for two reasons. First, it relies on a clear division of tasks and responsibilities between the FSASD (an institution that is clearly linked to the cantonal authority) and the City, formalized in 2011. For the FSASD, this type of agreement is not easy to reach, as the City is divided in 8 UAC sectors, while the FSASD is organised around 4 Centers, which are themselves coordinated from 4 up to 6 local “Antennes” (total of 20). Therefore, the innovative projects are usually developed at sub-local level without coordination and formal implication from the city authority. The multiplication of partners does not facilitate neither the development of common projects between the FSASD and the City (GE 9; GE 10).

Second, the project is a by-product of new task repartition between the City and the Canton that was decided in 2001 with the new on the CASS. From 2002, the municipalities are supposed to be concerned *in priority* by communitary action, while both the FSASD and the General Hospice are *in priority* concerned of the individual cases. Hence, in the case of “Around the table”, both the division of responsibilities of cantonal and local actors and the divisions of tasks allows for the implementation of an innovative project.

Lastly, as far as the City of Geneva is concerned, the project address the issue of governance of civil society. As we discussed in the previous point regarding participation, the social service have developed a specific approach of communitary action, that is build on new public instruments and aims at the creation and autonomisation of project through the development of associations, more than on the support of “spontaneous” community projects. In this context, “Around the table” appears to be a quite old fashion concept however, as it is mainly implemented through the public social service of the city.

The project is interesting regarding governance but also regarding the development of concrete *cooperation* in the field of HBLTC for elderly. In line with the community care model, it is part of a more general attempt to create new local or sub-local spaces, where social actors can answer territorialized issues, such as isolation of frail elderly. With the law of 2001, the CASS were supposed to become center of cooperation in the field of health and social care. Nevertheless, we have seen in point 2 that the concrete coordination did turn to a conflictual situation and the CASS experience was considered as a big failure. In this context, the project “Autour d’une table” can be considered as a good exemple –if not the only one - of successful collaboration at sub-local level, in the spirit of the law of 2001, even if it was without the third expected partner, namely the Hospice general (GE-5). Nevertheless, as we shall see, the development of the project was progressively controlled by the main cantonal HBLTC organisation and the city service did not get the leadership on the project.

A characteristic of this project regarding cooperation is that it is organised around a large “welfare mix” that includes the three points of the “welfare triangle” (Evers 1990): public regulation, market regulation and informal regulation. Its functioning is based on the collaboration of a non profit organisation (FSASD), public local actors (UAC), private for profit organisations (restaurants) and informal carers (volunteers). The non profit organisation (FSASD) is in charge of the professional and individual home-based care. Then, professionals can detect the elderly in risk of isolation and inform them personally about the possibility to join the project. In line with the law of 2001, the UAC (social service local units) are in charge of the communitary action dimension of the project at the scale of the

neighbourhood. They they try to inform the population in a more preventive way, they find the restaurant and the volunteers (with the help of voluntary organisations), and they assume the daily management of the sub-local project.

In this context, the role of the volunteers is valorized because they can develop *horizontal relations* with frail elderly, a kind of relation that can not be provided by a professional (nurse or social worker).

People eat, but they also meet regularly. There is a huge proximity, solidarities are created. There was a couple, two widows, very depressed, they were always moaning..they found each other! They are together ! They are still moaning but at least, they go out together ! For another, the group has become an affective shield (...). That is the innovation, the communitary approach, the fact that there is no professional, but volunteers. (...). For some of the elderly, it's the only moment when they get out of their apartment in the whole week. (GE 2)

Meanwhile, the managers of the restaurant have to accept to integrate a non profit logic. The important point here is, for the manager, to agree to reserve one table for two hours or more. Moreover, manager and waiter have to be sensitive to the specificity of the population of frail elderly (service takes time, a.s.o) and the manager has to agree not to be paid directly but on the bill. The recruitment of restaurant does not seem to be a problem (even if some are not interested or that in some case, the experience has been stopped).

In this section, we presented the most interesting features of the project "Around the table" regarding the four dimensions of HBLTC innovation content. Obviously, if we analyse it in a synchronic perspective, it is a project that can be considered innovant –in its concept and in its implementation - both with regards to the national policy orientations and gaps, and with regards to cantonal shortcomings. Nevertheless, a more dynamic analysis brings more moderated conclusions. The process of the development and of the institutionalisation of the project reveals the limitation of its scope and the normalizing of its content. In this perspective, we observe how the Swiss long term care system of financing and governance (including the specific tensions between sub-local, local and cantonal scales) can transform an innovant academic and political concept into a normalized and stabilised HBLTC services.

4. ANALYSZING THE PROCESS OF CHANGE

“A frail project for a frail population”

a) Innovation process

As a new concept, the project “Around the table” is the result of two interesting processes of innovation in the field of HBLTC. First a learning process and second, a political attempt to implement local community care through concret projects development. Both these process involved institutionalised and non institutionalised actors.

First, the development of the concept of the project can be considered as the result of a *social learning process*. The first impulse for change process came from the cantonal health department minister, who asked the main HBLTC non profit organisation (FSASD) about the possibility to develop such project. This reflexive moment arose just after that the evaluation of the implementation of new CAAS law pointed out many problems (Horber-Papazian and al. 2004). As a consequence, the FSASD initiates its own learning process about its meal-on-whee services by mandating an academic research from the University. The report provided evaluation of the services and the clients needs and satisfaction, but also the design of the project “Around the table”. Indeed, the project was concieved in the context of an evaluation of the HBLTC service impact on collectivity.

Morevoer, this project was supposed to start as a pilot project that has to be tested. When the city of Geneva got involved in the project development, we observe the same kind of learing process. Independent research were mandated to make an evaluation of policy, and community projects were concieved as experimental. The UAC was the unit of this social experiment. This kind of process (reflexive gouvernance, scientifically grounded decision, experimental implementation) is characteristic of a “reflexive” welfare state.

The service is concerned by the quality management criteria of the main cantonal home based care organisation. In this context, the definition of quality of the meal has been changed in a pragmatic way regarding this specific projet. This also can be refered to as social lerning. Indeed, the first dététicienne was quite rigid on the official nutritional criteria of quality. But this approche has changed and the new team radically change its criteria for evaluating the luch quality. (GE 1; GE 08). If this experience did not reframe the dominant conception of quality in meal-on-wheel service it must be noticed that some reflexion are still ongoing about the social dimension of lunch and new ideas are emerging (like inviting students to eat with the elderly) (GE 11).

Second, the project is the result of the political will (cantonal and municipal) to *develop community care* at local level. Indeed, the social service of the city was developing community interventions, in the context of the law of 2001 that has divided the health and social activities between the canton and the City. As the canton was mainly responsible for individual help, the City was now in charge of community action. This new configuration represented an opportunity window for the leader of social service of the City to develop the project she had in mind: this project was inspired by the experience of the canton of Bern 20 years ago (stam-tisch) (GE-6). This process towards community care has also been subject to extensive reflexions and analysis (Rossiaud 2007) and all the social service workers had to get trained in communitary action, in collaboration with the Geneva' Institute of Education and Social Studies (IES). Nonobstant this active collaboration with resaerchers, evaluators and Professional School, it has to be precised here thtat the direct transfer of this sociological concept to political and administative categorie did not occur explicitly while the training generated syndicalist but also conceptual resistances from some social workers.

The development of a community care concept for the city was also diven by experimental logic, at the level of the UAC. Hence, once the project started to be diffused in the UAC, the process of change was driven by the concrete collaboration between the different UAC of the city and the FSASD. At that level and from that moment, the development of the project can be attributed to motivated social workers with the support of the person in charge of the sector in the FSASD and the community partners. The project was included in the specific actitivities or functioning of each UAC and then develop with its own concepts.

b) Direction of change (horizontal and vertical)

The project "Around the table" follows two streams of development. On one side, it spreads horizontally, at city level and then in the other municipalities. On the other side, the social service attempes to develop a sub-local experience at the level of the city, but this vertical diffusion failed for political reasons.

Horizontal diffusion

First, the projects spreads *horizontally* from neigourhood to neighbourhood, building sub-local cooperation with the FSASD in the City of Geneva. This horizontal diffusion process was driven by the City UAC. At the sub-local level, it generated new forms of *cooperation*

between for-profit actors (restaurants), the voluntary sector, non-profit actors (FSASD) and public actors (social services units of the city of Geneva).

Regarding the diffusion process in the City of Geneva, the main dynamic were the changes in cantonal legislation and successive reorganisations of the HBLTC field at this level, due to recurrent problems of coordination between different actors (namely between FSASD, General Hospice and UAC). As such, the project is a by-product of new task repartition between the City and the Canton that was decided in 2001 in the new law on the CASS and effective in 2002. This law intended to clarify the responsibilities in the field of health and social service, including HBLTC. From 2002 then, the municipalities were supposed to be concerned *in priority* by communitary action, while both the FSASD and the General Hospice were *in priority* concerned of the individual cases. Indeed, the development of the project “Around the table” at the city level can be understood in this context of development of a local *community care* intervention in general, and addressing the issues of elderly in particular.

Table 1. Diffusion of the proect “Around the table” in the City of Geneva

Area	Start	2005	2006	2007	2008	2009	2010
City							
Servette/Petit Saconnex	04.2005	391	532	553	385	431	262
Saint-Jean/Charmilles	10.2005	96	854	1264	1337	1637	1666
Grottes	11.2005	29	619	1058	890	786	788
Eaux-Vives	08.2007	-	-	184	745	899	807
Pâquis	10.2007	-	-	32	213	394	328
Jonction	05.2008	-	-	-	152	447	323
Champel	09.2008	-	-	-	29	82	0
Total (city)		516	2005	3091	2921	4676	4174

Source: FSASD 2011.

Following the adoption of the law of 2001, some municipalities were reluctant or refused to change their ways of working and to give up individual social services, but the city of Geneva tried to use this new dynamic towards communitary action, build a new approach, transfer the individual cases to its partner (Hospice general), organise the training of its social workers (a

quite conflictual process) and start to develop communitary projects of its own. In the field of elderly care, the new project were developed in the UAC in the context of the previous activities adressing the elderly.

Secondly, the project also spreads to others municipalities. This process is mainly driven driven by the FSASD, that is negotiating different arrangements in the differents others municipalities. This diffusion started one or tow years after the city and is still going on. At the beginning, the municipalites had to manifest their interst first. Progressivly, the FSASD has taken a more “offensive” position –although with rather limited ambitions (GE-8, GE-11)

Table 2. Diffusion of the project “Around the table” in the canton of Geneva

Municipalities	Start	2005	2006	2007	2008	2009	2010
<i>Geneva City</i>	<i>2005</i>	516	2005	3091	2921	4676	4174
Onex	<i>03.2006</i>	-	32	346	629	455	413
Versoix	<i>03.2007</i>	-	-	202	268	246	302
Plan-les-Ouates (Bardonnex)	<i>05.2007</i>	-	-	38	57	116	101
Vernier-Lignon	<i>09.2007</i>	-	-	146	354	211	165
Meyrin	<i>03.2008</i>	-	-	-	95	151	206
Veyrier	<i>04.2008</i>	-	-	-	144	181	168
Trois-Chêne	<i>01.2009</i>	-	-	-	-	125	0
Bernex	<i>06.2009</i>	-	-	-	-	152	123
total		516	2037	3823	5303	6313	5652

Source: FSASD 2011.

Vertical diffusion

Te general process of diffusion is then a top-down process, driven by the FSASD for the cantona level and by the municipality for the local level. Nevertheless, there was a bottom-up procees that finally failed. Indeend, the social service of the City of Geneva also tried to develop a biggest project at the scale of the City –directly extending the concept of one the UAC first pilot projects of “Around the table”. This second project – named *Entourage-* was about to start when is has been canceled in 2011 for political reason.

The specific experience in one specific borough (UAC) was made possible because of the large autonomy of the UAC regarding the city social service. In this UAC, a small group of social workers develop a community care in a concept strongly inspired by empowerment models. Regarding elderly, they were concerned by their growing isolation. For different reasons, they observe that with the ageing process, the scale of action and relations of elderly got reduced and finally limited to their apartment or to a zone of 200-300 meters. This “big proximity” dimension was then a crucial one to be taken into account. The idea was to provide the conditions for those persons to keep social relations. In order to do this, elderly had to get in touch with the existing structures (library, “around the table” project, chess club, a.s.o). Hence, apart for *proximity*, an important concept was put forwards: the importance of *acompanying frail elderly*, to come with them at least the first time.

In this perspective, they try to contact elderly and first, to localise them. Inspired by an experience in an other municipalities (for unemployed), they develop the program to contact elderly, identify their needs and accompany them individually –both physically and symbolically. The social service direction approved the project but did not put money so they find money through private Foundation. In order to do the job, they find a motivated individual which was unemployed. The project was implemented, tested in 5 years. It includes “Around the table” project:

“We tried to orient them, to connect them to the tea room, to “Around the table”. Around the table functioned thanks to this at the beginning. If we had had to rely on the FSASD! Say, even today....(...). (GE-3)

After this first experience, the evaluation was encouraging. A report was provided. It was decided to focus on the people of 75+ instead of 65+. And to reduce the experience, with a stable job. Indeed, the volunteer of the UAC after testing this project was to get the condition to stabilize the project. The answer was not as encouraging as they hoped:

“The result ? its wonderful what you have done ! Specially for this unemployed person ! Temporary occupation, tis just wonderful. But good by. It was just a little awful. For the team, also, it was hard to hear. We were really waiting for a salary for this person.” (GE-3)

On this side, the social service decided that the idea was good enough to be developed at the City level. Hence, they develop a quite new concept at the City scale, providing services complementary to the one of the FSASD. The model was to contact frail elderly following the

method tested in the UAC, an to add different *social services* to frail elderly : help for administration; come with them to comunitary action like “Around the table”; mobility services, for exemple to reach the Senior City place; small rapair jobs. All theses services had to be paid by elderly users.

Interestingly, the first idea was to finance this project with the about 10 millions CHF (about 8 million euros) of the City social allocation for elderly. This allocation was strongly contested by the canton in 2006 and the social service though they may be reallocated for community projects agains the isolation of elerly. But the city finally conserved its compences in given allocation for elderly. The second attemp relied on jobs for unemployeeds, that were promoted by the cantonal Departement of Employment and solidarity and called “solidarity jobs”. Obviously, social services for frailed elderyl could become a new job market field. In order to get financed, the social service *created* a specific association, *Entourage*, including different partner of the associative and institutionalised field of elerdy care and HBLTC (including FSASD). But solidarity job was a highly political issue and the city authority (namely an other socialist minister) stop the project. Her eis the way a member of the City executive explain that blockage:

“Yes, the City executive does not want to work with solidarity jobs. Because solidarity jobs, its linked to the dismantling on the law on unemployment. What L does (note: the cantonal ministre), the idea is to created two markets: one for normal people working, and one for those who will never get a job. There are paid bellow to do a job that requires a degree of competence. They don’t do it as a neighbour or as a member of the family. They do it because they are send by an association, it is their job. Hence, they need to be trained. But if those people already have problems.. I mean relational problems.. Are they the best person to help frail elderly ? This has to be discussed. That’s why the city executive was reluctant” (GE-7).

From the UAC concerned, the disapointment was clear. As some interviewee sumed it up, the project Around the table did not diseapeard but lost most of its vivacity, speically concerning the contact with frail eldery: “I think it’s over. The wanted to do it so big that finaly, there is nothing. On our side, we could preserve some benefits, but the groups are fraying” (GE 3).

c) Discussion

The project to provide the opportunity for frail elderly to have their lunch in restarant and in company was conceived in the context of an innovant reflexion about the un-intented effect of

HBLTC and the meaning of alimentation services. Moreover, for the City of Geneva, it was framed into the new community care concept, as an opportunity to profile the local elderly policy around a specific approach that should promote neighbourhood vivacity and social solidarity. Nevertheless, the development of the project stays at a relatively low level in terms of meals provided and did not change the dominant conception of HBLTC. Moreover, the vertical diffusion attempt from innovative experience in the UAC to City level project failed. Hence, this specific case study allows us to focus on the factors that may have hindered the full potential of this project in this local, cantonal and federal context. Several factors can be mentioned: the first is related to governance, the second to coordination issues, the third to the concept of community care, the last to the financing.

Governance and leadership: the canton/city tension

This project has been conceived at both cantonal and local level. Hence, it has to be understood, on one side, in the context of a centralisation process of HBLTC (through the cantonalisation of HBLTC both in terms of organisation, financing and services) and on the other side, in the context of a de-centralisation process (through the de-centralisation of the operational section of HBLTC in specific areas and the attempt to anchor the project on a community base). In this context, the competition between the city and the canton appears to be central. Regarding the project “Around the table”, the city did not get the leadership it could or would have liked to get.

Historically, the social service of the City of Geneva have been directly involved in the preparation of this new law of the CAAS from 1999. For the City, it was an opportunity to develop communitary action *from* the municipality, and more precisely through its sub-local UAC. The UAC should have become the center of the CASS, they should have reviewed and evaluated individual requests and dispatch them to the other actors (like Hopsice or FSASD). Indeed, the City wanted that the UAC become the center of the sub-local coordination. This did not occur that way. In the case of the project “Around the table”, this loss of power from the municipality is manifest during the first pilot implementation. Governance issues as well as design and conceptual approaches tensions arose in the first pilot-project in the area of Servette that was launched in 2005. Soon, the FSASD profiles itself as the main regulator of the project (GE-1, GE-13, GE-5).

“We could make more pressure. Specifically regarding the limit they fix. But the financement, they got it. This setting, they got it. We got the volunteer’ recruiting, we got the choice of the restaurant. But they are the one who own the project”⁶⁷ (GE-5).

Today and more generally, the convention of 2011, that has been drawnd form implementation experiences is percieved by city official as hindering the development of the project:

“Yes, the convention was here to define who was doing what. But now, we have to get back to it. In fact, in was already signed up, but in the discussion, we could have asked more to the FSASD. (...). It’s a little bit like a “minimal service” they offer.” (GE-6)

Cooperation issue: the targeted population

These issue of a “glass ceiling” regarding the extansion of the project is differently interpreted in the network. For some actors, mainly from FSASD, it is explained by the fact that the potential clients of the FSASD that may benefit from such activities is quite reduced due to physical impairment or other kind of desires regarding social activities. For others, mainly from the City, it is due to the fact that involment of the FSASD is insufficient and to the fact that the project does not take into account a crucial dimension: the necessity to help elderly to make the first step. Hence, two approaches of the same population the coexist.

First, both FSASD and UAC were supposed to share the same population and to collaborate in order to improve service. But, clearly, it did not happened that way and the is a kind of “haring market” betwven both organisaiton. The cantonal FSASD “owns” the HBLTC clients from an individual perpective while the city is in touch with the more general population of 65+. In the case of the lunch in community project, this limit is an important one for the social service workers, that can not reach the most concerned elderly. As the FSASD will not transmit the list of their client, the City does not know exactly who sould be interested and can not develop active strategies to join them and to convience them to try at least once. Hence, a important link is missing in the project, namley the possiblity to come with the eldery at the first lunch:

« We know that the restaurant managers, we find them without problem. Maybe they are not the best restaurant but... Volunteers also, who agree to come once or twice a week, we find them easy. The issue is that eldery come and then stay. » (GE-6).

⁶⁷ « ...mais ce sont eux qui *portent* le projet »

This kind of activities has been developed, historically, by the City as the “aides ménagères” used to do this job in the 1990. Later, at the beginning of the project “Around the table”, the FSASD intended to do it but was limited by its budget but also by the health financial structure of the Swiss system that does not recognise such activities as official “care” or “cure”. Lastly, the UAC that developed such a service –at least find a way to contact elderly personally –could not continue with this project.

Hence, at the level of the UAC, the project management and development is really dependant on the capacity the FSASD or social workers to regenerate the groups of elderly (through information and detection of elderly in risk of isolation) and to create a social dynamic. The characteristic of the population targeted by the project (frail elderly, in risk of isolation) makes this task quite difficult. The project is often at risk of extinguishing itself. As an interviewee summed up: *“It is a frail project finally, because the concerned population is frail”* (GE-1). In this context, an alternative position for the UAC is to leave the frail elderly to the FSASD and to focus on preventive action, addressing youngest people before they become dependants, and then trying to fidelize them.

Implementing the concept of community care

There was a tension between sub-local and local level in the implementation of the project. This refers mainly to the concept of community action that was promoted at local level was quite ambivalent and was interpreted differently in each area. The lack of leadership also has been referred as generating frustration at sub-local level, as initiatives were encouraged but not supported further.

The community action concept that has been implemented by the social service of the city was a quite loosely defined concept. As it was first defined –and presented in the first trainings–, it was inspired by empowerment models experienced in Brazil. To be short, in this perspective, the community comes first, and not the city and its professional. Then, the social service shifted towards a quite different approach, more project oriented. The social service impels the new associations or projects and tries to help them to become autonomous. In the referential that was elaborated by the social service, the different approaches coexist.

In this context, “Around the table” appears to be a quite old-fashioned concept, as it is mainly implemented through the public social service of the city. Nevertheless, there were no strong directive lines regarding the “right meaning” of community action. Hence, during the implementation at the UAC level, there was much room for interpretation.

Different approaches were revealed regarding the issue of volunteers as well as the restaurant. Hence, the complementarity between professional and non professional as well as the implication of the local restaurants are an important part of the project, as it is influenced by community care model that emphasizes the role of the proximity actors.

Here precisely, a tension emerges in community care implementation between the “community” side and the “professional side”. Regarding the volunteer, the city approach considered them as important support, but essentially a support :

The volunteers represent an important resource. You have to know how to recruit it, how to train it, how to valorize it. But it remains a non reliable resource –well, its not the term – a volunteer is less reliable and more unsustainable than a collaborator. It’s a volunteer, with its own motivation. Punctually, its very important because it brings something more, but then, the volunteer leaves us. So, you can not compare. (GE- 6).

By contrast, in some of the UAC, the volunteers are valorized because they can develop horizontal relations with frail elderly, a kind of relation that precisely can not be provided by a professional. This tension is well summarized by a social service worker in a UAC:

“We had some small adjustment problems, because the project was first conceived for the people who get the meal, but not only, there was a strong care dynamic. The preoccupation was to guarantee the *supervision* of the group by a volunteer that should also be a “nursing-auxiliary”, that could be able to manage difficult situations, and to require a number of volunteer/elderly. But for us, the logic was different. It was to re-mobilize the inhabitants, the actors, like the restaurants managers, on this issue of the elderly, of isolation. Our logic was to promote the fact that everybody could contribute to help these people to maintain its relationships, get out of its home, preserve his autonomy (...). The idea was to say that *there is no need for specific competences* to get in touch with a inhabitant of his neighbourhood, even if he is older than we are. (...) The volunteers, we did not call them like this, we call them “supportive inhabitants⁶⁸”. The idea was that they get involved for the inhabitant of their neighbourhood, not for the UAC or the City of Geneva ” (GE-3).

A similar issue can be detected regarding the role and importance of private restaurants. As many observers in Geneva told us – as an hypothesis – it seems that this kind of practice is already diffused: some restaurant, and specifically in popular areas, already play an important roles for the elderly. They receive them but they can also bring them the meal at home, as elderly may prefer this solution. Regarding the project “Around the table”, some observers concludes that this is why the project did not spread in some popular area.

⁶⁸ « habitants solidaires »

Financing

During its development, the project around the table was regularly confronted with the issue of financing. Clearly, its scope was reduced or its design was conceived regarding the financing possibilities.

First, the mobilisation of volunteers can also be explained by the budget restriction. From the beginning, it seems that the social service of the city explored alternative to social workers (either professional of the FSASD, or volunteers), “for practical reason, because of our personal resources and because of our way of working” (GE-5). Second, and the same way, the mobilisation of professional of the FASD reveals to be too expensive. Member of the FASD first in charge of the project had developed a model including professionals, but they had to give it up for financial reason.

Third, innovative experiences like the one of the UAC that could reach personally the frail elderly in order to fight against isolation could not be continued, as there was no budget for that kind of activity. Fourth, as we noticed in the previous point, alternative have also been explored by the city in the context of a parallel project *Entourage*, like the new job created for the long term unemployed in the canton (“solidarity job”). This alternative was clearly considered for financial reason. As well as the creation of the new association by the social service, which would have allowed its financing. Five, the FSASD do not push for an extensive development of the project, as it would become costly in terms of management (GE-11).

More generally, this project can be interpreted as limited in the context of the withdrawal of community care model in the canton of Geneva. After a first period of development at the end of the 1990 and the beginning of the 2000, and the failure of the CASS experience, community care does not seem to be a highly prioritized topic, even if the HBLTC is clearly a renewed priority for the canton. But the recent changes in the federal legislation (LaMal) do not support preventive work of HBLTC institutions, and confirm the curative character of the Swiss model, as it is perceived by actors of the FSASD:

“I don’t even speak about the preventive dimension of action, with regards to the LaMal ! It’s just impossible. To do. For those few who know what does community health mean... it’s even a terminology that is vanishing today... We go directly to the 100% curative. If we can not save... you really feel that every community attempt is now... Well, except the City of Geneva, that really do

interestig thinks in community care, because they have the money. The Lamal, everything is goes, prevention, community care. This also discourage professionals.” (GE-10)

Hence, in this context, the City of Geneva appears as the last actor to be developing community action. Even if today, there may well be a shift towards a rediscovery of *personal care* into *community action*. Up to date, communitary action dimension of elderly care is still alive in Geneva.

As a conclusion, the process of the development and implementation of the project “Aorud the table” can be undertood as an innovative process, strongly influenced by social learning and by the political will to develop communitary action at local and sub-local level. Nevertheless, it aslo can be understood as a process of normalizing its innovant content and reducing its potentiel scope. In this context, the City of Geneva could not challenge the cantonal institutional definition and governance of the services of HBLTG, neither challenge the fragmented and cure oriented federal financement system. Moereover, it could not develop an effective territorial cooperation in sharing the population with FSASD. Nevertheless, the city and the FSASD succeeded in their collaboration, in allowing the development of innovant complementary services at sub-local level, even if it is in a quite un-systematic way.

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Interviews

GE-1	Social worker ⁶⁹ UAC 1	05.10.11
GE-2	Social worker UAC 2	06.10.11
GE-3	Social worker UAC 3	05.10. 11
GE-4	Social worker UAC 4	10. 01.12
GE- 5	City Social service	15. 04.11
GE-6	City Social service	12. 10.11
GE-7	City municipality	22. 12. 11
GE- 8	Direction FSASD	06.10.11
GE-9	Direction FSASD	10.01.12
GE-10	Direction FSASD	10.01.12
GE-11	Direction FSASD	16.01.12
GE-12	FSASD – CMD	18.01.12
GE-13	Researcher, Unige	22. 12. 11

⁶⁹ By « social worker », we mean employee of the social service, whatever its profession may be.

Knowledge management as a combination of specialist and generalist approaches in care provision – an organisational approach to care quality in Köniz, canton Bern, Switzerland (CH)

1 Introduction

The Köniz case study addresses the issue of quality development in outpatient long-term care. In this case, we explore a quality-related change at local level which is bound to a local organisation – the local non-for-profit provider of outpatient long-term care – but embedded in the wider regional (that is: cantonal) and even national Swiss context of processes of economisation and professionalization of outpatient long-term care services that in the same time seems to facilitate and endanger the observed development: The local non-for-profit provider of outpatient services in long-term care (non-for-profit Spitex organisation) in the city and region of Köniz (canton Bern, Switzerland) has developed organisational structures and processes to generate expert knowledge and facilitate knowledge transfer between staff members and thus contribute to a high quality of service delivery. This *bottom-up strategy of quality development* was backed by the cantonal association of the non-for-profit Spitex¹ organisations which is promoting a process of fusions of local Spitex organisations as well as the stepwise implementation of standards regarding structure, processes and outcomes of service provision (SPITEX Verband Kanton Bern, 2007). Taking into regard the hitherto relatively little emphasis on quality issues in Switzerland in the cantonal and federal context, the Köniz initiative may be regarded as an innovative approach that especially addresses complex cases such as persons with special needs for attendance and supervision or individuals who would reject professional help and support; among these may also be clients with psychiatric diagnoses; beneath this, also wound treatment is an addressed issue. Recently, the observed bottom-up change process seems to be put in question by top-down changes in the financing modalities.

2 Descriptive section

General contextual information on the local case

The municipality of Köniz is situated in the South-West of the city of Bern between the rivers Aare and Sense in the canton Bern in Switzerland. (Gemeinde Köniz, 2012d). With about 38,000 inhabitants Köniz is among the nineteen Swiss cities with more than 30,000 inhabitants (Bundesamt für Statistik BFS, 2010b, p. 9); yet, the population is spread over 23 localities in an area of about 51qkm. About 55% live in the northern, lower site that encompasses Niederwangen, Köniz, Liebefeld, Spiegel, and Wabern (Hornung & Röthlisberger, 2006, p. 5). It constitutes an agglomeration which is almost melted with the city of Bern, while in the southern, upper area, where the other 45% live, the rural character prevails (ibid.).

From the centre of the city of Köniz to the centre of the city of Bern it is 20 minutes by bus (connections are every 3 to 10 minutes); this makes Köniz attractive to commuters who work in Bern. But it also gives an impression of the high degree of suburbanisation which began in the 1960ies and 1970ies and led to the situation that in 2006 Bern had 128,000 inhabitants, but about 148,000 employees (Stienen, 2007, pp. 4-5). 65% of the employees who live in Köniz work in another municipality (Bundesamt für Statistik BFS, 2012b). But Köniz offers jobs, too: according to the municipality's own presentation more than 1,400 enterprises are based here, among them also some international companies. At the end of 2009, the registered local economy gives work to about 19,200 employees, the service sector is by far the biggest with about 76.7% of employees; about 20.8% are employed in industries, and about 2.6% in agriculture (in about 150

¹ In the German-speaking Switzerland, providers in outpatient long-term care are called "Spitex organisations"; "Spitex" stands for "spitalexterne Pflege" that is "long-term care outside the hospital".

enterprises) (Gemeinde Köniz, 2012c). The unemployment rate in 2010 is with in average 3.1% moderate (Switzerland: 3.7%) (Bundesamt für Statistik BFS, 2010a, p. 69, 2012b). Regarding the tax burden that Köniz imposes on its citizens, the municipality is ranked in the upper middle-field compared to other municipalities in the canton Bern (Gemeinde Köniz, 2012c), even though the local authority argues with reference to a study commissioned by the Crédit Suisse (Carnazzi Weber, Hürzeler, Rühl, & Stoll, 2011) that, effectively, households are less burdened with obligatory contributions in Köniz than in supposed “tax havens” (Gemeinde Köniz, 2012b). After several years of a positive financial balance of the municipal budget and a prospective overspending (Gemeinde Köniz, 2009a), the municipal executive decided to implement cost containing measures; parallel to this development, in 2011 is announced a change in the balancing mechanism between the canton and the municipality at the expense of the municipality (Gemeinde Köniz, 2012a, pp. 4-5).

Since 1988 the municipality has a social democrat president of the local SP, even though the conservative SVP has strong roots especially in the rural areas. The local executive consists of five municipal directors: two of the social democrat, one green, one of the conservative party of a local list (Gemeinde Köniz, 2009b). The 40 members of the local parliament represent altogether 8 parties; the strongest of them is the social democrats with 10 members; followed by the conservative SVP with 8, the liberal FDP with 7, the green party with 5, a former SVP-liberal wing with 5, the protestant party with 3, and two further representatives (Gemeinde Köniz, 2009b); compared to earlier years the conservative, social democrats, and liberals lost votes in the last elections, while a new green-liberal list and a new party of the right middle (BDP) won (Gemeinde Köniz, 2009c).

(Brief) historical description of the development of the local system of HBLTC for the elderly

2.1.1 Demographic development

In 2006, a study has developed two scenarios of the demographic development until 2025 in the municipality of Köniz and its 12 statistical districts (Hornung & Röthlisberger, 2006). The study predicts an increase in inhabitants between 6.7% and 11.8% from 2005 to 2025 that will concentrate in the lower site of the municipality which is closer to the city of Bern. The relatively high share of elderly persons who today live in these lower localities will decline during the next years. The upper, more rural districts will loose population; the share of elderly persons will rise here. In one of the districts the predictions assume that the share of persons aged 65 and older will double, the number of those aged 80 years and older will even triple (Hornung & Röthlisberger, 2006, pp. 4-6).

The share of persons aged 65 and older in Köniz has risen from 17.4% in 2000 (Bundesamt für Statistik BFS, 2012b; Gächter, 2005) to 19.3% at the end of 2010 (Bundesamt für Statistik BFS, 2012e, own countings). 15.5% of the inhabitants of Köniz do not have a Swiss passport; of these, 7% are 65 and older. Among all inhabitants at the age of 65 and older, only about 5.5% are of a foreign nationality (Bundesamt für Statistik BFS, 2012e, own countings). In 2005, 2,068 out of out 37,552 inhabitants of Köniz (5.5%) were 80 years and older (Hornung & Röthlisberger, 2006, pp. 14, 29). At the end of 2010, the share of inhabitants aged 80 years and older is already 6% (about 2.300 persons); 3.2% of them had not the Swiss nationality (75 persons) (Bundesamt für Statistik BFS, 2012e, own countings). Among the inhabitants without a Swiss passport, the share of persons aged 80 years and older was 1.2% at the end of 2010 (Bundesamt für Statistik BFS, 2012e, own countings). As in Switzerland in total, in the canton Bern the share of elderly persons probably will rise. Predictions forecast a rise from 17.8% of persons aged 65 and older to 26.9% in 2030 (medium scenario) (Bern, 2008, p. 9). In the “Concept ‘Ageing in Köniz’” for the municipality of Köniz, depending on the scenario, the population aged 65 and older still was assumed to rise only between 29.2% and 35.6% from 2005 to 2025 (Gemeinde Köniz, 2007, p. 8). The study on demographic change in Köniz forecasts a rise in the population aged 80 years and older from 2005 to 2025 of between 19% and 26.3% (Hornung & Röthlisberger, 2006, pp. 34-35). Regarding the future development of the share of elderly inhabitants without

Swiss nationality, we could not find reliable actual data. Referring to estimations of the federal office for statistics, the cantonal report on ageing policies predicted already in 2004 a fast rise of the number of elderly migrants (GEF, 2004, p. 8). For the city of Bern, a prediction of 2010 assumes a rise of persons aged 65 and older from 2008 till 2025 of more than 40% and the doubling of the age group 80+ (Stadt Bern, 2010, p. 10).

Table 1: Share of persons 65 and older, 80 and older of the population of Köniz, canton Bern and Switzerland in absolute numbers (% of the respective population group) according to years

Age group	2010					
	Köniz ^a		canton Bern ^b		Switzerland ^c	
	all	migrants	all	migrants	all	migrants
65 and older	7,510 (19.3%)	416 (6.9%)	183,878 (18.8%)	-	1,329,600 (16.9%)	134,600 (7.6%)
80 and older	2,317 (6.0%)	75 (1.2%)	54,650 (5.6%)	-	372,900 (4.7%)	22,400 (1.3%)

- data not available.

Source: ^a Wohnbevölkerung der Gemeinden (Finanzverwaltung des Kantons Bern, 2011, p. 36); ^b Wohnbevölkerung der Gemeinden (Finanzverwaltung des Kantons Bern, 2011, p. 39); Struktur der ständigen Wohnbevölkerung nach Kantonen (je-d-01.02.01.02.05) <http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/22/lexi.Document.20567.xls>, last Access: 1.3.2012 (Bundesamt für Statistik BFS, 2012d); ^c Statistik Schweiz – Alter, <http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/02/blank/key/alter/gesamt.html>, last access: 1.3.2012 (Bundesamt für Statistik BFS, 2012c); Bundesamt für Statistik 2012, Bevölkerung nach Alter und Staatsangehörigkeit am Jahresende 2010, http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/02/blank/key/alter/nach_staatsangehoerigkeit.html, last Access: 1.3.2012 (Bundesamt für Statistik BFS, 2012a).

2.1.2 Care needs

In the following section we consider the development of perceived issues and problems of care both at the cantonal as well as at the local level. A rich source to retrace the development of the perception of problems of care at cantonal level, are the cantonal reports on ageing policies of 2004, 2007 and 2011 as well as the cantonal concept for ageing policies of 1993 (GEF, 1995, 2004, 2007, 2011a). The concept for an ageing policy of 1993 aims at providing a common framework for the bottom-up development of decentralised municipal ageing policies. As a normative model are set out: the *promotion of independence and self-help*, opportunities for choice, and the maintenance of continuity in important life aspects (GEF, 1995, p. 3). This shall be achieved by promoting help to self-help, adapted and diverse living arrangements as well as regional networking and coordination of ageing-related services (GEF, 1995, p. 1). Against the background of the perception of rising demands and the perceived necessity to make efficiently use of the scarce resources, the concept calls for networking activities between ageing-related services (GEF, 1995, p. 15). Other care problems which are already mentioned in these early times, are the development of services at evenings, weekends and during nights, respite care services, the interface with inpatient acute care facilities, as well as the qualification of staff (GEF, 1995, pp. 15-16).

In the three reports on ageing policies (GEF, 2004, 2007, 2011a), we may establish a development of the perceived care problems from a relatively broad approach that focuses on societal developments in 2004 (GEF, 2004, p. 1) over a clear emphasis on the question of how to assure supply for prospectively rising demands in 2007 (GEF, 2007, p. 2) to changes in the structure of financing and in the organisation of this care supply in 2011 (GEF, 2011a, p. 3): Beneath the reference to demographic change and foreseeable *rising care demands*, the report of 2004 brings out the *rise in dementia illnesses* as an important care problem (GEF, 2004, pp. 4-5). Other issues are societal changes that could lead to a *decline in informal care supply* (higher mobility, rise in single-households, higher employment participation of women), the question of how

to assure the existence of *sufficient and qualified staff* as well as the *economic situation* of elderly persons which comes along with a general feminisation of old age (GEF, 2004, pp. 6-7). The needs of *elderly migrants* are mentioned to have been under-addressed and should receive more attention; potential barriers in communication as well as supposed differing social and cultural needs are perceived as the related challenges (GEF, 2004, p. 8). After the focus of the 2007-report on the foreseeable *rising demands of long-term care* and the issue of *how to assure the existence of qualified staff* (GEF, 2007, p. 2), the 2011-report emphasises the transition from object-related financing to subject-related *financing mechanisms*, the financing of *services of attendance and supervision*, as well as on *integrated care* (GEF, 2011a, pp. 16-17). Regarding the action field of supporting independence and health, the cantonal government claims to continuously focus on socio-economical disadvantaged population groups in old age as they in general have worse health chances (GEF, 2011a, p. 7).

Several processes are related to the development of perceived issues and problems of care in Köniz and the canton Bern: The delivery of home care services has grown since the 1990ies. The rise in service delivery was explained with increasing needs in the population due to the demographic development (Gemeinde Köniz, 2008, p. 283), and the municipality also raised the respective subsidies (Gemeinde Köniz, 2009a, pp. 90-91) which have been entitled to the financial balancing between the canton and the municipalities until 2011. Notwithstanding the argument of rising needs, with an overspending in one year, the foreseeable centralisation of the financial responsibility for the long-term care (from the municipalities to the canton) has rise the pressure to legitimize the development of costs. Related to this process, the perception and description of care needs becomes more differentiated – as does the service delivery. Against the background of a pressure for cost containment, two issues became more central in care-related discourses during the last years:

- the question of a “statutory duty to supply”, that is: the issue of *guaranteeing a sufficient and needs oriented provision* of long-term care services *in general as well as in the remote and rural parts* of the municipality of Köniz.
- the question which kind of *specialised services are perceived or declared as necessary or important and thus qualify for public subsidies and which might be left to private financing*.

Both issues are linked when it comes to the question if and how to guarantee such specialised and less often needed services also in remote and rural areas, like the upper parts of the municipality of Köniz.²

According to the above mentioned study on the demographic development of the city of Köniz, in the year 2000 every fifth out of all inhabitants of 80 years and older lived in residential facilities what would correspond to the federal average (Hornung & Röthlisberger, 2006, p. 22). As recent scenarios of the demographic development assume a considerably higher rise in the age groups of 65+ as well as 85+, the canton sees a continuing need for action and further claims investments in health promotion and prevention to stay very important in the coming years, even more as the cantonal government opposes to extend the number of places in residential and nursing care homes (GEF, 2011a, p. 16).

Summarizing, in the discourses at cantonal level which also shape the local perception of care needs, we find an emphasis on facilitating independence and self-help in the home dwelling setting, the considering of special target groups such as persons with dementia illness or migrants, and a continuous focus on coordinated and networked service organisation. Remarkable is the turn from a decentralised approach from

² This issue has been a highly debated one between the cantonal government and the non-for-profit Spitex organisations and their roof-association. For 2012, non-for-profit organisations have to assume the statutory duty to supply long-term care services and if applicable services of domiciliary care; therefore, they are entitled to an extra-contribution per delivered hour of 3.70 CHF as well as fixed rate of 14.90 CHF for each inhabitant in the municipalities in their catchment area; all providers, also those without duty to supply, are entitled to a fixed rate for distances of 6.00 CHF per service (GEF, 2012, p. 7).

the 1990ies on that just provided a framework for the municipalities to the recently clear centralisation of responsibility for the steering of the outpatient long-term care supply at the cantonal level.

2.1.3 The care market

In 1993 outpatient services in the realm of long-term care still were differentiated in community health care (“Gemeindekrankenpflege”), domiciliary care (“Hauspflege”), and house help (“Haushilfe”) (GEF, 1995, p. 15). But already then, the paper on planning principles for ageing policies formulated the aim of coordination as well as fusions and the integration of the several services at local level (GEF, 1995, p. 15).³ The 1993 concept for ageing policies admitted municipal spending on ageing policies to the balancing between the canton and the municipalities in case that certain preconditions would be met (GEF, 1995, p. 17). One condition for the admission to the financial balancing was the non-for-profit orientation and the provision of tasks in public interest; for-profit endeavours were excluded (GEF, 1995, p. 17). According to the law on the old age and survivors’ insurance (“Alters- und Hinterbliebenenversicherung”, AHV), non-for-profit providers who were organised under private law (not public) were entitled to AHV-contributions. These regulations clearly shaped the further development of the care market: Due to fusions of organisations their number declined 21.5% from 1997 to 2000 in Switzerland; in order to be entitled to contributions, public municipal providers were transformed into organisations under private law, mostly into non-for-profit associations, some into foundations (BSV, 2001, p. 24). Their share sank from 17% in 1997 to 7% in 2000 in Switzerland and from then on stayed more or less stable between 6% and 8% (BFS, 2010; BSV, 2001, 2005). The canton Bern recorded the most intense change with 89 public organisations in 1997 to only seven public organisations in 2000 (BSV, 2001, p. 25). It seems plausible to attribute this development to the above mentioned financial balancing scheme between municipalities and the canton which set an incentive for the municipalities to support their local Spitex associations financially. Only from 2010 on, the official statistics records also the for-profit organisations and self-employed nurses beneath the non-for-profit and public ones. In 2010, 43% of the organisations were non-for-profit associations (Bern: 33%), 32% were self-employed nurses (52%), 15% of the organisations were for-profit providers (12%), 6% non-for-profit foundations (1%), and only 4% were public organisations (2%) (BFS, 2011a, p. 6; 2011b, own countings).

Recently – with the reform of the financing of long-term care that cantonalised and privatised parts of the financial responsibility – also for-profit providers may apply for public subsidies (GEF, 2011a, p. 33).

Another recent development is the probable rising number of (clandestine) migrant workers in outpatient long-term care: We could not establish estimations on their number, but some of our interview partners from outpatient long-term care as well as from complementary services perceive migrant workers as providers of flexible and cheap services and attribute them a rising share at the care market.

All in all, the actual care market in Köniz can be described as only *scarcely fragmented, if not centralised*: Outpatient long-term care is provided by the local non-for-profit Spitex organisation and one for-profit provider; the list of providers of long-term care which is provided by the municipality of Köniz does not indicate any self-employed nurse (Gemeinde Köniz, 2011e). Complementary services such as meals or mobility services or home visits by volunteers as well as counselling are additionally provided by some charity associations and the churches; meals services are also offered by some local providers of nursing homes (Gemeinde Köniz, 2011c, 2011d, 2011f).

The cantonal government now seems to aim at moderately intensifying the competition between the different types of providers of long-term and nursing care but also of complementary services such as meals or mobility services. A representative of the canton frames this not as enhancing competition but as setting incentives for a better coordination and repartition of tasks between the different providers who should

³ The concept recommended that planning areas should at least encompass 5.000 inhabitants, so that municipalities with less than 5.000 inhabitants should cooperate for planning with others (GEF, 1995, p. 11).

specialize according to their respective strengths and weaknesses (BE_20110714-01, 211). From some interviews we got the impression that the cantonal government originally might have intended to contract identical prices with all providers, and thus level out existing differences between non-for-profit- and for-profit providers to raise competition. Notwithstanding, probably due to the lobbying of the non-for-profit providers and their cantonal association, in 2011 the non-for-profit providers of nursing and long-term care have still been reimbursed higher prices for their services than the for-profit ones. In return, they are obliged to guarantee care coverage in their respective catchment area. Non-for-profit providers receive less money for their services, but they may select which clients they want to care for.⁴ Not-for-profit providers reproach the for-profit ones to select clients according to aspects of economic interest and to provide their employees worse working conditions, such as contracts that are bound to certain clients. These reproaches are rejected by for-profit providers. We may not prove one side to be true; but we may state that the canton has formulated a relatively vague framework for contracts between the canton and long-term care service providers regarding structural, process or outcome quality of service provision or concrete standards of services. Yet, since 2011 all providers have to apply for accreditation which beneath other requires an operational concept, a concept for quality assurance, the employment of sufficiently professional staff (Regierungsrat des Kantons Bern, 2001, §6a (inserted the October 27th, 2010)). A further condition for contracting with the cantonal government is to stick to the locally and in this branch usual working conditions (GEF, 2012, p. 5).

Regarding the *establishment of integrated care paths* at the local level we identified *two different actor networks* which are limited to the respective sector of non-for-profit versus for-profit organisations: On the one hand, we found provider-overarching coordination activities between the out- and inpatient quasi-public non-for-profit long-term care providers. They are cooperating closely⁵ with the aim to offer an integrated long-term care path which would provide anything from rehabilitation over nursing, outpatient long-term care and complementary services up to inpatient long-term care in residential facilities. As their services are complementing each other and not competing, there seem to be only low if at all thresholds to such cooperation. Yet, the *interface between outpatient long-term care and medical treatment in hospital is described as rather difficult* and not yet satisfyingly developed. On the other hand, a big for-profit service provider who offers services also beyond the region of Köniz encompasses several types of services such as outpatient long-term care, a day care facility, three residential care homes, and some complementary services. The coordination of services here takes place in one huge organisation. According to a manager of this provider, the provision of outpatient-long-term and of the day care services shall contribute to the acquisition of new clients and bind them to the provider.

All in all, the *development of the care market* in the canton Bern as well as in the municipality of Köniz can be characterised both by *concentration and pluralisation*. On the one hand, the number of non-for-profit providers has declined and in the canton probably will continue to do so during the next years due to further fusions; on the other hand, new for-profit providers have entered the stage to provide their services and probably will rise in size or perhaps numbers as they now are also entitled to public subsidies.

Regarding *actors networks* at stake, it is important to notice the very recent *process of centralisation* of the responsibility for the steering of long-term care at the cantonal level (see below). To assert influence on the further development of the structures of long-term care in Köniz after this centralisation process, the local providers and the municipality in 2011 started to meet irregularly in a *strategy platform* “*Care for the elderly*

⁴ For 2012, the general terms and conditions for contracts between canton and providers contain unified prices for the different types of providers; the statutory duty to care in their catchment area is still limited to non-for-profit organisation who receive a fixed rate of 14.90 CHF per inhabitant in the contracted perimeter and additionally 3.70 CHF per reimbursable hour of care (GEF, 2012, p. 7). There was also introduced a fixed price for distances: each operation is reimbursed for distance with 6 CHF. Both regulations clearly privilege the Spitex organisations whose perimeters encompass the few cities in the rural canton and probably will promote fusions of organisations from the remote rural areas with more centred organisations.

⁵ Some of our interview partners see a strong regionalism in Switzerland that would sometimes hinder region-overarching networking, whereas inside one region networking partly seems to function as this example illustrates.

in the municipality of Köniz” (“Strategieplattform ‘Altersversorgung Gemeinde Köniz’”) (Direktion Bildung und Soziales der Gemeinde Köniz, 2011). The meeting was organised by the municipality, but an interview partner emphasised the important role of the manager of the local non-for profit Spitex organisation, an intensely networked person, who was said to have started this initiative. Issues at stake are the planning and coordination of in- and outpatient long-term care services on the local level under the condition of the centralisation of steering competences at the cantonal level.

2.1.4 Governance, complementarities and coordination, quality assurance, participation

Governance

The cantonal concept on ageing policies of 1993 assigned the responsibility for negotiating the adequate supply of outpatient care and help services for the aged to the municipalities who would contract with the local providers (GEF, 1995, p. 20). In 2003, social assistance had been included in the financial balancing between canton and municipalities, since 2009 also the expenses for complementary benefits to the old age and survivors’ insurance were included (Großer Rat des Kantons Bern, 2000).

In 2011 the canton Bern centralized the governance of long-term care services at the cantonal level. This was an answer to the decision at federal level. In 2008, the federal parliament had decided to transfer the responsibility for those care costs which are not covered by the health insurance benefits to the cantons. The cantons again could decide to transfer part of these costs to the patients (for details see below: chapter financing and spending). As an answer to this new cantonal financial responsibility, from 2011 on, the canton took away both, financial as well as content-related responsibility for outpatient health and long-term care (apart from the complementary services like meals, mobility services), from the municipalities and instead assumed this responsibilities on its own. According to a member of the cantonal administration, the aim behind this was to bring the responsibility for financing, cost controlling and steering together in one unit – the canton (BE_20110714-01, 3, 57, 63). The background for centralizing was thus a clear interest of the canton in financial and content-related steering of (long-term) care service supply. This included, beneath other, the aim to get an overview of existing services and their organization, to be able to avoid inefficiencies, and to enhance competition or, as a member of the cantonal administration puts it, “to optimize [...], to talk with each other, and to look who has where the best preconditions, and that this would be a reciprocal give-and-take” (BE_20110714-01, 211). Further fields of actions for which the canton claims to assume the responsibility are optimizing the interfaces between acute- and long-term care and in- and outpatient care (GEF, 2011a, p. 17). In this vision of repartition of responsibilities, the municipalities stay with the responsibility for steering the provision of complementary services such as visiting schemes, meal or mobility services (ibid., p. 33). The actual report on ageing policies assigns the municipalities the role to support the canton in shaping and steering the systems of health and long-term care; their responsibility would be to create opportunities for social integration and demand-oriented municipal as well as regionally services (ibid., p. 11). The report does not include the municipalities in the basic principles on design and steering of the system of health and long-term care (ibid., p. 12).

Thus, with its actual financing- and interface-oriented steering approach the canton seems to have distanced itself considerably from the sensitivity of the 1993-guidelines for a planning of ageing-related services that is embedded in the respective local context.

Regarding the governance of outpatient long-term care a process which may be called *corporatisation* seems to be interesting, too: The process of professionalization and fusions of the cantonal Spitex organisations has been accompanied by a cantonal roof organisation of the local Spitex units that are independent of each other. To accompany the process and contribute to the development of common standards, the cantonal Spitex association received some funding from the cantonal government. Thereby it could indirectly promote fusions of local Spitex organisations what finally facilitated the professionalization but also semi-

taylorisation of outpatient long-term care provision. In this, we may not only observe an indirect steering strategy via supporting third sector associations as a corporatist element (what may be regarded as typically for Germany and Switzerland), but we may also recognise a typical pattern of the negotiating public sphere or government: it needs a counterpart for dialogue; thus, in cases, where this counterpart does not yet exist, governments might set incentives to promote the development of such associations or organisations and empower them to a certain, yet limited degree. The aim to negotiate issues thus makes it necessary to define units that are legitimised to speak and at least provide them with a minimum power.

Coordination and cooperation

The aspect of *marketisation* has been introduced with entitling also the for-profit providers to public subsidies seems to have had also notably consequences for the *coordination and cooperation* between the providers at local level: For-profit providers have experienced a revaluation and were conceded caring contracts with the canton. Market is limited insofar as the non-for-profit providers in the first year were reimbursed higher prices for the same kind of services; in turn their contracts comprise the obligation to provide care in their whole catchment area, and they have to give reasons in case that they would reject a client.⁶ For-profit providers in contrast may limit their service-delivery to “attractive” clients, i. e. clients who need a lot of care, so that the share of time that is needed to get from one client to another is relatively little compared to the time that is spent with reimbursed actions.

During our investigation also the issue of services of domiciliary care and attendance was a hot topic in the canton: for-profit providers cover much less for these services than the non-for-profit ones, and there were reflections in the cantonal administration to quit the high reimbursement for the latter.⁷ This clearly *raised competition* between non-for-profit and for-profit providers. The non-for-profit providers in the canton in contrast argue that their domiciliary care and attending services would have preventive and health promoting effects and facilitate an early access to further aids where necessary; this could avoid later expensive inpatient care. Notwithstanding, there are no clear standards that would define the concrete character and quality of services of domiciliary care and attending services and thus would allow to differentiate between different kinds of services here.⁸ As a consequence, these services probably are or will experience a rise in pressure of economisation during the next years.

Quality

As characteristic for Switzerland, quality assurance, especially in the outpatient sector, had formerly not been a prominent issue. It was not until in the 2011-report on ageing policy that the cantonal government also included outpatient care services in its considerations regarding the field of action of quality; this had hitherto been preserved to the inpatient sector (GEF, 2011a, p. 59). Even now the report just states that the setting of minimal standards shall serve the health protection of the clients (ibid., p. 59). The centralization of contracting with the providers at cantonal level still brings the problem of lacking staff to control the adherence of providers to these standards.

A measure that should guarantee quality through participation is the *office of the Ombudsperson* (see below: care market).

Participation

Regarding senior citizens’ participation, the process of economisation actually seems to provide some opportunities to choose who should deliver what services and thus bring with it a shift from “client” to “consumer” or “customer”. This is not yet reflected in the last report on ageing policies of the canton, but

⁶ As reported, from 2012 on the providers are paid the same prices by the canton, but the non-for-profit providers who contract the statutory duty to care receive a fixed price per inhabitant and a fixed price per reimbursable hour of care extra (GEF, 2012, p. 7).

⁷ From 2012 the canton limited the subsidies to the level it formerly had granted to the for-profit providers (GEF, 2012, p. 9).

⁸ The contracts between canton and providers just enumerate the kind of service such as house cleaning, washing, shopping, preparing meals and other (GEF, 2011b, 2011c, 2012).

shows up in the interview with the local non-for-profit Spitex organisation; there, “customer” was used much more often than “client”, what again was used more often than “patient” (BE-20110712-1). Yet, the freedom to choose seems to be actually limited due to the definition of catchment areas and the limitation of the duty to supply to non-for-profit providers whereas the for-profit-providers may reject clients more easily.

Notwithstanding, the question arises in how far clients are really in the role of free, informed, competent, and independent consumers who might freely select the service that would fit best into their demand’s profile.

2.1.5 Financing and spending

Outpatient long-term care in Switzerland is financed by the private households, by public subsidies from general taxes of the federal, cantonal and municipal level (with changing shares) as well as from several branches of the social insurance, above all the health insurance and the old age and survivors’ insurance as well as complementary benefits (“Ergänzungsleistungen”), and social assistance allowance. Reforms of the financing modalities aim at a redistribution of the share of financing between the different financing agents.

Services of home help and care in the 1990ies were financed by the users or their health insurances according to the cantonal tariffs and by the public: the federal level paid contributions to private-law foundations and associations of outpatient care services; not covered operating expenses were covered by the canton and the municipalities; contributions of the latter could be admitted to the financial balancing mechanism between municipalities and canton (GEF, 1995, p. 21).

Regarding the contributions of health insurance, from 2001 on there had been skeleton tariffs which had been negotiated between the cantons and the insurers; with the revision of the financing of long-term care that was adopted at the federal level in 2008, a per hour-cost cap for the contributions of health insurers had been introduced (SPITEX Verband Schweiz, 2010). It was effective from 2011 on and differentiated the costs between three types of care: assessment and counselling, nursing care, and personal care (art. 7, par. 2, EDI, 1995, version 1st March 2011). The regulation of the financing of the surplus costs was left to the cantons.

In the negotiations that preceded the introduction of this performance-based reimbursement,⁹ the non-for-profit providers had asserted themselves with their claim for being paid higher prices for the three types of caring services as well as for domiciliary care than the for-profit providers. Overarching the three categories, the prices per hour that were contracted with the for-profit-providers were on average almost 38% lower than those that had been contracted with the non-for-profit providers who were obliged to guarantee service supply (34% for domiciliary care) (GEF, 2011b, 2011c).

The law further included *a strong element of possible privatization* of outpatient long-term care costs as it admitted the cantons to cover the patients for up to 20% of the highest price category per day (15.95 CHF per day). The implementation of this law was highly contested in the canton Bern: while the cantonal government wanted to involve patients in financing, the parliament opposed this after intense lobbying of the cantonal and local Spitex organisations. Notwithstanding this resistance, from April 2012 all care recipients at the age of 65 and older who are prescribed care by a general practitioner according to the health insurance law and who command of annual revenues of 50.000 CHF or more will be progressively covered for the long-term care they receive up to the maximum of 15.95 CHF per day (from annual revenues of 100.000 CHF on, compare GEF, 2012, pp. 7-8). The canton further reduced its subsidies for domiciliary care; private cost sharing here also is rising progressively according to ones revenues (ibid., p. 9). The canton arguments that the regulation would be socially balanced as patients might apply for complementary services, whereas the Spitex organisations fear that acquiring-opportunities will reduce and argue that this regulation, especially the one on domiciliary care, would set a threshold for patients to make use of the support of Spitex organisations what would lead to a later access to services and in consequence perhaps higher care costs due to higher needs.

⁹ Which is foreseen in the law on social assistance, according to the report on ageing policies of 2011 (GEF, 2011a, p. 32).

A recent study has estimated from a national economic point of view how many hours of daily needed care are cheaper to care for at home and from which number of hours on it becomes cheaper to provide care in a residential care home (Wächter & Künzi, 2011). The study shows the *relativity of the principle of “outpatient before inpatient”* which does neither include that cost differences would be publicly financed nor that infrastructure would be developed according to the principle (i.e. support of the outpatient sector) nor costs would be shaped according to the principle (there is a little tendency in this direction as the canton Bern organises financing in a way that makes long-term care in residential homes for persons with only few care needs more expensive).

Brief description of the local network of home based long-term care for older people

2.1.6 Available services and providers

In the municipality of Köniz, services of home based long-term care as well as complementary and additional services are provided by the local non-for-profit and the for-profit Spitex organisation, by two big charities (Pro Senectute and Swiss Red Cross), the churches, and the two local non-for-profit and for-profit providers of residential care. An overview is given at the website of the municipality (Gemeinde Köniz, 2011a).

Outpatient nursing and long-term care services are mainly provided by the local non-for-profit Spitex organisation in Köniz. Competitors are a small for-profit organisation of long-term care services that is part of an enterprise whose business is mainly residential nursing care, as well as migrant carers whose number we could not assess. The portfolio of the non-for-profit Spitex organisation includes beneath other assessment and counselling, nursing as well as personal care; as complementary services are offered domiciliary care services. There is a specialized unit for wound treatment as well as for community psychiatric care (CPC).

Inpatient long-term care is provided by eight providers of residential care homes at ten locations, underneath them one non-for-profit provider (the former municipal one) with three locations.

The cantonal directive on institutional settings addresses the issue of *security and participation* of elderly persons in need of care. This directive guarantees the right of every institutionalised person to complain with an independent office about being treated unjust (BE-20110628, 7). To implement this right, in 1991 the office of the Ombudsperson was created as an institution of the cantonal association of residential homes; since 2003 it exists as a foundation and receives cantonal subsidies, but works independently (BE-20110628, 9). Its mission first was only to defend the institutionalised elderly persons, but later on it was also charged to be available to clients in the outpatient sector (BE-20110628, 7).

The list of services which is provided by the municipality enumerates altogether seven lunch and dinner tables which are distributed unequally over the different parts of the municipality of Köniz (Gemeinde Köniz, 2011c). Most of them are provided by the residential care homes and by the catholic parish. We could neither assess how often they take place, nor how much the lunch tables in the residential care homes are used by external guests. Meals on wheels is provided by three providers, two residential care homes and one charity organisation (ibid.).

Mobility support is offered by volunteers who are coordinated by the Swiss Red Cross. Visiting schemes are provided via volunteers by the two big charities as well as the three church parishes. These are, apart from the Spitex organisation as far as it concerns its services and beneath the department for ageing affairs of the local authority, also the most important providers of information and counselling on financial issues and possible support.

Regarding medical care, the list of services which the municipality provides enumerates 16 general practitioners and 13 specialists for internal medicine (Gemeinde Köniz, 2011b). In and around Bern, there are three hospitals.

2.1.7 Reconstruction of the governance network

The governance network regarding outpatient long-term care services in the municipality of Köniz encompasses only a few actors who represent the cantonal and municipal administration as well as a few local providers and charities; most of the actors know each other already for several years.

On the public side, the most important actor seems to be the *cantonal office for ageing and disabilities* (Alters- und Behindertenamt, ALBA) as part of the cantonal department for health and welfare (Gesundheits- und Fürsorgedirektion, GEF); at municipal level there is an office for ageing, youth and integration as part of the department of education and social affairs. From the reports on ageing policies from 1995, 2004, 2007 and 2011 we may retrace the development of leading ideas of the cantonal administration and policy (see also above: care problems). First of all, we may state that with the 1993 guidelines, the canton set already a framework for the municipalities' ageing policies, while in the same time it clearly assigned responsibility for the concrete design of service arrangements to the local level.

Ten years later, the canton reframed policies by enumerating certain challenges for ageing policies: It pointed especially to the demographic change which would be related to a probable rise in care needs, a probable decline in care supply, and the probable rise in dementia illnesses (GEF, 2004, pp. 4-6). The report set out nine fields of actions that were also addressed in the reports of 2007 and 2011: 1) supporting independence and health, 2) supporting home help and care, 3) future-oriented living arrangements, 4) services for persons with dementia (2004) / care services in case of ill health in old age (2007, 2011), 5) broad discourse on age-related care, 6) needs-oriented supply of inpatient care, 7) staff recruitment, 8) quality assurance, and 9) revision of financing mechanisms (GEF, 2004, 2007, 2011a). *Independence, "outpatient before inpatient care" and health promotion and prevention* have been promoted as important ideas. These ideas seem to have also fallen under the *pressure of containing costs* as a consequence of the new repartition of financing tasks between the federal and the cantonal level in 2008.

The cantonal office for ageing and disabilities on the one hand seems to assume an active role in shaping the provision of long-term care in the canton, especially when it comes to design the new financing modalities, but also regarding the optimization of interfaces between the different sectors. On the other hand, the office nowadays seems to assign much less importance to the local steering of service structures and interfaces between sectors and services than in the 1990ies, what may be seen as part of the centralization tendency of long-term care affairs during the last few years in the canton.

With the transfer of the responsibility for contracting long-term care services with the providers from the municipality to the canton, the *municipality* clearly has lost influence in the governance network. Notwithstanding, it is still participating in a local round table which has constituted in 2011 (see below). By and by, the formerly municipal providers had been transformed into non-for-profit organisations by private law. The municipal administration is widely said to have had supported the local non-for-profit Spitex organisation by agreeing on an expansion of services – that could be introduced in the financial balancing mechanism with the canton and thus seems to have been reimbursed. The municipality has adopted a concept on age planning in 1998 which was replaced by another concept "Ageing in the municipality of Köniz" in 2007 (Gemeinde Köniz, 2007). In its preface the responsible local councillor sets the aim of a needs oriented expansion of services as well as a continuous adaptation to new challenges (ibid., p. 5); services are seen as facilitators to a life in independence and self-responsibility and –decision, what includes outpatient as well as inpatient services (ibid., pp. 9-10).

Beneath the cantonal and municipal administration, the *providers of services and their associations* are the third group of important members of the governance network of long-term care. For K niz, this is *above all the local non-for-profit Spitex organisation with its manager*. The Spitex organisation has expanded two times by including two formerly independent non-for-profit Spitex organisations; yet, in expanding their bases have been maintained to further assure a decentralized provision of care, even though some functions, e. g. financial controlling, have been centralized. The manager of this organisation is known in the municipality and the canton and assumes an active role in shaping the cantonal and regional conditions for the delivery of long-term care: she is engaged in the policies of the cantonal Spitex association and involved in direct negotiations with the canton. The Spitex organisation of K niz also was one of the organisations who defined additional services and let them evaluate in the process of transformation of the cantonal system of reimbursement into a performance-based one. The organisation and its management were referred to us by several actors at cantonal and municipal level as to be an engaged and innovative one that would provide good care quality.¹⁰

Beneath the local non-for-profit Spitex organisation, *the local providers of residential care* – among them the former municipal and nowadays non-for-profit one as well as a huge for-profit provider – are part of the local governance network of long-term care. They also participate in the above mentioned (see chapter: care market) *strategy platform “Care for the elderly in the municipality of K niz”* which was constituted in 2011.

The *non-for-profit associations* Pro Senectute and Swiss Red Cross act from the city of Bern and are organised at cantonal as well as at regional level. Some interviews gave hints that in some regard they actually might get in a competitive relationship – what on the other hand, seems to be indeed intended by the cantonal administration. Apart from Pro Senectute which claims to be a strong lobbyist for senior citizens concerns, we could not identify a strong civil society based movement of senior citizens which would have tried to influence the shaping of long-term care in the canton or municipality. Notwithstanding, the – also medially accompanied – hot debate on the introduction of the patients’ cost share in long-term care services in the canton was said to have been strongly rooted in the population, especially in the remote and more conservative areas; even though, this is attributed to the strong lobbying of the local and cantonal non-for-profit Spitex associations.

The role of the *church parishes* seems to be focused on providing counselling, cultural activities and lunch tables, whereas we could not establish them as central to the governance of the local system of home based long-term care.

2.1.8 The local authority system

In general, in Switzerland the local authorities are given a huge room for manoeuvre regarding financing, taxes and policies at local level. For long, this also encompassed contracting long-term care services with the former municipal, meanwhile non-for-profit Spitex organisation. Notwithstanding, responsibility for contracting and financing had been separated between municipality and canton as the cost-caps per hour had been negotiated with the canton. The municipality could order a sufficient amount of hours; but reimbursement happened according to the actual performed hours of services, not to the plan numbers. Expenses could be introduced by the municipality into the financial balancing with the canton. As mentioned above, this system recently has been centralized and the canton assumed the responsibility for contracting long-term care services, while the municipalities stayed with the opportunity to contract complementary

¹⁰ E. g., an external observer who himself has an economical education and is used to the analyses of enterprises perceives a high identification with the caring profession and the “mission” of care in the local non-for-profit Spitex organisation; actually, this opinion is based on interviews with employees from this provider; thus the externality of the view is limited. According to this perspective the local Spitex organisation would be parting from the clients’ needs and would have an only moderate economical orientation: there is no extra position of a controller, this task is assigned to the provider’s manager. The obligation to guarantee care would be taken very seriously: if the provider perceives a client as challenging this client would not be dismissed. Instead, an ethical commission would be established that would think on how to deal with this (PS20110713-02, 13).

services such as meals or mobility services. Municipalities have to apply for being admitted to introduce their respective spending into the financial balancing.

Regarding the implementation of the local concept on ageing in the municipality of Köniz, according to a member of the local administration only few of the intermediary measures which have been projected in the concept actually have been implemented, as the money would not have been provided by the local council. Yet, we could not prove this finally.

At least discursively, the municipal administration still claims to be involved in shaping local ageing policies, e. g. by supporting local networking activities of providers from in- and outpatient sectors, day care, volunteers, counselling, by designing public space, by creating barrier-free apartments, by financing additional services which the municipality holds to be necessary (even though this is not yet explicated) (Direktion Bildung und Soziales der Gemeinde Köniz, 2011, p. 8).

3 Analytical section

In the following section we shortly describe the community based psychiatric care service as well as the internal and external knowledge management of the Spitex RegionKöniz which combines a generalist with a specialist approach (3.1). We then give an overview of the process of change, its actors, motives, facilitators, barriers, and consequences regarding the four analytical dimensions (3.2). After having laid this basis, we will go into the more detailed analysis of the addressed problem (3.2.1), the type of change (3.2.2) and factors that may explain the character of the change process (3.2.3). Finally we will evaluate the result of the change: has it facilitated continuity or brought a categorical break (3.2.4)? We will close with a look on the question about perhaps unforeseen and unintended consequences (3.2.5).

3.1 Description of the innovative long-term care-model for the elderly: Knowledge management as a combination of specialist and generalist approaches in care provision – an organizational approach to care quality

Against the background of the above described context of professionalization, standardisation and economisation of service delivery in outpatient long-term care in the canton Bern during the last years, the issue of delineation, standardisation and pricing of services is at stake in the canton. The local non-for-profit Spitex organisation in Köniz has developed its own, specific ways of answering the thereof arising challenges. One of them is the implementation of an internal knowledge management that combines specialist and generalist approaches in care provision which will be presented in the following.¹¹ The combination of generalisation and specialisation of knowledge in one organisation may be regarded as an especially interesting and innovative bottom-up instrument for quality assurance.

During the last years the organisation has implemented an *internal scheme of knowledge transfer and professionalization* that it is still further developing. As it involves the staff of the organisation in general it potentially has effects on all clients.¹² The knowledge transfer scheme consists of professional training and coaching on the job and aims at assuring quality but also at assuring and enhancing employability, motivation and competences of the staff. Thus, this is also an answer to the widely perceived issue of a shortage in professionals in the area of nursing and long-term care. Concretely, the scheme of knowledge transfer provides the staff with the opportunity to meet and exchange experiences and discuss questions and

¹¹ It is important to have in mind, that even though the organisation has been referred to us by several actors, for the presentation of these features we mainly rely on the perception of the organisation itself as well as to a not published evaluation report which was done on commission of the provider as a basis for negotiations on pricing with the canton; due to this, we do not cite directly from this report (Ecoplan, 2011). Thus there is a certain risk for the presentation to be biased. Notwithstanding we may bring this in a line with the general interest-constellation that we sketched in the chapters before and thereby may also judge it critically.

¹² It is important to have in mind, that even though the organisation has been referred to us by several actors, for the presentation of these features we mainly rely on the perception of the organisation itself; thus there is a certain risk for the presentation to be biased. Notwithstanding we may bring this in a line with the general interest-constellation that we sketched in the chapters before and thereby may also judge it critically.

find solutions to care problems that rise from their daily work. Regular opportunities for professional exchange are established as part of the organisational structure, and colleagues with higher professional education and specialized knowledge take actively part as well as those with lower qualifications. An internal system of training and education has been established as well as, in cooperation with the Swiss Red Cross, a course to qualify domiciliary care workers including their enablement to judge if they should refer a certain situation to their nursing colleagues.

Beneath this approach of general qualification, the organisation has also opted for a specialisation of knowledge. Examples for this are *the community based psychiatric care team* and a specialist for wound treatment who keeps herself up-to-date with recent developments regarding her subject and who may be contacted by her colleagues in case of arising questions. The community psychiatric care scheme (CPC) is a low-threshold service that is offered by the provider to clients with psychiatric diseases and aims at providing them with sufficient attendance and care. This service may be interpreted as an intent of the provider to assure comprehensive care under the conditions of a shift to performance-based financing mechanisms which menaced to only include a very limited spectre of actions into reimbursement (the above mentioned three defined care tasks: assessment and counselling, nursing care and personal care).¹³ With this measure the provider hopes to provide an adequate care and low threshold access to services also to clients that are perceived as “challenging” and who would probably reject the provided care – e. g. support with structuring one’s daily living, but also help with the housework – if this care provision would depend on an official declaration of a psychiatric diagnose such as depression, or a messy syndrome. Where an official diagnosis is missing, in the perception of the provider “challenging behaviours” still require bigger efforts to provide a comprehensive care for those persons. Beneath this, the interest of the provider is also to secure the employability and health of its employees who have difficulties to provide adequate care under conditions they perceive as challenging. These conditions comprise the behaviour of clients, but they also seem to result from the basic framework under which long-term care is provided. Staff and clients perceive that there is only little time for the care provision, and care-delivery seems to become more and more oriented at concrete, palpable actions whereas social attendance and communication are not explicitly defined as part of the provision of care. The establishment of the community based geriatric care team addresses these aspects with regard to a group of clients who obviously oppose frequent changes in the attending staff. Regarding this issue, another aim of the CPC is to secure that these clients are attended by only a small number of employees. This shall facilitate communication between the staff and contribute to the development of trust between staff and clients. In difficult situations or when they have questions on how to deal with the needs that these clients express, the staff may address the community based psychiatric care team. Sometimes the regular staff delegates activities to the specialised team which they themselves find too challenging, e. g. removing things out of a flat of a person that is opposing this.

In addition to the established structure of internal knowledge management, the provider networks at municipal level and contributes to professional networking of non-for-profit Spitex organisations at cantonal level (*external knowledge management*): The manager of the provider and her staff organise or contribute to meetings of professionals which are in charge of psychiatric care, domiciliary care, wound treatment, management, and professional education which serve professional exchange and learning (SpitexRegion KÖniz, 2011, p. 7).

Notwithstanding, internal as well as external knowledge transfer is not a service which may be brought into account with the health insurers, even though it is very time consuming. As a consequence, to refinance this element of service-performance results difficult under the recently introduced financing mechanisms.

¹³ It seems interesting that the provider addresses the issue of comprehensiveness of long-term care in its practice, while discursively putting it in question by emphasising the professionalization of service delivery which would perform nothing more than needed. This argumentation serves to delineate the own services from those of a growing competitor: the comprehensive services of migrant carers who live in the households of their clients and – in the view of the local non-for-profit provider – limit the care recipients’ autonomy.

Therefore, the provider indicated the different elements of its approach to knowledge management as additional services to the canton. In 2011 they have been reimbursed. Regarding the future, the canton and the provider (and the providers' associations) were in negotiations about the further development of the future system of long-term care.

Against the background of a widespread shortage in highly qualified professionals, another claim of the local non-for-profit Spitex organisation is to *provide good working conditions* for its employees. The organisation itself claims to pay its employees well and generally give them regular working contracts; thus, they would not only be hired to care for a certain client and dismissed if this care contract ends, but receive regular working contracts (PS20110713-02, 13). Yet, a consequence of this is that the employees often switch between clients. According to a survey which the provider did among its clients, many of them lament that the attending and responsible employees would change frequently. This problem shall be addressed by another measure: the introduction of a relation-oriented care system in which every client is assigned one staff member who is the responsible contact partner.

All these innovative approaches to assure quality operate at the very local or even the organisational level of service delivery. The external knowledge transfer takes place at the cantonal level and also affects other non-for profit providers of long-term care.

3.2 Historic-analytical description and evaluation of the change

3.2.1 Addressed Problem

With the centralization of the governance of long-term care, in 2011 it was the canton and no longer the municipalities who contracted with the long-term care service providers; an obligation for accreditation was introduced, too (GEF, 2011a, p. 33). For the first time, non-for-profit and for-profit providers both received contracts with the public hand and thus qualified for subsidies. Notwithstanding, conditions varied for non-for-profit and for-profit providers and a basic performance-based financing mechanism was introduced: While the non-for-profit Spitex organisations received higher subsidies per delivered hour and care category¹⁴ and therefore had a statutory duty to supply in their catchment areas, the for-profit-providers were contracted lower reimbursements per hour and type of care, but without being subjected to statutory duty to supply (GEF, 2011b, 2011c). It soon became clear that some of the non-for-profit providers would not be able to cover their costs with this remuneration (while others would receive more than before). The more expensive non-for-profit providers partly explained their differing cost structures with different portfolio and different quality of delivered services as well as differences in their respective conditions for service delivery (such as far distances in remote areas or clients with only marginal care needs). To cushion the consequences of the change in the financing modalities, the canton in the first year provided the non-for-profit Spitex organisations with the same budgets as before, and the latter could indicate which additional services they would deliver that would explain the higher costs. These additional services were subjected to an external evaluation. The evaluation should give recommendations if these services should further be financed publicly – either as standard or as additional service – or if their provision was more in the economic interest of the respective provider than in public interest.

The context for outpatient long-term care service delivery in the canton Bern and so in the municipality of Köniz thus was shaped by the *development of a performance-based remuneration mechanism* and uncertainty among the providers about the (future) cost containment ambitions of the canton. What was at stake was *a process of delineation, definition, standardisation, and valorisation of services*. To delineate,

¹⁴ Reimbursement was granted as fixed rates per hour and, newly, one of three categories of care which had been introduced with the revision of the directive on the benefits resulting from the health insurance law: a) assessment and counselling, b) nursing care, c) personal care (art. 7, par. 2, EDI, 1995, version 1st March 2011). This was a change to the hitherto prevailing contracting of cost caps where a maximum price per delivered hour had been negotiated, disregarding the kind of delivered services.

define, standardize and valorise services, it is necessary to have a close and analytical look on which services exactly are delivered and analytically separate them from the comprehensive process of care delivery. The result might be regarded as a shift in direction of *taylorisation* of the care work, even though services were still brought to account per hours, not per service unit.

For the setting of standards it is necessary to decide about their logic and define a minimum standard for each service and how this should be priced. The canton seems to favour to rather set minimum standards (GEF, 2011a, p. 59). This may be interpreted as to show the cantonal interest to maintain a plurality in providers and to avoid the emergence of monopolies of huge providers and thus to foster competition between providers; an argument against this interpretation is that the canton appreciates reorganisations and fusions of Spitex organisations which would allow them to face the future challenges (ibid., p. 32).

The *special or additional needs of clients with psychiatric disorders and dementia* are another debated issue in the context of rising pressure for cost containment and changing financing modalities. The local non-for-profit Spitex organisation and its cantonal roof association argue that providing adequate domiciliary and social care with and for these clients would need more time than in other cases and a special qualification of the carers. A low-threshold access to these clients would be important, as some of them would reject services if they were linked to be attributed as a person with psychiatric condition. Therefore the Spitex argues that it would be important to provide a low threshold access in order to avoid hospitalisations of clients who would reject support and as a consequence would be in need of inpatient care earlier than with the outpatient long-term care services.

Social attendance, that is time to talk, to reflect and plan the day, gone experiences and upcoming tasks, seems to be another care need which is perceived by the Spitex organisation. It is neither part of basic social care nor of nursing care; it may be conceived as part of basic psychiatric care which beneath other comprises measures for the supervision and support of persons with psychiatric conditions in their every-day-life, e. g. development and practice of a structured day, training for the promotion of social contact, or support with using orientation aids and security measures. Thus, basic psychiatric care seems to – at least partly – address some quite *typical needs of persons with dementia, but also isolated persons*.

Another controversial issue is the *publicly accepted and subsidised quality of help with housework*: while the canton refers to the fact that for-profit long-term care providers as well as specialised facilities offer help with the housework for much lower prices than to the non-for-profit long-term care providers, the latter argue that they provide housework by staff who are especially trained to recognize further needs of long-term care or dangers which they might prevent, e. g. falls, and provide some social attendance in the same time. While the cantonal government had plans to reduce the income-related subsidies care recipients could receive for these services,¹⁵ the non-for-profit Spitex organisations claim *domiciliary care to be a part of prevention and health promotion*. This clearly links to the cantons position to regard prevention and health promotion to be one of the most important pillars of the cantonal ageing policy as they contribute to the maintenance of existing abilities (GEF, 2011a, p. 7). The prominent discourse and normative idea of the importance of *prevention and health promotion is here referred to in function of legitimising public subsidies for the service*. An employee of a local non-for-profit long-term care provider states that they had done their work in the same, highly qualitative way for some years, but without explicitly pointing to the – according to their view already in those times existing – positive effect on prevention and health promotion.

¹⁵ Meanwhile these plans are almost implemented: according to the Berner Zeitung of 15.2.2012, the patients| cost sharing will rise for clients with an annual income above 20.000 CHF, and from an annual income of 50.000 CHF clients should pay for domiciliary care on their own (Holzer, 2012, last access: 5.3.2012).

3.2.2 Type of change

As the local non-for-profit outpatient long-term care service provider can be conceived as a non institutional actor, the original, professional intention to provide good quality of services may be attributed to a non or semi-institutional actor and its normative, professional considerations and ambitions. To develop the kind of services as it has been done in the municipality of Köniz, the local non-for-profit Spitex organisation depended on the generous financing of the municipality. The municipality made use of its opportunity to be reimbursed for expenditures related to long-term care services and complementary services via the mechanism of financial balancing between canton and municipalities and among the municipalities. Thus, the convenient opportunity structure for the local Spitex organisation may be attributed to a cooperating institutional actor who himself could rely on a advantageous institutional framework – that is: the mode and content of financial balancing between federal state and canton as well as the mode and content of financial balancing between municipalities and canton – that had been set by federal and cantonal institutional actors.

The changes in this opportunity structure –changes in financing responsibilities, logics, and modalities – to a large extent build the context for the implementation of the original innovation and finally contribute to shape it. These changes in the issue of financing may be attributed to institutional public actors and top-down logic. The processes at stake set strong incentives for long-term care service providers to revise and (re-) define the services which they deliver according to these incentives.

Notwithstanding, there are further elements of bottom-up-processes and social learning: successful lobbying of the regional Spitex organisation with parliamentarians and in the rural, remote areas. An example gives the failure of the cantonal government to introduce to cover patients part of the costs for long-term care services that are prescribed by the doctor but above the limit the insurers pay for. Due to the mobilisation activities of the regional Spitex organisation and the rootedness of Spitex care in the rural areas the obligation of private financial contributions could for a first moment be fended off. Party politics were addressed, and a very broad coalition in the cantonal parliament from far right to the middle voted against the obligation. Even though, in the second step the cantonal government asserted its position in 2011 and introduced a progressive and income-tested private cost share regarding services of outpatient personal care and domiciliary care from 2012 on.

All in all, in the case of Köniz a bottom-up initiative from a non- or semi-institutional actor is implemented by this actor in an environment under change that is driven by institutional actors and shapes the implementation and discursive framing of the innovative practice.

Regarding the analytical dimensions provided by Streeck and Thelen (2005, p. 31), the most adequate description of the Köniz case seems to be *displacement*: quality seems to be of a slowly rising salience and is actively cultivated by the local organisation inside the existing institutional setting; management practices which before had been unfamiliar by and by have been applied. Both takes not only place in this single provider, but can be observed as a more general process in some of the cantonal Spitex organisations and in the cantonal Spitex association that provides e. g. standards for service delivery and promotes fusions of organisations.

3.2.3 Explanation of the process of change (regarding the national and the regional level)

Providers assume and perceive that clients are interested in a care that is comprehensive and universalistic. Thus, one challenge for the local provider is to provide comprehensive care¹⁶ in the cantonal context of economisation and quasi-taylorisation. In Köniz, the local provider developed a comprehensive care strategy.

¹⁶ The comprehensive character yet stays quite limited what may not only be attributed to aspects of the long-term care system but also to the historically transferred self-understanding of the non-for-profit long-term care providers. E. g. for long time there has been considerable reluctance at the side of the non-for-profit providers to expand the guaranteed services such as providing a standby service by night or even regular attendance by night or very early or late services (even though the provider in Köniz offers these services).

It did so despite the evolving opposite logic of the respective long-term care system which does not encompass time-intensive care situations as they result from dementia illnesses or patients' behaviours that are not diagnosed as psychiatric diseases but still are perceived by the providers' staff as challenging. Against the background of the transition to the performance-based remuneration logic in the canton, the provider had to make explicit its organisational practice and clearly define it as "additional services". This practice may be held as part of an ongoing process of delineation, definition and valorisation of services in the canton. Thus, the addressed problem raised less from changed needs of clients but actually more from the changed logic of financing of services.

The innovation that is under investigation here, addresses (indirectly, not by intent) the little preoccupation with general and binding standards for quality assurance in outpatient long-term care. There are only little quality requirements at national level. In the case of the canton Bern there are also only little explicit standards at the cantonal level, and controlling staff is lacking. The change could take place thanks to the federal financing of the non-for-profit providers of outpatient long-term care in their beginning, and later it was promoted by the mechanism of financial balancing between the canton of Bern and the municipalities which provided the local Spitex organisation with enough money to develop its services and hire highly qualified staff. With changes in financing that were induced by the federal as well as by the cantonal level, the local non-for-profit Spitex organisation of Köniz had to legitimize its high amount of working hours that are not reimbursable according to the health insurance law as they do not correspond to caring activities as they are defined in the health insurance law. The local non-for-profit Spitex had to show the canton that its services in terms of qualifying staff and providing a dense system of knowledge transfer and communication would contribute to a common interest of high quality of care and would go beyond a mere business interest (in terms of competition). This put the organisation under pressure to clearly delineate and define its services and argument how they would contribute to a common interest. Part of this is the only recently explicit argumentation that provided domiciliary services would be of a strong preventive character.

3.2.4 Evaluation of the result of change: continuity or discontinuity regarding our four dimensions

Regarding our four analytical issues – governance, coordination and complementarity, participation, and quality – the described change has had varying impact:

Regarding *governance*, it seems plausible to conclude that the non-for-profit provider could gain some influence due to its well-networked, engaged and canton-wide visible management. The *process of the evaluation and its discussion* serves the canton, the Spitex organisation and the evaluating institution as a mechanism for the joint discussion of the further development of the system of long-term care in the region, e. g. regarding how to handle with the issue of the statutory duty to supply, and thereby may be held a *governance instrument in itself*.

When we look on *coordination and complementarity*, it becomes clear that the provider sees itself in the centre of care management. Interfaces with other sectors are still perceived as problematic, even though also this issue was addressed by an exchange project of the provider with one of the three hospitals in the region. Migrants are not addressed as a special target group; we could not assess if this means that they are actually excluded or that their inclusion is taken for granted.

The canton of Bern, like other Swiss cantons, has observed a process of professionalization of services of long-term care from local nurses who had provided outpatient care on the basis of an altruistic attitude and voluntary engagement over the establishment of municipal outpatient care services to the foundation of the non-for-profit Spitex organisations which aim at providing outpatient care according to common standards. This process is not yet accomplished, and there still remain ambivalences and opposition to this development. Notwithstanding these remaining ambivalences and differences, the processes of professionalization and economisation seem to have had an implicit effect on quality issues: Professionalization seems to have partly

enhanced quality and comparability of services which culminated in the catalogue of standards which the non-for-profit Spitex organisations adopted in 2007 with the aim to implement them within four years. E. g. as there is a continuous pressure on providers to provide at least a basic service at nights and weekends. Even though, many of our interview partners emphasise the remaining strong differences in the character of the various non-for-profit providers. On the other hand, economisation – that is the introduction of a performance-based financing mechanism as well as enhancing competition between non-for-profit and for-profit providers – seems to lead to trade-offs regarding quality: Protagonists perceive that services have to be delivered under much more time pressure, more taylorized and less comprehensive.

The other side of the coin of the long-standing negligence of *quality issues* in outpatient long-term care is that staff in management positions in well-financed providers like the one in Köniz had the *opportunity to shape the quality* of the locally provided services. This allowed internal, autonomous and self-defined quality development at high-level instead of just fulfilling external requirements. Further, the association of non-for-profit Spitex organisations has developed and after ten years revised and complemented a manual on quality which the local organisations may implement in their practice. The local Spitex organisation that is investigated here seems to have developed such an approach of professionalizing which may be retraced to a kind of professional proud as well as a strong orientation on patients' needs. An interview partner who is no member of this non-for-profit provider assigns the management of this organisation the aim of spreading “the right thing” even without receiving money for it. Beneath this, another motivation of this provider to develop a high standard of quality seems to be the general shortage of high qualified nursing professionals. The organisation claims to aim with its quality policy at acquiring high qualified and engaged employees whose performance is state of the art. A precondition for this was the existence of sufficient financial resources. This was facilitated by respectively high cost caps that were negotiated with the canton, a supportive municipality (who formerly could indicate respective expenses for the financial balancing mechanism), as well as a supportive board of directors of the Spitex association itself.

Regarding the issue of *participation* we see some ambivalence: notwithstanding the provider claims to assure independence and self-determination of its clients, the frequent change of carers seems to counteract this ambition. The institution of the Ombudspersons has hitherto not been used by clients of the provider. On the other hand, we see a strong commitment of the provider to provide a high *quality* of services as was described above from a professional point of view, but also regarding early access and contributing to health promotion and prevention.

3.2.5 Unforeseen consequences

The logic of the long-term care financing system does not acknowledge time-intense care situations which result from patients' behaviours that are perceived by the providers' staff as challenging, but without being diagnosed as psychiatric diseases. As a solution, the provider operates with the *community psychiatric care scheme* (CPC). This constellation could lead to a kind of stigmatization of patients with “challenging” behaviours who just do not behave in a way that allows an ‘efficient’ delivery of care.

3.2.6 Summary of the analysis and evaluation of the change

The basic discourse and political process in the canton at the moment is on delineation, definition, valorisation, and financing of services of home based long-term care. The political conflict at stake is on how to define quality, on what quality is in whose interest, and on who has to pay for what. The change which was investigated here may be regarded as an answer to this. There may be established a twofold motivation behind the development and definition of the described internal knowledge management which encompasses a mode of comprehensive care delivery for clients that are perceived to show challenging behaviours. On the one hand, it has been motivated by the challenge of rising and changing care demands, e. g. a rising share of dementia illnesses and the accompanying needs of the clients. On the other hand, the transition to a

performance-based remuneration system and the cantonal ambition to introduce uniform contracts and prices for non-for-profit and for-profit providers has set a strong incentive to specify the concrete elements of the quality of the provided services. As far as we might tell from our interviews, the manager of the provider was a central character in promoting these elements of service provision. Notwithstanding, the manager's ambition had been backed by the board of the providers association as well as by the staff. Facilitating factors were the sufficient financial resources on which the provider could count for long time as the municipality also backed the expansion of services. Another important factor that surely facilitated the development of these – more expensive – services is the strict limitation of competition for long time: the quasi-monopoly of the organisation had been preserved as long as the for-profit providers had not been admitted to public subsidies; and still the non-for-profit providers are assigned disjunctive catchment areas. The change further had been facilitated by the sufficient financial resources under the former financing regime as well as by a pronounced professional self-understanding, a very engaged and multiply qualified management and a supportive providers' association at local as well as at regional level. In addition, also the historically strong roots in the population and the quasi-monopoly of the provider in its single-catchment area seem to have contributed to a strong position and good financing.

The parallel processes of professionalization and economisation thus had ambivalent effects: While professionalization seems to have contributed to quality and comparability of services, economisation seems to have led and lead to a semi-taylorisation of service delivery. The protagonists at least perceive that services have to be delivered under more pressure and with trade-offs regarding the relational quality.

All in all, the strategy of the local non-for-profit long-term service provider in Köniz may be described as making use of the ongoing trends of professionalization and economisation to oppose parts of their consequences.

4 Literature