Peer Review on "Germany's latest reforms of the long-term care system"

Berlin, Germany, 11-12 January 2018

Synthesis Report

DG Employment, Social Affairs and Inclusion

Written by ICF

March, 2018

EUROPEAN COMMISSION

Directorate-General for Employment, Social Affairs and Inclusion

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1 Introduction

1.1 Background and purpose of the Peer Review

An ageing population, the expansion of age-related neurodegenerative diseases, changing family structures and women's increased participation in the labour market mean that Member States of the European Union, while diverse, face a common challenge of growing needs for long-term care (LTC). Improving access to quality and affordable long-term care services, in particular to community-based care, provided by adequately qualified professionals and support for family carers is therefore crucial across Europe.

The Peer Review, which took place on 11 and 12 January 2018 in Berlin and was hosted by the German Federal Ministry of Health, discussed Germany's latest reforms to its long-term care system with a specific focus on the three 'Long-Term Care Strengthening Acts' that were implemented from 2015 to 2017. Germany has, since 1995, developed a comprehensive system of long-term care that has implemented various good practices and solutions. Latest reforms have responded to a number of challenges that have emerged over time, for instance with respect to improving support for people suffering from dementia, comprehensive access, community-based care provision, and the coordination between different types of support mechanisms across the health and social care divide.

The Peer Review was attended by Government representatives and independent experts from twelve Member States, namely Austria, Bulgaria, Czech Republic, Cyprus, France, Ireland, Malta, Portugal, Latvia, Lithuania, Slovenia and Spain[1]. The European Commission also participated in the event. In addition, two study visits were organised: to a local advisory centre for people with care needs and their families, and a nursing home with an integrated general practitioner service.

The participating countries learnt from each other, and in particular from the host country's example, to inform – and potentially influence – policy development in their national contexts.

1.2 European policy context

Long-term care across Europe

Long-term care, although defined slightly differently across Member States, offers help, care and support to people of all ages with a wide range of needs arising from disability, illness or other life situations. It helps people to live as independently as possible, protects people from harm in vulnerable situations, balances risks with rights, and offers essential help at times of crisis. More broadly defined, it is concerned with enabling people to live full lives, participating in families and communities.[2]

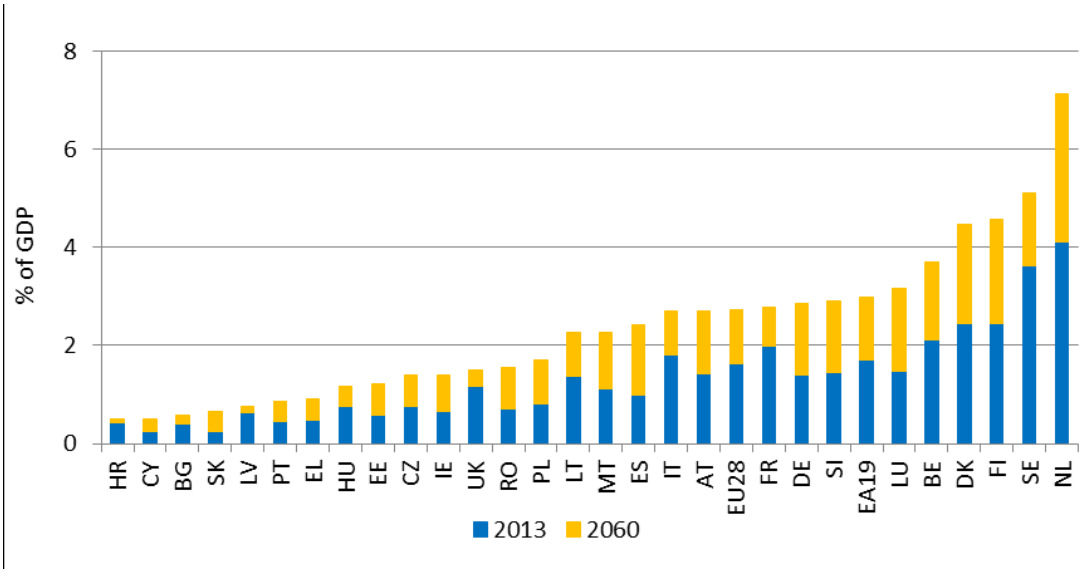
Support is offered (in different proportions across Member States) in people's own homes, residential care facilities as well as other semi-residential facilities. The aim is to help with the ADL – *activities of daily living* (for example eating, bathing etc) – and IADL – *instrumental activities of daily living* (shopping, housework etc). This is often provided in combination with medical care, such as *nursing care* (medication, wound management etc) and preventative, rehabilitative and palliative services. Long-term care combines therefore both, health and social aspects, which are often differently organised and funded. Long-term care often also includes services that are provided to informal carers, such as information and advice and respite care.[3] People of all ages may need long-term care services, however the risk of becoming dependent is higher towards older age as people are more likely to become frail or develop multi-morbidity conditions.

[1] Independent experts participated form the following countries: Austria, Czech Republic, France and Spain.
[2] The King's Fund, What is social care and how does it work?, 2017
[3] European Communities, *Long-Term Care in the European Union*, 2008

Long-term care has become a crucial policy issue across Europe as all countries face the challenge of an increasing demand for long-term care services whilst the required services will have to be provided by a shrinking workforce, combined with spending cuts in many countries as a consequence of the financial crisis. The increasing demand for long-term care services puts states under fiscal pressure and, compared to pension and health care payments, public expenditure on long-term care is projected to have the highest percent increase in most European countries.[4]

There is also a wide diversity of approaches to long-term care in Europe, ranging from universal with high state expenditure to minimalist interventions by the state and the family as the sole provider of care. However, some countries with a long tradition of family care, such as Spain or the Czech Republic, have taken steps to provide social protection against the risk of need for long-term care.[5] In terms of funding models, they range from tax-based systems, insurance-based systems (such as Germany) and systems that mainly build on out-of-pocket payments by the service user. Public expenditure will increase across the EU significantly, in particular for countries that have already high expenditure on long-term care as a percentage of GDP, for example Sweden and the Netherlands will reach more than 5% of GDP in 2060.

Figure 1. Public expenditure on long-term care, % GDP 2013 and forecast for 2060



Source: European Commission, The 2015 Ageing Report

While this increased expenditure poses direct questions on fiscal sustainability, the differences in public spending today also reflect the extent to which older people in need of care receive public support. Current barriers to access adequate long-term care may include a lack of insurance coverage or high financial costs, but also insufficient availability of support (geographical disparities in supply, lengthy waiting lists for certain treatments, lack of information, and complex administrative procedures). Most of the long-term care is still provided by family carers which impacts on the availability of workforce and often leaves families with the financial burden of care provision. Furthermore, the costs associated with long-term care are

[4] European Commission Directorate-General for Economic and Financial Affairs, 2015

[5] See Thematic Discussion Paper of Peer Review on "Germany's latest reforms of the long-term care system"

not evenly distributed among the population, as those more likely to need care may actually be less able to afford to pay for its costs[6].

EU programmes offer Member States support in their efforts to tackle some of these challenges, while recognising that long-term care is firmly the remit of Member States. In the context of the Open Method for Coordination Member States have agreed on three common objectives, namely to guarantee access to adequate care, to promote its quality and to ensure its affordability and sustainability. The Employment Guidelines emphasise the need to improve the quality, accessibility, efficiency and effectiveness of long-term care systems, while safeguarding sustainability and their role in the reconciliation of family and working life. The Commission, in line with the Open Method of Coordination, emphasises the need to recognise long-term care needs as a social risk to be covered by social protection systems. In the light of public financing and sustainability, it aims to support mutual learning with regards to 'adequate' long-term care services that are accessible, affordable, high in quality and support family carers. Moreover, the Social Protection Committee, especially in the framework of the Open Method of Coordination, has been promoting exchange on solutions for adequate support of people in need of long-term care. The 2014 report on long-term care[7] outlines that demand for long-term care will increase, whilst an insufficient supply of formal carers may impact on access and quality of long-term care services. Although the report acknowledges the different approaches to long-term care policies across Europe, it suggests to focus on prevention and rehabilitation, independent living and productivity of care delivery. In line with national policy goals, the European Pillar of Social Rights identifies barriers to accessing adequate long-term care systems and emphasises community home care, quality and work-life balance.

The Peer Review sought to discuss participant countries' efforts to develop quality and affordable long-term care in Europe, with a special emphasis on the following elements:

- definition and assessment of needs;
- development of services in the community;
- development of new forms of residential services; and
- coordination and integration of health and social care.

2 The German approach to Long-Term Care

The German social and private long-term care insurance introduced in 1995 is a compulsory insurance to cover a portion of long-term care costs. For home care, entitled beneficiaries have a free choice between benefits in kind provided by professional nursing and personal assistance services and cash benefits for informal care. Benefits in cash and in kind can be combined and the long-term insurance also offers counselling when choosing the provider. In addition, benefits are provided for care in residential care homes and semi-residential facilities (e.g. day care). In 2017, about 3.3 million people received support from the long-term care insurance funds, and about 73% of these beneficiaries got long-term care at home.

Between 2015 and 2017, Germany's Federal cabinet passed the three 'Acts to Strengthen Long-Term Care'. The Acts build on successive reforms since the establishment in 1995 of the German programme to provide universal support for the cost of long-term services and support though compulsory long-term care insurance.

[6] See Thematic Discussion Paper of Peer Review on "Germany's latest reforms of the long-term care system"

[7] Report jointly prepared by the Social Protection Committee and the European Commission services, Adequate social protection for long-term care needs in an ageing society, 2014

The Acts redefine long-term care as providing assistance in maintaining independence and making the most of a person's abilities. In line with that, a new assessment framework which weighs physical, mental and psychological impairment equally has been implemented. It therefore significantly improves access to services and higher benefits for people suffering from dementia. The assessment is carried out by the 'Medical Service of the Health Insurance Funds (MDK)' which will then result in the allocation of one of the five care grades, ranging from minor impairments of autonomy and skills (care grade 1) to severe impairments of autonomy and skills (care grade 5).

To complement the new definition of care needs, Germany has invested into measures to strengthen long-term care at home, such as support for family carers, local support structures, the development of new forms of housing for care recipients and increased numbers of staff. As the bulk of care is still provided by informal carers, measures have been taken to secure pension and insurance contributions for those providing more than 10 hours of care at home. This ensures carers are able to access unemployment benefits (including support to become reemployed) if they decide to leave work in order to care for relatives. To support the Acts' implementation, the 'First Act to Strengthen Long-Term Care' foresees a rise in contributions to the long-term care insurance and from 2017 an additional 5 billion Euros have been made available annually.

With the new care grade 1, up to an additional 500 000 people will now get access to selected long-term care insurance benefits, making support available earlier to those who do not yet require personal care, but may benefit from care counselling and information and home adaptations. In line with this preventative approach there has been a renewed focus on rehabilitation before care, also with a focus on prevention and rehabilitation in the new assessment process.

People in need of long-term care are entitled to receive support and information about available services. The 'Third Act to Strengthen Long-Term Care' emphasises the role of municipalities to set up local support structures and highlights the role of local 'Advisory services' (Pflegestützpunkte) to provide information, but also to coordinate and network at local level with different stakeholders providing services to older people.

Advisory services for people in need of care and their family members

Advisory services for people in need of care and their family members have been set up by many German regions since 2008. People who will apply for or already receive benefits get advice about existing services and potential care arrangements. The advisory service is provided by trained care consultants with special expertise, in particular in social and social security law. Most care consultants are employed by the long-term care funds, but the municipalities also provide advisory services. They help to prepare for the assessment of needs, advice on available services and benefits and may also propose an individual care plan for specific groups of clients whom they follow with a case-management approach.

3 Main themes of the Peer Review

3.1 Definition and assessment of long-term care needs

There have been ongoing discussions in many European countries about how to better meet the needs of an ageing population in the provision of long-term care services.

The definitions of long-term care needs vary across Europe and access to formal long-term care services or funding support depends on the assessment of these needs.

Next to the assessment of long-term care needs other criteria may decide over the access to support, such as age criteria, the income (means-testing) or the family situation.[8] Traditionally, assessment and eligibility processes have been 'deficit-based', determining access on the basis of severity of physical and cognitive impairment. In Latin-based languages (but also in others) the traditional 'deficit-based' approach is also reflected in the terminology, e.g. 'dependency' (French: 'dépendance', Italian: 'non-autosufficienza', Spanish: dependencia), although latest legal regulations have underlined to improve the autonomy of people with long-term care needs. However, there has been a shift toward 'asset-based' or 'resource orientated' approaches in some countries. This implies determining what a person has (in terms of physical and social assets) and can do first, before thinking about what they do not have and cannot do.

In Germany, prior to the recent reforms, needs (if assessed as eligible) were assessed as being in one of three levels, determined by the time and tasks required. This 'deficit-based' approach was replaced by the new definition of care that focuses on independence. This new framework aims to assess needs better in order to provide more personalised care, taking also cognitive and psychological impairments into account, with the explicit aim to improve eligibility for people suffering from dementia. Professionals of the Medical Advisory Service of the Health Insurance Funds (MDK) conduct the assessment of long-term care needs, based on assessment guidelines and the newly developed assessment instrument. They assess all criteria in the following six modules on a four-point scale, and the points in each module are then weighted for the final assessment result:

- Mobility (five criteria) – weighted 10% in the final assessment score;
- Cognition and communication activities (11 criteria) - weighted 15% in the final assessment score;
- Behaviour patterns and psychological problems (13 criteria) - weighted 15% in the final assessment score;
- Self-supply (13 criteria) - weighted 40% in the final assessment score;
- Coping with illness-and therapy related demands and stress (16 criteria) - weighted 20% in the final assessment score; and
- Organizing everyday life and social contacts (six criteria) - weighted 15% in the final assessment score.

The result is a score from 1 to 100, determining the care grade:

- Care level 1: 12,5 to 27 points= minor impairments;
- Care level 2: 27 to 47,5 points= considerable impairments;
- Care level 3: 47,5 to 70 points= serious impairments;
- Care level 4: 70 to 90 points= severe impairments; and
- Care level 5: 90 -100 points or special need constellation= most severe impairments.

The results of the assessment are a starting point for the individual care planning process, depending on whether the person chooses benefits in kind or in cash. The assessment also considers the needs for preventative and rehabilitative measures.

As said above, the definition of long-term care needs and therefore eligibility to access formal long-term care services or funding support is assessed in various ways across

[8] See Thematic Discussion Paper of Peer Review on "Germany's latest reforms of the long-term care system"

participant countries, and the threshold at which people are granted support is set at different levels, reflecting different political and financial priorities. The definition of needs varies across Europe, depending on which criteria are taken into account and whether there is a standardised assessment tool.

Like Germany, some Member States have started to widen their assessment criteria as an answer to an ageing population and therefore an increase of people with neurodegenerative diseases, but also as an answer to better accommodate for aspects like social participation and support for family carers. For example, Austria also considers cognitive impairments in their needs assessment scheme, in line with the implementation of the Austrian Dementia Strategy "Living well with Dementia". Their assessment also seeks to take an asset-based approach, beginning with abilities, and assessing levels of independence rather than focusing narrowly on time/tasks. There is some interest in developing 'asset-based' or 'resource orientated' approaches in other counties too. However, this approach also needs to consider very vulnerable people with severe care needs. This approach is also at odds with an explicitly 'medical model' in some countries, where assessments are very much focused on medical diagnoses. Some countries have a definition of long-term care needs based on functional abilities of the person due to their long-term health conditions. This results in an assessment framework focusing on physical impairments which is more likely to fail in assessing the extent of dependency on care by people with mental disorders. For example, the issue of a possible 'underestimation' of long-term care needs was brought up by the Czech Republic which might be the consequence of a low standardisation on the assessment tool or because the assessment tool rather focuses on physical abilities, not sufficiently considering psychological and cognitive impairments.

Other criteria to be considered in the assessment include the social environment where the challenge lies in balancing local determination with equity in the definition and assessment of need. While it is important to maintain equity and to avoid too much variation, some countries have started to consider the amount of family care provided in the assessment process, which is important for care delivery, but might increase inequalities if it leads to a reduction of services in cash or in kind.

A significant share of the countries included in this Peer Review carry out the assessment of needs using standardised instruments (see Table 1 below). For example, in France, the national scheme called AGGIR assesses long-term care needs considering also psychological impairments, like in Germany. A national assessment tool might have the advantage to assess long-term care needs equally, which is not always guaranteed in countries. For example, in Lithuania, different assessment tools are used.

The assessment of long-term care needs may be carried out by appointed staff from a single assessment body, like in Germany, specially trained medical staff or in teams working across different sectors. For example, in Portugal, the assessment is done by Referral Teams composed of at least three different professionals, often a doctor, nurse and social worker. In the Czech Republic, the assessment is done solely by a physician employed at Medical Assessment Service, nevertheless, a field report from a social worker who reviews the social context of the person in need for care is necessary for the assessment. Across countries, however, the participation of beneficiaries and informal carers in the assessment process is in many cases still underdeveloped.

The relation between the assessment and care planning was also discussed at the event, which also depends on the organisation of the provision of long-term care services. In smaller countries like Malta, a multi-disciplinary team assesses long-term care needs and is then also responsible for the care planning process. In Spain, a personal intervention plan based on an assessment of individual care needs leading to a discussion of services and funding between the family and a social worker is developed. In Germany, the local advisory services play a key role to link the

assessment of long-term care needs with further information and coordination of available services.

Table 1: Assessment of needs by standardised instruments in selected countries

Country	**Standardised instrument**	**Needs considered for eligibility (a)**	**Who is assessing**
Austria	Yes, comprising 21 elements	The deciding factor is solely the specific need for care and assistance due to physical, mental/psychological or sensory disability for at least six months and amount to at least more than 65h in a month. ADLs and IADLs as well as cognitive impairment; at least one ADL together with one IADL must be present. Some ADLs are weighted differently in the assessment (i.e. awarded higher times) such as dressing and cooking-depending on the severity of care needs.	Medical officer, qualified nurse can also act as expert in the re-assessment of increased care needs.
Bulgaria	No	Individual assessment	A team of specialists (at least two people), they may be psychologists, social workers, rehabilitators, all employed by social service providers.
Cyprus	Yes	Health and social needs considering aspects like mobility, self-help and cognitive impairments.	Health care needs are assessed by the community nurse and social needs by a social worker.
Czech Republic	Yes, semi-standardised	10 basic living needs are assessed: ADLs and IADLs caused by long-term health conditions. Reported limitations in assessing care needs of rare conditions and early stages of dementia.	Doctor by the Medical Assessment Service (a home visit is also done by a social worker but he or she does not assess needs)
France	Yes	17 items: ADLs (except incontinence) and cognitive impairment; eligibility set an at least 2 ADLs or cognitive impairment.	Medical-social teams
Germany	Yes, comprising a scale with six domains or areas of life	Point-based scale divided into five levels (total of 100 points) comprising cognitive impairments, ADLs and IADLs. Different ADLs and IADLs are weighted differently.	Experts of the Medical Advisory Service of the Health Insurance Funds
Ireland	Yes	ADL, IADL	Healthcare professionals and social workers

Latvia	Yes, scale with 18 domains	Point based scale divided in 4 (four) levels. Self-care and cognitive impairment (deficit-based), as well as included ADL, IADL	Social worker, healthcare professionals and psychologist (multi-professional team)
Lithuania	Not one tool	ADLs, social participation	Social workers (in case of medical conditions health care staff is also involved)
Malta	Yes	Medical diagnosis, psychological state, Barthel Index, IADLs, need for social support, social environment and risks.	Different professionals (nurses and social workers, depending on the service applied for)
Portugal	Yes	Five dimensions (mobility, self-care, social participation, general and specific competences and fine motoric skills)	Referral teams composed of at least three different professionals, often a physician, nurse and social worker
Spain	Yes, comprising a scale with 10 elements (51 tasks) or 11 elements (59 tasks) for those with cognitive impairments.	ADLs and IADLs as well as cognitive impairment; eligibility based on points. There is a specific assessment scale for children under three years of age (EVE).	The different Autonomous Communities determine the assessment bodies of the dependency situation. Health and social train team that move to the place of residence of the person to perform the evaluation.
Slovenia	No	Individual approach	

Source: Adapted from Carrino and Orso (2014), Rodrigues, Huber and Lamura (2012) and Colombo et al (2011) and input from participating counties at Peer Review.

With increasing access to long-term care services, public authorities need to take steps to ensure that demand for preventative and early interventions is matched by a supply from the private, state or charitable sector. Countries will also need to be realistic about rising costs and availability of services and workforce as a result of widening access. This has proved a challenge across participating Member States. In terms of preventative approaches the German approach aims to provide benefits also to people from an early stage on, also to prevent a further increase of needs and emergencies. In other countries however, e.g. in Austria, the eligibility threshold has been increased. There is more evidence needed on this issue, i.e. whether the provision of benefits to lower the level of needs is cost-effective.[9]

3.2 Development of services at home and in the community

Home care services are those provided for people in need of care living in their own home, generally as a combination of help with the activities of daily living and instrumental activities of daily living, i.e. 'home help' and nursing care. It may also cover assisted or adopted living arrangements as well as the use of day or night care centres. Residential care facilities, on the other hand, provide accommodation and long-term care as a package to people, covering health care, nursing care and other types of support due to reduced autonomy with activities of daily living. In some cases, the term 'community care' or 'care in the community' is also being used for

[9] See Thematic Discussion Paper of Peer Review on "Germany's latest reforms of the long-term care system"

home care. This also describes the intention to ensure living at home of people in need of care by means of coordinating home care as well as other services, facilities and stakeholders, e.g. including housing, pharmacists, shops etc.

Across Member States, there is widespread policy aspiration to support people at home for as long as possible, while 'deinstitutionalising' the experience of those in residential care settings. The extent to which physical and mental impairment engenders dependency is influenced by a person's perception of their ability to manage despite functional limitations. It matters a lot whether people are encouraged and enabled to cope. The ability to 'age-in-place' and avoid institutional care is usually beneficial for the mental and physical health of older people. This is also clearly reflected in people's preferences.[10] If they develop a need for long-term care in some form, the overwhelming majority of older people would prefer to have home help and home care, enabling them to remain in their homes.[11]

The ability of care recipients to stay in their own home depends on several factors: whether the person lives alone, if he or she has support from informal care givers, and whether his or her home is 'age-friendly', so that it is easily accessible. In terms of care provision, it also depends on whether formal home care is available and affordable or if it is possible for informal care givers to provide a certain extent of care (which might result in reducing or even giving up paid employment). While it is important to recognise the aspirations of individuals to be cared for in their own homes, it is also an aspiration of Member States to deinstitutionalise residential care settings, i.e. to make them more engrained within communities to prevent segregation and to personalise all care. This is clearly articulated in a recent European Study: *"The organisation of support and assistance for people is not determined by the type of building they live in, but rather by the needs of the individual, and what they need to live, where, and how they choose. High levels of support can be provided in ordinary housing in the community, for example. This approach involves treating the person as an individual and providing sufficient support to meet their needs and promote a good quality of life, not trying to fit the person to the already existing services."*[12]

In Germany, about 3.3 million people received support from the long-term care insurance funds in 2017, and about 73% of these beneficiaries get long-term care at home where they can choose between benefits in kind provided by professional nursing care services or cash benefits for informal care (or a combination of both). From these 73% of beneficiaries who receive care at home two thirds (1.56 million people) are cared for solely by informal carers (relatives, friends or neighbours). In order to support informal care givers, they receive social security benefits form the long-term care insurance (pensions and statutory accident), leave from work for up to 10 days to arrange care, or 'Family Care Leave' for up to a year (with the possibility of an interest free loan). There is also an allowance for a respite care of up to six weeks per calendar year, e.g. during periods of illness or vacation of the informal care giver. Informal carers are also supported by counselling and training, short-term care in nursing homes, and benefits for covering the cost of day- and/or night-care.

To further support people at home, in-kind low-threshold personal support (day or night care, short-term care or daily life support) in private homes (in form of a voucher for 125 Euro monthly) is available for all care grades. With the new care grade 1, up to 500 000 people will get first-time access to the long-term care system, i.e. to the voucher mentioned above and other benefits, such as an allowance for self-organised flat-sharing care communities up to 214 Euro monthly, benefits for care devices and care utilities. With this new care grade, a new target group enters the long-term care system to receive support at an early stage of care needs.

[10] European Commission, Long-term care in ageing societies - Challenges and policy options, 2013

[11] World Health Organisation, The solid facts: home care in Europe, 2008

[12] The University of Kent, Deinstitutionalisation and Community Living, 2007

Across Member States, policies strive to support people at home for as long as possible. There have however been varying levels of success, influenced by the various contexts, including an inheritance of an institutionally-focused service provision in Central and Eastern Europe. Still, countries like Bulgaria, Latvia and Lithuania have increased their capacities also in the provision of home care. This is driven not only by cost considerations, but by evidence of the negative impact of institutional care on individual wellbeing as well as concerns about quality and safety. Germany's system clearly reflects the preference of beneficiaries for home and family care: to a large degree they choose benefits in cash that are used to compensate family carers. Apart from a similar use of cash-benefits that are paid to people in need of long-term care in Austria some provinces and local authorities have introduced a threshold to regulate the access of beneficiaries to residential care facilities (as they are under the competency of the nine regional governments): only people with a higher level of care (levels 4 to 7 in the Austrian 7-level system) will be supported to receive care in a residential setting. This is similar in the Czech Republic, where residential care homes do only accept residents with consistent long-term care needs.

Strengthening care at home in all European countries relies heavily on family carers who are providing the bulk of care. In many countries, people with care obligations are allowed leave from work, though mostly as an unpaid leave. It was also underlined that local support for care recipients and their families through local counselling structures or case managers are an important asset. This support is needed not only to inform the person in need for care, but also their family about possible care leave arrangements, respite care, training options and services that can also facilitate measures such as peer support.

Table 2: Overview of some support measures for informal carers

Type of support	**AUSTRIA**	**CZECH REPUBLIC**	**FRANCE**	**GERMANY**
Short-term leave	One week Normal wage	Up to 9 days, 60% of monthly wage, only for caring of relatives living in one household with the carer	Up to 21 days	10 working days Wage compensation
Contribution to social security	Yes (full social security coverage)	Yes, if care is provided to relatives with care allowance of II grade and higher	Yes	Yes, (10 hours and at least two days a week at home and not employed for more than 30 hours a week)
Long-term leave	Full-time/part-time care leave up to 6 months with care leave allowance (55% of daily net income) Family hospice leave up to 6	Three months, 60% of monthly wage	Family Solidarity Leave three months with compensation Family Support Leave: Unpaid leave for up to six months	Six - 24 months Interest-free loan for subsistence

	or 9 months (when caring for a seriously ill child) with care leave allowance			
Respite care	Yes, up to 28 days/ year with allowance (depending on care stage)	Yes	Yes	Yes

Participants discussed the difficulties of cultural change: the ideal would be that there is no stigma in caring for a relative in need of care and to use related services and respite such as 'care leave'. It remains to be seen, if such a development – in analogy to the use of childcare facilities – will be realised across Member States to reduce the currently disproportionate burden (and cost) of care on women and the related consequences for their participation in employment and public life.

In terms of home care provided by formal carers, participants discussed the need for flexibility of services, quality and workforce issues. The challenge is to organise the right support at the right time, as the individual needs for long-term care vary, not least depending on the family situation. More flexible care arrangements with home care providers would help to support people in changing situations. For people with complex needs, 24/7 care or rapid response initiatives can offer support that enable them to stay in their familiar surroundings. Community networks supported by volunteers or neighbourhood help can support with tasks like shopping or social activities. Here the case-management approach might play an important role in coordinating different formal care services and informal structures in order to organise personalised support.

Participating countries discussed the quality aspect of home care, provided by formal and informal carers. In order to ensure that the care is person-centred and his or her needs are met, possible risks are reduced and family carers are protected and supported, some form of regular control is desirable. In Germany, home care provided by informal carers (based on the cash allowance) includes a mandatory regular counselling at home by a qualified and approved nurse. Formal community care services have an annual quality audition by the Medical Advisory Service of the Health Insurance Funds. The quality inspections in care services comprise a survey and an assessment of a sample of beneficiaries (or their legal guardian) who need to give their consent to participate. While providers of home care services are accredited and audited in Germany, countries like Cyprus and the Czech Republic face a challenge of 'unregulated' providers which impacts on quality of both home care services and residential facilities.

Strengthening care at home also requires addressing the workforce issue. A high number of vacancies in several countries are also due to demanding working conditions, including shift work and stress. These problems might intensify due to a shrinking workforce and an ageing population, which risks putting even more pressure on the existing workforce to provide quality care. The improvement of payment and working conditions and the development of clear career paths as well as skills development across health and social care are required to address this issue. Furthermore, a new mix of trained staff with different skill levels was discussed, for example case-managers, community or district nurses (see 3.4). Moreover, there is a need to re-think workforce and skills development from an international perspective. In some countries home care is often provided by migrant carers who live with the person in the need for care. To improve their working conditions, but also to improve

the quality of 24-hour care, the Ministry of Social Affairs in Austria has developed a subsidy model to support care services for persons in need of care and support, who had previously worked undeclared. As part of this reform, families who employ 24-hour carers may now claim a means-tested benefit to help pay for the additional costs of formally hiring 24-hour carers (e.g. social contributions owed).

To enable people to stay as long as possible at home, the local community also plays a vital role. People in need for support and their families must be enabled to access information and services more easily, but also to take part in society and community activities. In many countries, local structures engage volunteers to support people who are isolated. In Germany the local advisory centres play a key role in providing this support. Other countries like Spain have regional active ageing strategies that facilitate active participation of older people. In Malta, a focus lies on local community support in which younger and older people support each other.

However, participants also underlined the difficulty of developing community capacity and assets in a situation where local government and other public bodies have found themselves in difficult financial circumstances. This had a knock-on effect on civil society organisations.

3.3 The development of new residential and semi-residential care

The ability to 'age-in-place' and how to avoid institutional forms of housing by new residential and semi-residential was discussed by participants. Innovative, more flexible forms of older-people's housing examples were mentioned, such as shared flats or assisted living. The development of these different examples often depends on local conditions, the involvement of the community, the availability of housing stock that older people can live in, funding, and, most importantly, preferences of the inhabitants. The development of 'new' residential forms aims at promoting independence and community participation. This includes the enhancement of more traditional sheltered housing and the use of technology.

In Germany, the number of people living in 'alternative' living arrangements is still small, at around 2% of all people aged over 65. The National Association of Statutory Health Insurance Funds is currently running a pilot programme to evaluate 53 projects of different living arrangements in order to identify good practice and innovative projects to be further expanded. These projects are all over Germany and comprise assisted living, shared flats, integrated living arrangements and mobile services with a high degree of security of supply, combinations of home and residential care services by providing more choice regarding medical care, laundry and cleaning services, and individual support (services can be also delivered by relatives) in a residential care setting. The first results show that the projects help older people to remain independent, provide more security and continuity of services, better match individual preferences, habits and privacy as the person has more self-determination with regard to interior design, day structure, staff, housemates, use of services, shared responsibility and social participation.

In France, a mixed model between home and residential care are the so called 'autonomy residences' (résidences autonomie), specialised accommodation combined with home care services, that accommodate 102 000 people. Another form of housing are the so called 'beguinages' which comprise of 10 to 20 single-storey private dwellings. Based on the historic model of the Beguines, people live together under the aspect of common support and self-determination. In Austria, in Vienna and Styria specifically, shared housing has developed. However, the development of new housing forms has only really started in six out of nine regions (Burgenland, Carinthia, Upper Austria, Styria, Vorarlberg and Vienna) as new, alternative forms of housing also need to be supported by the residents and older people might often object to the idea to move out of their home. A way to encourage the openness for new forms of living might be low-threshold financial incentives, as provided in Germany, where people can receive an allowance for shared living arrangements which might also be a way to

prevent a sudden increase in care needs. In all participating countries, the use of new forms of living for people with long-term care needs is still low, and there was general consensus amongst participants that more evidence is needed for further development of new forms of housing.

When developing the different forms of housing for people in need for long-term care urban and rural geographies also need to be considered. The development and connection of community and civil assets in rural communities is vital to the development of new forms of accommodation. There was a general feeling amongst participants that sensitivity was important in order to 'go with the grain' of community life, rather than disrupt or antagonise through radical development.

Moreover, the availability of age-friendly adaptations of older people's homes and the availability of technology also influences the way people with long-term care needs will live. Technology to share information electronically, devices for self-monitoring, self-care and self-management and assistive ICT-solutions in homes may have the potential to organise some parts of long-term care more efficiently. In addition, communication technology can also facilitate social interaction with family and friends and allow for emotional support when people are largely confined to their homes and relatives do not live nearby. There is however little evidence of the efficacy of products of the communication and information technology aiming at the support of home care and it is not widely used in most Member States. However, in Spain, telecare, a remote care service (often consisting of a button to call for help and other varying monitoring systems in the home) used since the 90s, has a higher number of users. As of December 2016, it served 38,854 people and the number of telecare actions during 2016 was 1,812,440 which represents 15.32% of the total spending of dependency benefits.

3.4 Coordination and integration of health and social care

In order to strengthen home care and to increase the effectiveness and efficiency of long-term care systems, many European countries have started to address the coordination between health and social care. All countries see the need to provide more care outside of hospitals and long-term residential care by developing integrated care, especially for key groups such as frail older people and people with multiple chronic conditions. The delivery of integrated care services by medical and social care staff also plays an important role to help people to stay longer at home. However, no participating country had been able to avoid boundaries within and between organisations, as well as between the various types of services such as primary care, hospital care and social care, or between professionals such as general practitioners, hospital doctors, and community care staff. These boundaries reflect many differences identified in funding, organisational responsibilities, professional approaches as well as in how and by whom eligibility for care is assessed and determined.

Especially people with multiple needs, such as people suffering from dementia, need support from various actors, ranging from health care, personal support, preventative services that enhance autonomy to social participation and support for care givers. To begin with, people who receive the diagnosis need help to find orientation in the system of different support services. In Germany, the 'Dementia Care Networks' aim to improve information about treatment and care for people with dementia by working across different stakeholders from community care services, medical doctors, therapists, hospital facilities, self-help organisations, and local authorities. The support often consists of a 'Dementia Care Manager' who supports with information, identifies unmet needs (medical, nursing, psychosocial, social) and ensures a follow-up. The networks are not implemented nationwide in the same way, there are regional differences in terms of funding, structure and involved actors. An interdisciplinary longitudinal evaluation of the 'Dementia Care Networks' funded by the German Federal Ministry of Health looked into 13 networks with 560 patients and their caregivers with the aim to develop recommendations for the initiation and improvement of 'Dementia

Care Networks'. The results have shown that the networks are effective on neuropsychiatric symptoms, medication, caregiver burden, quality of life (of people living in partnership) and participating GPs see a positive impact on treatment and care and support the work of the networks.[13] The networks have the potential to be translated into routine care, as some preconditions already exist in Germany such as the new definition and assessment of long-term care needs and care advisory services.

In Spain, efforts to integrate care provision have been made on regional level, often with the development of strategic plans on regional level to be broken down to local level. In these regional approaches, there is a focus on person-centred care to ensure that needs are met. This includes a discussion about how to involve service users and to co-design services with them and their families. In terms of a better coordination between the different sectors, systems to share electronic information have been established, new joint leadership structures and professional roles have been introduced, such as care managers or coaches for service users and families. To share good practices of integrated care, the National Institute for Older People and Social Services (Imserso) has set up a good practice database.[14]

Similar to Spain, several countries introduced interdisciplinary teams who cooperate to provide information, assess needs and to coordinate and facilitate the provision of care. In Portugal the National Network of Integrated Care is working on national, regional and local level. At local level, multi-disciplinary teams work to support discharge processes from hospital, to assess care needs and facilitate support for service users. They aim to work across boundaries between hospitals and primary health care, social services, communities and the service users themselves aiming at rehabilitation. At regional level, teams of the health and social security administration review capacities, availability of services and support with the communication between partners. At national level the Central Administration of the Health System coordinates the whole network, sets guidelines and procurement terms for providers. The French model MAIA integrates home care and assistance services (méthode d'intégration des services d'aide et de soins à domicile) and operates also at different governance levels. Almost nationwide 358 MAIA facilities offer support to older people and professionals with shared and standardised tools as well as coordination between health professionals, social care services and household services. People with complex care needs receive support by a case manager in a MAIA one-stop-shop. At a strategic level, a consultation body composed of decision-makers and funders and a more operational body bring together professionals from the different sectors involved.

There are also professional roles who work at the transition of one sector to the other, for example professions who support individuals who are medically fit to be discharged from hospital but they need further services outside of hospital. This is for example done by the 'Community Nurses' in Cyprus who also support the 'Home Care Mechanical Ventilation Service' described in the box below.

[13] Thyrian et al. JAMA Psychiatry 2017

[14] See Peer Country Comments Paper – Spain of Peer Review on "Germany's latest reforms of the long-term care system"

Home Care Mechanical Ventilation Service in Cyprus

In Cyprus home care is provided by health (home nursing) and social care services. Due to the lack of a comprehensive statutory scheme most families finance long-term care services through out-of-pocket expenses. Home nursing services in Cyprus are active in three sectors: general nursing, Liaison Nursing Services and home nursing for mechanical ventilated patients. The Liaison Nursing Services (community nurses) support with the discharge from hospital, provide information and help to organise a safe home environment.

The reason to establish the 'Home Care Mechanical Ventilation Service' was that patients requiring prolonged mechanical ventilation are rapidly increasing. The benefits of the service are an early discharge from the hospital, decreasing costs by less hospitalisation, reduced exposure to hospital-borne infections, a quicker integration of patients in their family environment and into the community and the improvement of quality of life of the patients and their families. The community nurses are trained to support the patients at home, they do the assessment if the patient can be transferred home and are in constant contact with the 'Improved Intensive Care Unit' at the hospital. The nurses also train family members and provide regular, repeated hands-on training on basic care giving procedures and ventilator use. The community nurses visit patients two to three times per week to assess the situation, and to give support.

While the challenge to improve coordination of long-term care services is shared by all countries, national approaches are very different, not least due to organisational and related funding issues. While the French MAIA case has been experimented at local level and then scaled up to national level, federal states such as Germany or Spain have made efforts to share good practice of regional approaches. However, evidence concerning the cost-effectiveness of integrated care is still lacking.[15]

A shared aspiration in this respect lies in the use of information and communication technology. Several countries are working on new solutions and sharing good practice is therefore seen as beneficial, e.g. regarding the challenges of shared care records across organisational boundaries or other communication tools to share information between health and social care services. Here, overcoming the technical aspects is only one part of the broader problem as getting consensus on privacy issues and overcoming information governance were seen as larger obstacles.

Finally, the coordination of different services requires qualified workforce and the definition of new roles, tasks and ways of cooperation (delegation, substitution of tasks). This requires also a 'cultural change' to work with another sector that might have a different work philosophy and terminology. Shared leadership, transparent communication, the agreement on a common terminology, the definition of new roles who work between sectors might be possible solutions. One example is the role of the community nurse, as described above in Cyprus, who engages in transitions and coordinates the various stakeholders involved. In terms of a common use of digital solutions, the Berlin example below shows how this can have beneficial gains for workforce and users. However, only approximately 30% of German nursing homes are using digital solutions. One reason might be data protection concerns, but there might also be a certain reluctance of staff to use data, as well as an adverse attitude from medical staff to make their work practice more transparent by sharing patient records.

[15] See Thematic Discussion Paper of Peer Review on "Germany's latest reforms of the long-term care system"

'Nursing home with integrated general practitioner' (Agaplesion Bethanien Sophienhaus)

In many German residential care homes, nurses have to talk to up to 40 GPs, which is often not possible. Since 1999, the family doctor Dr. med. Landgraf has been working with the care home Bethanien Sophienhaus in Berlin Steglitz. She has approximately 100 patients in the care home and uses, together with the staff from the care home, a secured telemonitoring system for the patients in which both parties can enter and check real-time information.

Their Berlin project 'Care with the Plus' has won several awards for their innovative concept. The project has shown many benefits for nurses, for care home residents and also the care insurances. The GP has gained more time as she managed to reduce home visits in the care home or emergencies. The nurses gained more experience in working with digital tools and exercising simple health checks.

An evaluation result (with the small sample size of 100 patients) shows that 14% of the patients need less medication annually and hospitalisation went down by 17%. In order to gain more liable evidence, there will be an evaluation of a similar project with 4 000 patients.

Finally, in order to implement a 'resource-based' approach to enable people to stay independent for as long as possible and to promote self-care, workforce needs to involve the service user, from needs assessment to care planning, including the ownership of health and care records and the ability to make choices over care as being central to integrating services from the person's perspective.

4 Conclusions and recommendations

Population ageing has both increased and changed the profile of care needs, in particular those associated with dementia. At the same time, users are now, for the most part, more conscious of their preferences and the need for high quality care. Long-term care systems seem to be evolving in line with these trends, both in terms of adapting the eligibility and assessment procedures and in terms of developing new forms of care that fit users' preferences.

However, a wide range of challenges remain. Fiscal sustainability of public expenditure on long-term care will be an issue for some countries in the future – while Germany has been able to invest significantly in long-term care, most other countries participating in this Peer Review are concerned with how to keep costs manageable while recognising long-term care as a social risk with respective public support. In a longer-term perspective there are encouraging signs that strengthening the integration of health and long-term care systems to address complex conditions will not only improve the experience of users along the continuum of care, but at the same time reduce expenditures. To realise this potential, it will however be necessary to invest in devising, scaling up and adapting innovative ways to deliver long-term care. This Peer Review has shown that there is a large range of national and European experiences that can trigger mutual learning processes, e.g. in terms of funding mechanisms, of designing support for informal carers, of promoting alternative housing arrangements, and of integrating health and social care.

Participants underlined the following learning points as most important for their further engagement in assessing care needs and strengthening long-term care in the community:

- To standardise an asset-based, comprehensive needs assessment with an integrated care approach.

- The focus on prevention and rehabilitation should be emphasized, whether it is in the care needs assessment process or in providing lower-threshold and information services to people with little support needs.
- To provide advisory services and other support measures for informal carers.
- To improve case and care management.
- To better connect GPs with home care services and residential care.
- To push the establishment of local networks, including volunteers. This may be connected to the provision of information and advisory services.
- To promote the professional profile of new job roles working across sectors, such as the 'community nurse'.
- To decrease out-of-pocket contributions of people in need of care.
- To boost long-term care friendly environments by the involvement of the community, research and dissemination on innovative projects and exchange on and effective and efficient use of technology.

The Peer Review in Germany also inspired other countries to stage such an event to demonstrate their progress in the area of establishing long-term care systems and to further exchange their experiences.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