

# CEOQA

LTC network

Quality and cost-effectiveness in long-term care and dependency prevention



## COUNTRY REPORT

# The German LTC policy landscape

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# Quality and cost-effectiveness in long-term care and dependency prevention: the German policy landscape

## I. Introduction

The establishment of the long-term care (LTC) system in 1994 introduced a new branch of social security within the German welfare state (Social Code Book 11, or SGB XI) – which has seen dramatic expansion in benefits in recent years, particularly for those affected by dementia (Rothgang & Kalwitzki, 2015; Rothgang, Müller, Mundhenk, & Unger, 2014). After nearly two decades of waxing and waning political debate, the introduction of the LTC system in 1994 emerged as a response to ongoing socio-economic and demographic challenges facing Germany (Götze & Rothgang, 2014). These included the rising demand for LTC services due to an aging population coupled with constant low birth rates since the early 1970s; a growing feminization of the workforce that rendered the traditional unpaid female caregiver model increasingly obsolete; as well as the lingering effects of the economic turmoil of the 1970s (ibid.). In more recent years, demographic challenges have been particularly salient. Germany presently has one of the world's fastest ageing populations, with people aged 65-79 accounting for 15.4% of the population and those aged 80 and over accounting for 5.4% (Golinowska, Huter, Sowanda, Pavolova, Sowa, A., & Rothgang, 2017). Both figures lie above the European Union (EU)-28 averages of 13.4% and 5.1% respectively (ibid.). These trends have been accompanied by life expectancies that are commensurate with EU averages, but also by lower levels of healthy life expectancy at birth compared with other EU member states (ibid.). Germans are therefore older and living longer with disability than other Europeans, trends which promise to continually drive up demands for LTC services in years to come.

Given demographic pressures, the highly restrictive legal definition of 'need for care' that characterized the German LTC system at its foundations has since been the subject of various reforms. In recent years, the issues of improving access to services through a new definition of entitlement and as a matter of social justice have been key policy goals (Rothgang, Müller, Mundhenk, & Unger, 2014; Rothgang, Kalwitzki, Müller, Runte, & Unger, 2015). Whereas a concern for access in a maturing LTC system has taken centre stage in German policy discourse, a number of other areas and activities are also salient. Most notably, a burgeoning interest in defining and ensuring the quality of care (Hasseler 2014; Rothgang 2017), as well as in expanding social protection for family caregivers can be observed. In what follows, we provide an overview of the various themes that have shaped the German policy landscape over the past ten years, before proceeding to discuss how they relate to the four policy themes of interest to the present project – namely, reducing dependency cost-effectively; supporting unpaid carers; use of innovative care models/technologies; and strategies for maximising care coordination. For the purposes of establishing context, we begin by outlining the basic features and organization of the German LTC system.

## II. Organization of the LTC system in Germany

The German LTC system is based on a model of subsidiarity which emphasizes a strong role for informal care alongside formal care services offered within the individual's home, with institution-based care viewed as a last resort (see Rothgang 2010 for details). Amongst the system's various policy objectives (see e.g. Schulz 2010), an interest in

enabling the autonomy of beneficiaries for as long as possible – and thereby reducing dependency on inpatient care – as well as formally recognizing the contributions made by unpaid carers have been central. The LTC system was created with one major prerequisite in mind – strict cost control – which would be achieved through capped benefits and a tight definition of the ‘need for care’ and thereby by recourse to a narrow entitlement rule (Götze & Rothgang 2014). This prerequisite has often been at odds with the LTC system’s other main policy objectives, which include:

- Providing social security against the risk of needing care in a manner that is akin to insurance against illness, accidents and unemployment, and protecting income in old age;
- Helping to reduce the physical, mental, and financial stresses related to need for care;
- Enabling persons to stay in their homes or to ‘age-in-place,’ as long as possible, with services based on the principles of prevention and rehabilitation before care, outpatient care before inpatient care and short stay care before full-time inpatient care;
- Improving social security for caregivers who are otherwise not employed in order to encourage people to provide care for relatives/friends and to compensate for the effects of having to give up employment in order to become a caregiver;
- Expanding and consolidating the care infrastructure and encouraging competition amongst service providers (Schulz 2010: 1-2).

### Coverage

The 1994 Act introduced a mandatory system covering the entire population. Anyone covered by social health insurance mandatorily (i.e., employees earning up to a certain income threshold, pensioners and family members who do not earn more than €425 per month) or voluntarily (i.e. high earners with a gross monthly salary of more than €4,390 who choose not to opt-out, as well as civil

servants and the self-employed who choose public rather than private health insurance) is automatically included in the social long-term care insurance (S-LTCI) scheme. For those holding private health insurance, a mandatory private LTC insurance (P-LTCI) policy offering benefits at least as high as S-LTCI must be purchased. In 2007, when health insurance was made compulsory for all, LTCI also became mandatory. Unlike other LTCI systems, for example that in Japan, entitlement does not depend on the age of the individual, nor does it depend on income or wealth. However, more than 80% of all beneficiaries are aged 65 years or older; and more than 55% are at least 80 years old (Rothgang Müller, Mundhenk, & Unger 2014). The two-tiered system currently covers almost 90% of the population under S-LTCI and special systems for the police, the military and the fire service, and some 10% under P-LTCI (ibid). Together, the LTCI Funds contract directly with service providers which have the right to be contracted as long as certain technical prerequisites are met, irrespective of any assessment of ‘need’ for a new care service to enter the market.

### Administration

S-LTCI is administered by the LTCI Funds which were founded as branches of the Sickness Funds of the social health insurance system. S-LTCI is independent but under the umbrella of health insurance. Unlike in the case of health insurance, however, there is no competition between the funds, as contributions go into one fund which covers all expenditure. Competition only takes place at the provider level. Compulsory P-LTCI instead is administered by private health insurance (PHI) companies: this is the first time in German welfare state history that private insurance has taken on a public, regulatory task (see Wasem 1995 for details). This included the right for all PHI companies to impose a mandate on members to buy P-LTCI policies. It is worth noting that all PHI companies have to accept all entitled applicants, regardless of previous health status.



## Financing

S-LTCI is a pay as you go system, with contributions levied on income from wages and salaries up to a certain income cap. The contribution rate, which in 2017 stands at 2.55%, or 2.8% for persons without dependents, is set by Parliament. Half of the contribution rate is paid by employers and the other half by employees. (In order to compensate employers a bank holiday was eliminated when the LTCI was introduced.) Contributions are made in relation to income (excluding assets), not risk. In the event of unemployment, S-LTCI contributions are taken up by the unemployment insurance, whereas the self-employed and pensioners have to pay full contributions by themselves. P-LTCI on the other hand is a funded scheme in which members build up provisions for old age during their healthy years and pay premium rates based on risk-rating versus in relation to income. Compared to private health insurance, however, risk rating is much less comprehensive: gender and health status are not taken into consideration in calculating premiums; pre-existing conditions may not be excluded from coverage; and P-LTCI companies may not charge more than the maximum contribution rate of S-LTCI. In addition to insurance contributions, in order to meet gaps in coverage especially for institutional care, out-of-pocket payments and social assistance also play an important role in financing (see e.g. Rothgang, Kalwitzki, Müller, Runte, R., & Ungar, 2016). Since 2013, subsidized private supplementary LTC insurance is available (so-called 'PflegeBahr'). However, less than 1% of the population has taken advantage of this so far, while about 3% of the population holds unsubsidized private supplementary LTC insurance (see Jacobs & Rothgang 2012).

## Benefits

LTCI benefits are defined by law and are capped or take the form of lump sums. Beneficiaries can choose between home care, day and night care, and nursing home care. In the case of home care, recipients can choose between in-kind benefits for community care by professional service providers,

and cash benefits at a lower value – typically half that of professional community care. Where the latter is chosen, the use of cash benefits is at the beneficiary's discretion, and he/she may choose to pass on the payment to a family caregiver. Hence, informal home care is formally recognized by the German LTCI system, and, as in earlier years, is still seen as the first resort for caregiving. Meanwhile, community care is provided by both non-profit and for-profit organizations, and their costs are covered, up to a cap, by the insurance funds. Cash and in-kind benefits can also be combined, and since 2015 the use of day care or respite care no longer reduces claims for cash or community care.

For both types of benefits for home care, payments are made in line with grades depending on the assessed level of care for the beneficiary. Originally, levels I-III were available, supplemented since 2007 by a 'level 0' aimed at providing care especially for individuals with cognitive impairment who do not qualify for level I or above (to be discussed). Care assessments are carried out by the Medical Review Board (*Medizinischer Dienst*, MDK) for S-LTCI members and a private company, Medicproof, for the privately insured. At levels I and II, benefits for people in institutional care are higher than in-kind benefits for people receiving care within the home. Beneficiaries opting for in-kind benefits can choose among the service providers with which LTCI funds have contracted; and can also choose the specific interventions (from a catalogue of services) they wish to receive from their chosen provider. In an effort to encourage competition, the service provider market has been opened to both public and private providers of at home care. This has led to a large influx of private providers servicing both social and private insurance beneficiaries (Rothgang, Sünderkamp, & Weiß, 2015b).

Despite its significantly lower value – about half that of in-kind benefits – the cash payment option has enjoyed greater popularity, reflecting the consistent preference of beneficiaries for care provided by a relative or friend over a professional service provider: in 2015, for example, whereas 1,330,000 S-LTCI insurees took up cash benefits for care, only

181,000 opted for in-kind services. A further 408,000 combined cash and care, with 677,000 staying in a nursing home (Rothgang, Kalwitzki, Müller, Runte, & Ungar, 2016: 72). In recent years, however, a small and gradual increase in the number of beneficiaries opting for the in-kind service option or for mixed awards of cash and services can be seen (ibid). This is likely to be indicative of demographic trends and family mobility, making it more difficult to have a family member to take on care for a dependent.

In the case of in-kind benefits, providers are contracted and paid directly by the LTCI Fund. There is no role for co-payments formally built into ambulatory services. Beneficiaries receive a budget commensurate with the level of care (now called 'care grades,' as discussed later) they are assigned upon evaluation. The beneficiary then has full discretion as to which services he/she will take up, based on a catalogue of services available. If the beneficiary goes beyond his/her budget, the co-payment is 100% for all services beyond this threshold.

Within this system, cash benefits qualify as non-taxable household transfers which are not explicitly tied or circumscribed to paying for care. There is therefore no monitoring or control as to whether they are in fact being used to pay an informal caregiver, or whether an informal caregiver is actually delivering the care they are paid for. The only control or check comes in the form of an annual assessment carried out by a member of the S-LTCI Board to assess the general care needs and situation of the beneficiary.

With respect to nursing home care, LTCI only contributes to the costs of care, while costs for room and board as well as refinancing of investment costs<sup>1</sup> have to be paid out of pocket. As a result, in December 2015, the average total monthly co-payments at the different levels were €1,520 (level I), €1,736 (level II) and €1,966 (level III). This includes

€681 for room and board and €413 for investment (Rothgang & Domhoff, 2017:139).

The federal government reserves the right to make adjustments to the benefits cap. However, up to 2008, there had been no adjustments, not even for inflation, leading to a decline in purchasing power of more than 20% between 1994 and 2008. Following a reform in 2008, the government is now obliged to examine the need for adjustments every three years. Since then, purchasing power has more or less remained the same in community care, while for nursing home care in levels I and II the decline in purchasing power continued until 2015 (Rothgang, Müller, Mundhenk, & Unger, 2014: 37ff.; Rothgang, Müller, Runte, & Unger 2017: 139ff.).

### III. Major reforms

Over the course of the last ten years, a series of reforms have been passed to strengthen and expand the LTC system. Of the various themes arising within and across the reforms, a concern for expanding benefits and improving access to services and quality of care has been most prominent.

#### Better access to care: expanding benefits and enlarging the number of potential beneficiaries

At its establishment, the German LTC system was characterized by a tight definition of 'need for care' as a means of cost control. By the early 2000s, the Ministry of Health acknowledged the need for reform that would expand access, particularly for dementia sufferers who did not fall within the eligibility criteria for care levels I to III or received low levels of benefits as set against the care demands of their conditions. Until 2002, Levels I to III were based on measures of Activities of Daily Living (ADLs) which failed to capture strictly cognitive impairments. Though cognitive impairments do lead to difficulties in ADLs, those suffering with dementia were particularly seen as receiving insufficient support. With the passing of a critical reform in 2002 (the Pflegeleistungs-Ergänzungsgesetz), a new

<sup>1</sup> Types of costs may vary, but generally refer to building maintenance or property/rental costs.

category for people with dementia, mental handicaps or mental disorders ('Personen mit erheblich eingeschränkter Alltagskompetenz,' hereafter 'PEA') was introduced, granting them new, additional 'extra care benefits' ('besondere Betreuungsleistungen'). However, in community care at the time extra benefits for semi-professional home care services were restricted to people in care level I and were very limited in scope (€460 per year). This led to poor take-up, with only about €25 million spent in 2002–2008, only 10% of the budget allotted for such services (Rothgang, Müller, Mundhenk, & Unger, 2014). Recognizing this problem, the government increased the yearly amount claimable for extra benefits to €1,200 or €2,400 (for more severe cases) per year and also granted them to those below the threshold of care level I, thus introducing a 'level 0' for those not legally defined as care dependents but who have claims against the insurance system. Since then, take-up has grown considerably (Rothgang Müller, & Unger, 2013: 194ff.).

However, the introduction of 'extra benefits' did not provide a systematic solution to the problem of unmet needs, particularly for those suffering with cognitive impairments.

The government therefore set up a process to evaluate the definition of need for care more thoroughly (Table 1). In 2006, an expert commission started to evaluate the adequacy of the definition of entitlements and, in two reports issued in February and May of 2009, argued that there was a need to change it. Though all major political parties approved the results, the legislative process implementing them was hampered by the 2009 general election and the ensuing change in government. As a consequence, the definition of need for care remained untouched until 2012. To show some activity, in the last year of the legislative term the government established another expert commission to resolve some open questions, which reported shortly before the general election in 2013.

Table 1: Commission-based process leading to expansion of benefits

Report(s)	Years	Outcome
First Expert Commission	2006–2009	Two reports (2009): Suggested a new assessment and definition of entitlement; made more detailed suggestions for its design.
Second Expert Commission	2012–2013	Report (2013): Made suggestions for the implementation of a new definition of entitlement.
Third Expert Commission	2016 on	Oversees the implementation process.

Additionally, the Long-term Care Adjustment Act (2012) was passed, signalling some improvement for people with dementia. As part of the Act, people with dementia in care level 0 enjoyed, for the first time, access to regular cash and in-kind benefits, while the caps for PEA in care levels I and II were increased.

After the 2013 general election, the government initiated legislation to introduce the new entitlement

rules. The three expert commission reports formed the basis of a series of legislation ('Pflegestärkungsgesetz' I, II and III) culminating in new entitlement rules in 1 January 2017. The rules contained a broader understanding of need for care that systematically incorporated cognitive impairment (Rothgang & Kalwitzki, 2015). Table 2 delineates the major changes in benefits from 2008 to 2017.

Table 2: Expansion of benefits

Reform	Year	Changes in benefits
The Long-Term Care Development Act (Pflege-Weiterentwicklungsgesetz)	2008	Cap for extra benefits (semi-professional, home care benefits) was increased from €460 annually to €1,200 or €2,400. Entitlement to these benefits was extended to people falling beneath care level I, effectively creating 'care level 0.'
The Long -Term Care Adjustment Act (Pflege-Neuausrichtungs-Gesetz)	2012	Entitlements for cash and in-kind benefits were extended to PEA in level 0. Respective benefits for PEA in care levels 1 and 2 were increased.
The Long-Term Care Strengthening Act, Parts1–3 (Pflegestärkungsgesetz (PSG) I, II and III)	2015–2017	A new definition of 'need for care' or entitlement eligibility was formulated and took effect on 1 January 2017.



Along with the new entitlement rules, amounts of benefits had to be fixed for the new ‘care grades.’ For existing beneficiaries in ambulatory care, care levels were transformed into care grades which

resulted in substantial increases in benefits for more than 95% of existing beneficiaries (Rothgang, et al 2015a: 41ff., Tables 3 and 4).

Table 3: Cash benefits

Care level/grade	Benefits as of 2015 (€)	Care level/grade as of 2017	Benefits as of 2017 (€)
0 with EA*	123	2	316
I	244	2	316
I with EA*	316	3	545
II	458	3	545
II with EA*	545	4	728
III	728	4	728
III with EA*	728	5	901

Table 4: Ambulatory, in-kind benefits

Care level/grade	Benefits as of 2015 (€)	Care level/grade as of 2017	Benefits as of 2017 (€)
0 with EA*	231	2	689
I	468	2	689
I with EA*	689	3	1,298
II	1,144	3	1,298
II with EA*	1,298	4	1,612
III	1,612	4	1,612
III with EA*	1,612	5	1,995
Extreme case**	1,995	5	1,995
Extreme case** with EA*	1,995	5	1,995

\* EA refers to ‘Eingeschränkte Alltagskompetenz’ in German, roughly ‘reduced capacity for daily living’ in English. This term and the respective term ‘PEA’ is no longer in use since 2017.

\*\* An ‘extreme case’ is translated from the German ‘Härtefall’ and refers to care receivers in level III whose needs are especially resource intensive (e.g. illnesses in end stage; severe paralysis; advanced dementia etc.). The proportion of ‘extreme cases’ has legally been limited to 3% of all care receivers in level III in home care.

Source: Adapted from Rothgang, Kalwitzki, Müller, Runte, & Unger, 2015: 42.

For some care dependents in nursing home care, benefits in the old care levels were higher than in their respective new care grades (Table 5). However, the difference is covered by the LTCl, ensuring that

in nursing home care, as in ambulatory care, the co-payment does not exceed the amount paid before the reform.

Table 5: Full-time, nursing home care benefits

Care level/grade	Benefits as of 2015 (€)	Care level/grade as of 2017	Benefits as of 2017 (€)
		1	125
0 with EA*	0	2	770
I	1.064	2	770
I with EA*	1.064	3	1.262
II	1.330	3	1.262
II with EA*	1.330	4	1.775
III	1.612	4	1.775
III with EA*	1.612	5	2.005
Extreme case**	1.995	5	2.005
Extreme case** with EA*	1.995	5	2.005

\*EA refers to 'Eingeschränkte Alltagskompetenz' in German, roughly 'reduced capacity for daily living' in English. This term is no longer in use since 2017.

\*\*An 'extreme case' is translated from the German 'Härtefall' which refers to instances in which care needs are especially resource intensive (e.g. illnesses in end stage; severe paralysis; advanced dementia etc.).

### Ensuring quality through the better definition of standards

Despite earlier attempts to prioritize quality as a main policy objective in the German LTC system (see e.g. Igl, 1999; Bieback, 2004; Ollenschläger, 2007; Rothgang, 2017) – which also included the passing of the LTC Quality Assurance Act of 2001 (Pflege-Qualitätssicherungsgesetz) – it was not until 2008 that mandatory internal quality management and expert standards of care were introduced (Schiemann, Moers, & Büscher, 2014). More specifically, the LTC Development Act of 2008 increased the frequency of quality control by a factor of ten and required extensive reporting on the

part of nursing homes so as to increase transparency and competition amongst providers of inpatient care (Hassler, 2014). As the provider organizations had to agree on the criteria for reporting and service providers quickly learnt how to receive good results on these criteria almost all providers get top marks. As a result the published 'care quality grades' are useless for potential users (Sünderkamp Weiß, & Rothgang, 2015). Despite the increased emphasis on reporting, therefore, there is still a paucity of reliable data that might provide a comprehensive picture of quality in German LTC (Hassler, 2014). The lack of reliable data derives

partly from systemic limitations that do not allow for the development of indicators of quality that go beyond infrastructural and procedural aspects. Given the large influx of private providers of inpatient care in recent years, for example, an assessment of differences in quality of care between the public and private sectors has been carried out (Weiß, Sünderkamp, & Rothgang, 2014). However, this too is limited to structural indicators of quality (e.g. number of beds; staff to patient ratios) as opposed to direct measures of outcomes of care (ibid; Hasseler, 2014). Interestingly, findings point to no significant differences between private, social, or public providers. Nor does quality of care – measured accordingly – seem to depend upon size, ownership, or regional settlement (Weiß, Sünderkamp, & Rothgang, 2014). Given the limitations of such research, only tentative conclusions can be drawn. Generating strong evaluative research on quality is a crucial next step for policymakers and academics alike.

This is also true for another recent development aiming at ensuring quality: the introduction of ‘expert standards of care’ (‘Expertenstandards’) which give detailed advice on certain issues such as prevention of bedsores, chronic wounds, management of chronic pain, maintaining and encouraging mobility, etc. (see [www.dnqp.de/de/expertenstandards-und-auditinstrumente/](http://www.dnqp.de/de/expertenstandards-und-auditinstrumente/)). Although ten expert standards have been developed so far, there is little evaluation of their effects (see Rothgang, 2017).

## IV. Policy themes

### Policies aiming to reduce dependency cost-effectively

Over the course of the past ten years, key efforts to reduce dependency have focused on health promotion and prevention activities that address the entire life course. These have culminated in the definition of national targets for ‘Healthy Ageing’ in 2012 (BMG, 2012), followed by the passing of the Preventive Health Care Act (Präventionsgesetz or PHCA) of 2015 (BMG, 2015). As concerns the

former, a process of defining national health targets was initiated as early as 2000 in line with a resolution of the Conference of Health Ministers in 1999 (Golinowska, Huter, Sowanda, Pavolova, Sowa, & Rothgang, 2017). This resulted in a detailed report on ‘Healthy Ageing’ as one of eight targets. The report comprised guidelines and recommendations focusing on three areas of activity in particular: (1) health promotion and prevention to preserve autonomy, including efforts to increase social participation and physical activity, as well as to improve the diet and oral hygiene of the elderly; (2) better access to medical and psychosocial services and nursing care; as well as improved conditions for caregivers; and (3) endeavours to address the special challenges surrounding the wellbeing of older disabled people, such as the improvement of mental health and dementia (ibid.: 26).

Despite the introduction of national health targets, however, great variation in the nature and scope of health promotion/prevention activities continues to exist between and within states in Germany, mainly owing to the dominant role of regional and local actors in the design and implementation of programs (Golinowska, Huter, Sowanda, Pavolova, Sowa, & Rothgang, 2017). Accordingly, one goal of the PHCA of 2015 has been to institutionalize a framework for cooperation that integrates a wider range of actors and levels in the development of interventions, with a far more pronounced role for the social insurances.<sup>2</sup> The law has also aimed to increase early access to LTC services as a means of delaying progression to advanced care level grades – and thereby more costly forms of dependency. Accordingly, the Peak Association of the LTC Insurances was assigned the task of drafting changes to the evaluation guidelines in advance of the new definition of ‘need for care’ which took effect in January 2017.

<sup>2</sup> The PHCA relies on the cooperation of the private health insurance schemes and P-LTCI; however, it centres on the social insurance system which falls within the jurisdiction of the federal government.

To summarize the main policy objectives and changes introduced by the PHCA, it has established

- a new mandate for prevention within the S-LTCI system, which also provides for activities to promote the health of those already in nursing home care;
- a strong emphasis on vaccination as part of all routine health check-ups, as well as allowing health and nursing care facilities to turn down job applicants based on vaccination history (i.e. absence of vaccines);
- a commitment to developing programs aimed at the personalization of early detection and risk of disease for all age groups;
- a financial commitment on the part of the health and LTC insurance schemes to invest more than €500 million per year in setting-oriented (i.e., child care facilities, schools, work place, nursing homes etc.) health promotion and prevention activities, which are considered more effective than individual-centered activities such as participation in courses;
- increased financial support (around €30 million more) for self-help groups; and
- new measures to improve cooperation and coordination among policy actors involved at various levels in health promotion and prevention for all age groups; as well as new forms of cooperation between all branches of the social insurance system (health, pension, accident, and LTC) involved in health promotion and prevention.<sup>3</sup>

Also of critical importance, the PHCA introduced a new central structure referred to as the National

Prevention Conference ('Die Nationale Präventionskonferenz' or NPC) which consists of representatives of the social insurance funds and private health insurance funds; as well as a consultative role on the part of the federal and state governments, the Federal Employment Agency, various social partners, patient representatives and the Federal Association for Prevention and Health Promotion ('Bundesvereinigung Prävention und Gesundheitsförderung e.V.') (Golinowska, Huter, Sowanda, Pavolova, Sowa, & Rothgang, 2017). Thus far, the main contribution of the NPC has been the development of a National Prevention Strategy, which included the adoption of national basic recommendations on health promotion and prevention in 2016 (NPC, 2016). The recommendations incorporated a focus on healthy ageing and defined relevant areas of activity, target groups and participating institutions. The recommendations presently serve as a basis for framework agreements being adopted by the 16 German states ('Bundesländer'). They will further specify the responsibilities and coordination activities of public health institutions and service providers. Just how these efforts will ultimately translate into programs and projects, as well as their potential for reducing dependency, remains to be seen.

As concerns activities already underway or else concluded within the last ten years, various good practices have been cited in the literature (see e.g. BZgA, 2015; Golinowska, Huter, Sowanda, Pavolova, Sowa, & Rothgang, 2017). By way of example, a number of these are highlighted in Table 6. Activities include a range of nationwide healthy lifestyle campaigns; programs targeted at specific sub-groups of the elderly population, such as those with migrant backgrounds; regional projects; research projects; as well as EU-funded actions involving significant involvement by German institutions.

<sup>3</sup> For an overview of the Prevention Law (in German), see the Ministry of Health website: [www.bundesgesundheitsministerium.de/themen/praevention/praeventionsgesetz.html](http://www.bundesgesundheitsministerium.de/themen/praevention/praeventionsgesetz.html).

Table 6: Examples of good practices in health promotion and prevention

Activity/project/program	Years	Description/objectives/results
National Action Plan 'In Form'	2008–ongoing	<p>A nationwide plan encompassing various projects, activities, and on-line resources. Established in 2008 by the Ministry for Nutrition and Agriculture, as well as the Ministry of Health, In Form aims to improve the eating and activity patterns of people in all areas of life and at all life stages including old age.</p> <p>See: <a href="http://www.in-form.de">www.in-form.de</a>.</p>
Fit im Alter – Gesund essen, besser leben (Fit for old age – eating healthy, living better)	2008–ongoing	<p>Part of the National Action Plan, 'In Form,' the program supports providers of food services for beneficiaries of LTC – whether living at home and in receipt of meals on wheels or living in nursing facilities. An evaluation of the project evidenced significant changes in nutrition, but not in activity levels or quality of life.</p> <p>See: <a href="http://www.fitimalter-dge.de">www.fitimalter-dge.de</a>.</p>
New Ageing in Cities (NAIS)	2007–ongoing	<p>A volunteer project in cooperation with the city of Bruchsal, which aims to develop local strategies to activate the elderly including increasing access to local services; improving care for the socio-economically disadvantaged; as well as activities to promote physical activity, better nutrition, and mental health.</p> <p>See: <a href="http://www.neues-altern.de/index.html">www.neues-altern.de/index.html</a>.</p>
Equity in Health	2003–ongoing	<p>A cooperation network established in 2003 by the Federal Centre for Health Education (BZgA), aimed at health promotion for at-risk populations including the socio-economically disadvantaged elderly. The network has since established institutional structures across all German states. Among other achievements, the network has developed quality and good practice criteria for health promotion activities and projects.</p> <p>See: <a href="http://www.gesundheitliche-chancengleichheit.de/gesundheitsfoerderung-bei-aelteren/gute-praxis/">www.gesundheitliche-chancengleichheit.de/gesundheitsfoerderung-bei-aelteren/gute-praxis/</a>.</p>
Diabetes Counselling on Wheels	2003–2014	<p>A program focused on early detection and counselling on diabetes for elderly people of Turkish background living in hard to reach rural areas. Project evaluation is currently underway.</p> <p>See: <a href="http://www.chrodi.eu/wp-content/uploads/2016/03/160307DiabetesCounsellingOnWheels_DraftProgramme_5.pdf">www.chrodi.eu/wp-content/uploads/2016/03/160307DiabetesCounsellingOnWheels_DraftProgramme_5.pdf</a>.</p>

Adapted from the more detailed overview of good practices provided by Golinowska, Huter, Sowanda, Pavolo-va, Sowa, & Rothgang (2017).



### Policy measures to support unpaid carers

Owing to the historical reliance on care provided by family members (particularly females), from its outset in 1994, the German LTC system introduced cash benefits that could be passed on to any person(s) in order to continue the predominance of informal care arrangements. Indeed, taking cash benefits – as opposed to in-kind benefits for ambulatory care – is still the most favoured option amongst beneficiaries. As recently as 2015, for example, of those covered by S-LTCI about 1.3 million received cash benefits as against 181,000 who opted for in-kind services and a further 408,000 who combined cash and in-kind care (Rothgang, Kalwitzki, Müller, Runte, & Ungar, 2016: 72). Hence, financial support for informal caregivers through tax-free household transfers for beneficiaries remains a staple of the German system.

The main responsibility for providing informal care lies within the family, with one third of all beneficiaries being cared for by either children and/or spouses (Schmidt & Schneekloth 2011; Schneekloth, Geiss, Pupeter, Rothgang, Kalwitzki, & Müller, 2017). The proportion of beneficiaries in receipt of informal care by their children has increased by nine percentage points since 1998 (ibid.). This suggests that cash benefits not only reinforce but also incentivize informal caregiving, particularly amongst male children: between the years 1998 and 2010, for instance, the share of persons in receipt of care by a son doubled (Schmidt & Schneekloth, 2011) and has since remained relatively constant, while still less than that of care by daughters (ibid.; Schneekloth, Geiss, Pupeter, Rothgang, Kalwitzki, & Müller, 2017). With the creation of care level 0 in 2009, introducing LTC benefits for persons living with cognitive impairments, the proportion of informal caregivers who are parents (primarily mothers) has also risen (ibid.).

Beyond support extended through cash benefits, an interest in the social protection of informal carers has also emerged in recent years. Beginning with

the passing of the Care Leave Act of 2008 (the ‘Pflegezeitgesetz’ as part of the LTC Development Act), family members were given up to ten days leave from work for the care or organization of care for a close relative (parent, child, spouse or sibling). In the case of more chronic care needs and for persons working in companies with more than 15 employees, a person could extend this leave for up to a 6-month period, either taking complete leave of absence or going part-time. However, employers were not legally required to continue to pay employees for part-time employment. Accordingly, while allowing employees to return to full employment after a limited period of providing care, the 2008 law did not go as far as to attach financial benefits to leave conditions.

In an effort to expand the protections afforded by the 2008 law, the Family Care Act (‘Familienpflegezeitgesetz’) was passed four years later which introduced financial support for persons who reduced their working hours in order to care for a close family relation. More specifically, employees would now be granted – for a period of up to 24 months – wage compensation by employers for reduced employment of a minimum of 15 hours. Compensation took the form of an advance on wages which would be paid back to the employer in-kind by having the employee continue to work – following the care leave – for a fixed period on reduced salary. To cover the initial costs assumed by employers, the Federal Ministry for Family and Civil Society (BAFzA) provided them with interest free loans. The 2012 law therefore established a precedent for at least partial financial security during care leave. However, it did so by shifting costs to employees in the period following caregiving (Schneekloth, Geiss, Pupeter, Rothgang, Kalwitzki, & Müller, 2017).

Given the fact that family care leave need not be officially applied for or reported on by employees, statistics on the number of persons who requested wage compensation as part of this scheme are not available. However, in the years directly following the reform, the number of applications by employers

for BAFzA loans suggests that the take-up of the policy was remarkably low: there were only 53 applications for the interest free loan during the whole of 2012 (Rothgang, Müller, & Unger, 2013: 22ff.). This is particularly striking given that 40% of family caregivers had either reduced employment or entirely given up employment due to caregiving (Schneekloth, Geiss, Pupeter, Rothgang, Kalwitzki, & Müller, 2017). As a result of the limited success of the 2012 act, a more ambitious reform to provide better financial security for informal caregivers was soon deemed necessary, culminating in the Care Leave Act of 2015 (Schneekloth, Geiss, Pupeter, Rothgang, Kalwitzki, & Müller, 2017).

Representing the most significant piece of legislation to introduce support for family caregivers, the Care Leave Act of 2015 ('Pflegezeitgesetz') built on the foundations laid by previous laws while adding legal entitlement to financial provisions. Among the changes introduced by the law, wage compensation for acute care leave of up to ten days (typically 90% of net earnings) is now available through LTCI in the form of 'Pflegeunterstützungsgeld' or 'care support payments'; family care leave is available for those providing care for minors living outside the home (such as in institutional facilities); and leave of up to three months is available for people supporting family members at the end of life (e.g. those in hospices). Moreover, the law has allowed for a broadening of the definition of 'close family relation' to include step-parents, life-partners and the siblings of spouses/life-partners, as well as the spouses/life-partners of siblings. While financial support for leave exceeding a ten day period is not provided through the LTCI system, carers may apply directly to the BAFzA for an interest-free loan providing monthly payments covering half of the net earnings foregone due to reduced working hours. Hence, although it represents a substantial achievement in improving the social protection of informal carers, the Care Leave Act of 2015 ultimately still shifts costs on to persons providing lengthier periods of care for family members (Schneekloth, Geiss, Pupeter, Rothgang, Kalwitzki, & Müller, 2017).

### Innovative care models/technologies to improve outcomes for people with LTC needs

#### Models: The case of German shared housing arrangements<sup>4</sup>

One of the more innovative forms of care which has gained attention in recent years in Germany is shared housing arrangements or residential groups with care ('ambulant betreute Wohngemeinschaften'). Generally, a limited number of people in need of care, often people with dementia (if necessary, with the support of their relatives), rent private rooms while they share a common space, domestic support, and access to nursing care. The concept aims to provide a small-scale, home-like care facility with ample leeway for individual activities that differ from the daily routines of traditional nursing homes. The concept particularly supports residents in maintaining independence and autonomy. Further, shared housing arrangements seek to integrate care with support from relatives, friends, neighbours, voluntary workers or the community, alongside the purchase of professional services. Internationally, similar concepts are known as 'small-scale living' in the Netherlands, 'Cantou' in France, or 'Green House' and 'Woodside Place' models in the US and Canada (Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009).

In Germany, shared housing arrangements first developed in the late 1980s and 1990s as self-organized projects, with the first residential group founded in Berlin in 1996 (Wolf-Ostermann & Gräske, 2014: 17). The concept has since gained acceptance by public authorities and financing institutions, as well as nursing care providers (Fischer, Worch, Nordheim, Wulff, Pannasch, Meyer, Kuhlmei, & Wolf-Ostermann, 2011). Shared housing arrangements are now included in the laws enacted by the states (Länder) replacing the federal Nursing Home Act ('Heimgesetz'); while the LTC Adjustment Act of 2012 ('Pflege-Neuausrichtung-Gesetz') has

<sup>4</sup> We wish to thank Dr Achim Schmid of SOCIUM (University of Bremen) for his contributions and insights under this heading.

introduced special grants to support the implementation of shared housing.

The states' laws generally distinguish self-organized shared housing ('selbstverantwortete Wohngemeinschaften') from provider-organized projects ('anbieterverantwortete Wohngemeinschaften'). The latter are regarded as a promising approach between traditional domestic care and the traditional nursing home which combines a home-like environment with high quality round-the-clock care (Hasenau, Hastedt, Michel, & Müller, 2016: 9-10).

Self-organized residential groups are characterized by a strict separation of the corporate body providing housing and the organization providing care and support. The residents exercise property rights and determine daily routines and are free to choose the amount of nursing care they receive. In theory, they can each also choose care from different providers, although this is unlikely in practice due to coordination problems. The nursing care providers may not intervene in decisions of the residential group or the body of representatives set up by the group. The classification as 'self-organized' also means that the residential group is not affected by further regulations (e.g. 'Ordnungsrecht' or administrative law) beyond the general requirements that all providers of nursing care have to meet (Wolf-Ostermann & Gräse, 2014: 23).

In provider-organized shared housing, the nursing care provider is responsible for housing as well as care and general assistance, or cooperates with housing associations. Even so, housing contracts and contracts for general assistance have to be separate from contracts for nursing care in order to give residents leeway to define the amount of care purchased and organized by dependents or friends. Provider-organized shared housing is covered by administrative law and the states' laws that have replaced the federal Nursing Home Act. For example there are building/structural requirements and sometimes the obligation to report the establishment of a residential group to the nursing

care authorities. Groups are limited to a maximum of 12 participants and there are limits to the number of groups within a certain area.

Generally speaking, LTC reforms since 2008 have gradually improved the environment in which shared housing care models flourish. First and foremost, the government has increased financing for nursing care provided in an outpatient setting (§ 36 SGB XI, Pflegesachleistungen) in several steps. Services can also be claimed through the S-LTCI. In 2013, the LTC Adjustment Act took effect, introducing a monthly lump sum of €200 per resident (later increased to €214) to finance the coordination involved with residential groups. Further, financing for the combination of nursing care and day care has been increased and involves highly profitable business models for nursing care providers. The latter have evoked criticism, since some providers have established models which maximize income from the LTCI while failing to achieve the core aims of shared housing: maintaining independence and autonomy, flexible choice of care, and a home-like environment (Wolf-Ostermann, Rothgang, Domhoff, Müller, Schmid, & Schmidt, 2018; Frisina Doetter & Schmid, 2018).

The number of residential groups has increased from about 143 (including groups for disabled persons) in 2003 to an estimated 3,121 in 2015 (Fischer, Worch, Nordheim, Wulff, Pannasch, Meyer, Kuhlmei, & Wolf-Ostermann, 2011; Schuhmacher, 2016). Assuming an average size of 8-9 placements per group, this amounts to between 25,000 and 28,000 placements. This is about 3.6%–4.0% of people who claim outpatient LTC services or 2.9%–3.3% of people in nursing care homes. Current surveys<sup>5</sup> point to around 3,900 shared housing arrangements, a cautious estimate since there is no general obligation to report the groups. In Berlin and the northeast of Germany shared housing is more prevalent than in other parts of Germany; the

<sup>5</sup> First results of a survey currently organized by a government funded research project at the SOCIUM, University of Bremen (see Wolf-Ostermann, Rothgang, Domhoff, Müller, Schmid, & Schmidt, 2018).

numbers have increased largely in North-Rhine Westphalia, whereas the numbers in Bavaria have likely tripled across years 2012 to 2017. These figures and trends have yet to be validated.

To date, there is limited evidence about the quality of care provided within these small-scale, homelike LTC-settings. Most evaluation studies refer to residential groups for LTC-patients with dementia located in Berlin. Comparing residential groups with care units in nursing homes shows no significant advantage in quality of life (Wolf-Ostermann, Gräske, Worch, Fischer, Wulff, 2012). Differences with respect to bedsores or injuries related to falls are likely to reflect the different clienteles choosing residential groups or more traditional nursing care (Klingelhöfer-Noe, Dassen & Lahmann, 2015). One study points to positive effects for nutrition of residents in shared housing compared to nursing homes (Meyer, Fleischer-Schlechtiger, Gräske, Worch, & Wolf-Ostermann, 2014). Further, a qualitative survey suggests superior working conditions and job satisfaction in small-scale, homelike settings (Reimer & Riegraf, 2015). The integration of family members in the care concept has also proven difficult (Gräske, Meyer, Worch, & Wolf-Ostermann, 2015; Wolf-Ostermann, Gräske, Worch, Fischer, Wulff, 2012). Finally, residential groups for LTC-patients with dementia do not have cost advantages over nursing homes (Wübbeler, Aßmann, Blaut, Lueke, Hoffmann, & Fleßa, 2015). An evaluation of a series of pilot projects and models (supported by § 45 e, f SGB XI) is currently being led by the Peak Association of the Social Health Insurance ('GKV-Spitzenverband') to investigate the potential gains from shared housing concepts and the problems involved.

**Technologies: Increased public financing for research and development**

As part of a larger campaign ('Technik zum Menschen bringen') to increase social innovation through the use of technology and digitalization, the German Federal Ministry of Education and Research (BMBF) has provided financing since 2015 for various projects that introduce technical solutions to

increase the mobility and thereby quality of life of the elderly (BMBF, 2015). One example is the project 'UrbanLife+'<sup>6</sup> which, through careful city planning, aims to improve the sense of security experienced by the elderly living with mobility problems in urban areas. Implementing technology that makes for 'smarter' public infrastructure (e.g. interactive monitors and sensors that provide pedestrians with clearly visible/audible cues and information regarding nearby public restrooms, transport etc.), the project seeks to extend the notion of Ambient Assisted Living beyond the domestic context and into the public sphere. Neighbourhood-based technological support is also being developed to increase social inclusion by keeping the elderly abreast of local events and activities.

By 2022, the BMBF will have also invested €20 million in a research cluster referred to as 'Future of Care' or 'Zukunft der Pflege,' led by the Pflegeinnovationszentrum (PIZ) at the OFFIS institute in Oldenburg.<sup>7</sup> In cooperation with the University of Oldenburg, the University of Bremen, and Hanse Institute of Oldenburg, PIZ will engage in the evaluation of innovative technologies (existing and newly developed) that support all sectors of LTC, whether home-based on inpatient, as well as carry out extensive knowledge transfer activities. Beginning in 2018, PIZ will also collaborate with four practice-based centres in the states of Baden-Württemberg, Bavaria, Berlin and Niedersachsen. This collaboration is intended to encourage exchange between research institutions and practice. Being located at OFFIS, the centre is also expected to benefit from research into the applications of robotics and augmented virtual reality in LTC.

### Maximising coordination in care provision

Efforts to improve the coordination of care in the German LTC system have centred on the introduction of access to individual consultations for beneficiaries made available within the home or at

<sup>6</sup> For more information, see [www.urbanlifeplus.de](http://www.urbanlifeplus.de).

<sup>7</sup> For more information, see [www.offis.de](http://www.offis.de).



‘care support centres’ (or ‘Pflegestützpunkte’) across Germany. The right to individually-tailored, cost-free and independent consultations was introduced with the passing of the Long-Term Care Development Care Act (2008) which took effect in 2009 (§ 7a SGB XI). This precedent was reinforced in the passing of the Long-Term Care Adjustment Act of 2012, which ensures that all persons be granted access to a free consultation or else be given a voucher for a consultation at a specifically named care support centre within two weeks of applying for benefits. If requested, the consultation may be carried out in the presence of a family member. Following the results of an early evaluation on the quality of consultations provided across Germany, which pointed to enormous heterogeneity (Klie, Frommelt, Schneekloth, Behrend, Göhner, Heislbetz, Hellbusch, Püchner, Riesterer, Schmidt, Schumacher, & Ziller, 2011), the Peak Association of the LTC Insurances has now introduced a number of requirements for care consultants, as well as the nature and content of consultations (Long-Term Care Strengthening Act II of 2016 –§7a, 3, SGB XI). These include recommendations on the number of consultants per provider and their respective qualifications and training, as well as guidelines on a standardized approach to providing consultations (Rothgang, Müller, Runte, & Unger, 2017). The Peak Association has also committed providers to collaborating on two reports to improve the quality of consultations: a first report on the experiences and ongoing development of consulting services, which will include aspects of structure and organization; and a second report which will provide a summary of the implementation, results and effects of consulting within the home, as well as on the ongoing development of consultation structures (ibid.).

An additional form of care consultation taking place within the home for beneficiaries of cash transfers in particular involves routine assessments carried out by professional service providers contracted by the LTCI. The frequency of such assessments depends on the care grade of the beneficiary: for those categorized under grades 2 and 3, assessments take place semi-annually, whereas care grades 4 and 5 receive quarterly assessments (§37III, SGB XI). Assessments aim at providing some measure of quality control of informal care, while also allowing beneficiaries access to professional case management.



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