Peer Review on “Germany’s latest reforms of the long-term care system”
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Peer Review on “Germany’s latest reforms of the long-term care system”

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1 Introduction

Long-term care\(^1\) has gained increasing relevance in Europe as an ageing population and other societal changes (such as raising labour market participation of women, or changing living arrangements in old-age) have increased the demand for long-term care services. For the welfare state this raises concerns about the fiscal sustainability of care systems, with public expenditure on long-term care projected to have the highest per cent increase in most European countries in comparison with pensions or healthcare (European Commission Directorate-General for Economic and Financial Affairs, 2015). For individuals and their families, the concern is that in the absence of publicly-funded care, the costs with long-term care will render it unaffordable. Existing estimates for England, for example, place lifelong costs at around 100,000 GBP for the upper decile of care needs (Commission on Funding of Care and Support, 2011). Concerns about these costs is heightened by the limitations of individual (private) long-term care insurance in allowing individuals to spread the risk throughout their life (See Barr, 2010 for a discussion). Furthermore, the costs associated with long-term care are 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 fully, thus raising the risk of inequitable situations to arise (Rodrigues, Ilinca and Schmidt, 2017).

Given these constraints, several EU Member States have taken steps to recognize long-term care as a social risk liable to be addressed by social protection systems. At the same time, social protection of informal carers has been strengthened, namely through cash benefits and care leave schemes. The challenge is how to ensure that public financing of long-term care remains fiscally sustainable, while delivering services that are affordable, high quality and able to meet the preferences of users.

While European countries diverge quite significantly as to how they organize, fund and provide long-term care (Colombo et al., 2011), there seems to be a markedly broad consensus about expanding care provided at home and in the community, thus responding to expressed wishes of users (European Commission, 2007); developing new forms of semi-residential arrangements\(^2\) that allow for rehabilitation or provide respite care to informal carers; and improving the coordination of health and social care services (i.e. to improve integrated care provision). At the same time, the diversity of care arrangements within the EU make this area a potentially fertile ground for exchange of experiences and practices among its Member States.

This discussion paper highlights approaches to develop quality and affordable long-term care in Europe, with a special emphasis on the following elements:

- definition and assessment of needs,
- the development of services in the community, including new semi-residential services
- integration of health and social care.

The paper is organized as follows. The next section provides the policy context, comparing the diversity of care arrangements in Europe (with an emphasis on availability and possible inequalities) to long-term care services. After this, a series of national developments and approaches among the countries participating in this Peer Review are described. These examples are them discussed in the subsequent section taking into account, whenever possible, existing evidence about its cost-effectiveness; before some conclusions are presented. Finally, besides the host country, Germany,

\(^1\) Long-term care refers to care (delivered by formal and informal care providers) that is provided to people in need of support with activities of daily living (ADLS – such as bathing, eating) and instrumental activities of daily living (IADLS – such as shopping), for a considerable period of time (in most definitions for more than 6 consecutive months).

\(^2\) The term semi-residential care includes day care centres, short-term residential care (e.g. for respite care) and rehabilitation centres.
the countries included in this Peer Review are Austria, Bulgaria, Czech Republic, Cyprus, France, Ireland, Lithuania, Latvia, Malta, Portugal, Slovenia and Spain.

2 Policy context
2.1 Models of care and defining need

There is a wide diversity of approaches to long-term care in Europe and Table 1 presents one of the several possible ways to cluster ‘care regimes’ in Europe. The different models fundamentally reflect dissimilar divisions of responsibility between the state, the market and the family, with the latter still providing the bulk of care, even in countries with a relatively generous provision of care services.

Table 1: Stylized models of welfare protection in long-term care

<table>
<thead>
<tr>
<th>Model</th>
<th>Eligibility and access</th>
<th>State</th>
<th>Market</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal</td>
<td>Universal (based on needs), low private expenditure and high service provision</td>
<td>High public expenditure (mostly in-kind benefits), limited availability of cash benefits</td>
<td>Limited albeit growing role in service provision</td>
<td>High share of informal care, albeit with supplementary role in type of care tasks (e.g. shopping)</td>
</tr>
<tr>
<td>Means-tested</td>
<td>Means and asset-tested (except for some health care)</td>
<td>Provides a safety net for those too poor to pay for care</td>
<td>Very important provider in residential care and growing in home care</td>
<td>Main provider of care with some state (cash) support</td>
</tr>
<tr>
<td>Familialist with state support</td>
<td>Usually universal (based on needs), medium/high private expenditure and limited services</td>
<td>Mostly provides support through cash benefits and vouchers that can be used to pay informal carers</td>
<td>Important 3rd sector and for-profit sector, informal markets of migrant carers</td>
<td>Main provider of care with relatively generous state (cash) support and in tandem with migrant carers</td>
</tr>
<tr>
<td>Minimalist</td>
<td>Means-tested, with very limited benefits (cash or in-kind) and high private expenditure</td>
<td>Cash benefits of limited amount and very limited in-kind provision</td>
<td>Limited supply</td>
<td>Main (often sole) provider of care with limited state support</td>
</tr>
</tbody>
</table>

Source: Adapted (with permission) from Rodrigues (2017 table 8.1).

These differences are reflected also in public expenditure in percentage of GDP and the share of dependent older people that receive some sort of publicly funded care either at home or in institutions (Figure 1). Judging from the gap between older people with a perceived need (i.e. self-assessment limitations or impairments) and those with access to benefits, there seems to be not only a wide variation in available resources but also different definitions and assessment of needs among the older population in Europe. It is worth bearing in mind that comparisons between countries are also often made difficult due to lack of harmonized data on public expenditure, namely due to different definitions of long-term care used and particularly national

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differences in terms of what benefits are accounted for from the health and social care budgets.

Figure 1: Share of dependent older people receiving long-term care benefits

Source: Rodrigues, Huber and Lamura (2012)

Notes: Dependent older people defined as those with self-reported severe or moderate limitations in Activities of Daily Living, EU-SILC. Possibility of overlap between cash and in-kind home care benefits for Italy.

Access to care services or cash-benefits is conditional on the assessment of needs, but the definition of these needs varies considerably as to its scope (i.e. what limitations or health problems warrant access to benefits), whether they follow a standardised assessment mechanism (such as the AGGIR scale in France) and the degree of discretion/standardisation afforded to those empowered to assess needs (Table 2). Reflecting the raising prevalence rates of dementia and Alzheimer among the old-age population, a growing number of countries are specifically recognizing cognitive impairment in their needs assessment (e.g. Austria, Germany). Besides needs assessment, access may also be made dependent on other criteria. Chiefly among these are:

- Age: access to some benefits is limited to age in some countries (e.g. France for the APA – Allocation Personnalisée d'Autonomie)
- Income and assets: besides the income of the individual or household, access to benefits may also be conditional on assets, namely house ownership. This is mostly the case with access to publicly funded institutional care (e.g. Germany, France, Ireland) (Rodrigues, Huber and Lamura, 2012). In other situations, the amount of the benefits may be conditional on income, even if access is not (e.g. Spain and France) – in what has been dubbed targeted universalism (Colombo et al., 2011).
- Family situation: an increasingly higher share of countries is taking the family situation of users as a criterion for eligibility for long-term care services. For
example, in Latvia, the amount of informal care that co-residing relatives may be able to provide is also part of the eligibility criteria for home care services. However, there is some evidence that such policies may increase inequalities (Ilinca, Rodrigues and Schmidt, 2017).

In other countries, there has been an additional change in the assessment criteria to include also broader ‘assets and resources’, namely those available in the closer social network of users or those in existence in their communities (e.g. volunteers). Arguably the best examples of such approach to needs assessment comes from countries not included in Peer Review, such as England (for more information on what this see: https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/strengths-based-approach/what-is-a-strengths-based-approach.asp). While some have lauded this approach has empowering – by recognizing the social and human capital of individuals and taking into consideration their wishes – it has also been criticized as a move by stealth to shift responsibilities (but also costs) with care to families and communities (Ranci and Pavolini, 2015).

Table 2: Assessment of needs by standardised instruments in selected countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Standardised instrument</th>
<th>Needs considered for eligibility (a)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>Yes, comprising a scale with 21 elements</td>
<td>ADLs and IADLs as well as cognitive impairment; eligibility set a 60h/month. At least one ADL together with one IADL must be present.</td>
<td>Some ADLs and IADLs are weighted differently in the assessment (i.e. awarded higher times) such as washing, dressing, cooking, doing housework.</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>Yes, comprising a scale with 10 areas of basic daily needs</td>
<td>ADLs and IADLs as well as cognitive impairment; eligibility based on points</td>
<td>Reported limitations in assessing care needs of rare conditions and early stages of dementia</td>
</tr>
<tr>
<td>France</td>
<td>Yes, comprising a scale with 8 items</td>
<td>ADLs (except incontinence) and cognitive impairment; eligibility set an at least 2 ADLs or cognitive impairment.</td>
<td>--</td>
</tr>
<tr>
<td>Germany</td>
<td>Yes, comprising a scale with 6 domains or areas of life</td>
<td>Point-based scale divided into 5 levels (total of 100 points) comprising cognitive impairments, ADLs and IADLs.</td>
<td>Different ADLs and IADLs are weighted differently: mobility (10%), cognitive and communicative abilities, and behaviour patterns and psychological problems (15%), self-sufficiency (40%), self-management of condition and therapies (20%), and structure of everyday life and social contacts (15%)</td>
</tr>
<tr>
<td>Spain</td>
<td>Yes, comprising a scale with 10 elements (51 tasks) or 11 elements (59 tasks) for those</td>
<td>ADLs and IADLs as well as cognitive impairment; eligibility based on points</td>
<td>Some ADLs (eating and toilet use) have greater weights in the assessment</td>
</tr>
</tbody>
</table>
with cognitive impairments.

Source: Adapted from Carrino and Orso (2014), Rodrigues, Huber and Lamura (2012) and Colombo et al (2011) and Peer country comments papers.

**2.2 The evolving care-mix of service provision**

The majority of old-age population receiving publicly funded care is able to remain in their homes for most of the countries that comprise this Peer Review and indeed in Europe (Figure 1). Furthermore, once demographic ageing is accounted for, there is no evidence that use of institutional care has increased for the majority of countries for which reliable time series are available (Rodrigues, Huber and Lamura, 2012, p. 89). Even countries with a legacy of institutionalization (e.g. former Communist countries from Central and Eastern Europe) have taken steps to increase the availability of home-care and provide alternatives to institutional care (Ilinca et al., 2015). De-institutionalization is also recognised by the European Union as a policy goal to pursue – namely in its European Disability Strategy 2010-2020 – in connection with the United Nations Convention on the Rights of People with Disabilities (UNCRPD). To this end several funding mechanisms have been made available to Member States and Acceding Countries to contribute to the de-institutionalization (for more details see: http://ec.europa.eu/regional_policy/en/policy/themes/social-inclusion/desinstit/). At the same time, it is fair to recognize that the characteristics of institutional care have also evolved, most notably in the Nordic countries, which have set out to re-adapt institutions to individual dwellings or assisted living residencies and adapted group housing located in common dwellings (Ilinca et al., 2015).

Perhaps what is remarkable is that the relative shares of those in home care and institutional care are remarkably similar for both the 65+ and 80+ (OECD Health Database, assessed on 12th December 2017). The situation is somewhat different when it comes to gender though. Women not only make up the majority of users receiving care in institutions (as well as at home), but they are disproportionately more likely to be in institutions than men: in fact, around twice as much in countries such as the Czech Republic, France, Germany, Slovenia and Spain (Rodrigues, Huber and Lamura, 2012, p. 93). This gender inequality may be attributed to differences in living arrangements, but also possible differences in the targeting of institutional and home care in the absence of informal carers.

Apart from the gender inequalities, there is also evidence of ample unmet needs for care among the older population (García-Gómez et al., 2015). On the issue of socio-economic inequalities, the picture is complex. On the one hand, it seems that social assistance renders institutional care affordable for low income people, while in comparison, costs with home care for severe care needs can be high (Muir, 2017). Studies on actual use of services however, show limited signs of socio-economic inequalities in home care use across Europe (Rodrigues, Ilinca and Schmidt, 2017), but high socio-economic inequalities in transitions into institutional care (Nihtilä and Martikainen, 2007; Van den Bosch, Geerts and Willeme, 2013). Self-selection (i.e. low income high-needs older people that move into institutional care and are therefore not sampled among home care users) may explain these results, which would mean that in practice low income older people may have limited possibilities to age in place. Furthermore, socio-economic inequalities are consistently high for informal care, regardless of the type of long-term care system (Rodrigues, Ilinca and Schmidt, 2017).
3 National approaches

3.1 Expanding access to affordable care

As mentioned above, a number of countries have sought to recognize long-term care as a social risk and provide adequate social protection against the costs associated with this risk. The expansion of access (i.e. eligibility) to publicly funded care has not, however, taken place uniformly across the countries considered in this Peer Review.

Czech Republic and Spain stand as two examples of countries that recognized long-term care as a social risk under their social protection system during the past decade. The Czech Republic introduced a universal long-term care allowance in 2007, with four levels of care needs and benefits, which attempted to empower users to act as purchasers of care. Available evidence suggest however, that the benefit is mostly used to pay for informal care and service provision has not caught up, with the latter experiencing also quality issues (Sowa-Kofta and Wija, 2017). Spain also introduced a universal long-term care benefit in 2007, comprised of three levels of care, which created a minimum level of care protection for users at a national level3 (Guillen et al., 2017). Its planned phased expansion has been limited by budgetary cuts implemented in 2012, which among other measures have reduced the amounts of the benefit and the intensity of in-kind care packages awarded to users (Gallego, 2014). Most significantly however, the austerity-driven budgetary cuts have produced changes in the legislation that severely curtailed the possibility of users with lower level needs to be upgraded into higher needs (following assessment) and has created large and lengthy waiting list to access benefits (Peña-Longobardo et al., 2016). In Slovenia, there has been ongoing discussions about enshrining long-term care as a social risk and enacting a long-term care social insurance system (similarly to Germany) or a tax-funded universal benefit, but the legislation has not yet been approved.

As for Portugal, it has continued to expand its National Network of Integrated Care (Rede Nacional de Cuidados Continuados Integrados) originally established in 2006; which by 2016 had reached a capacity of approximately 14600 places (Administração Central do Sistema de Saúde, 2017). However, institutional care (e.g. nursing homes, inpatient palliative care) makes up for the majority of available places and home care capacity has actually diminished in the recent years.4

Since the establishment of the German long-term care insurance, there has been a broadening of the eligibility criteria that sought to expand the narrow (and overly concentrated on physical needs) definition of needs originally in place (Doetter and Rothgang, 2017). Cognitive impairment, specifically dementia, has since then been specifically included in the assessment of needs and the benefit amounts increased, particularly under the more recent reforms enacted in the period 2015-2017.

France has also taken steps to increase access to care, by introducing small changes to its main long-term care benefit, the APA. The 2015 Act on Adapting Society to an Ageing Population in effect reduced the amount of the income-related user ‘copayment’ to the APA (the APA is a universal benefit but its value is income-related as an amount based on the beneficiary’s income is deducted from it) and increased the number of hours to which users are entitled to in their home care packages (Gouvernement Français, 2015).

In Austria, policy developments have gone in seemly contradictory directions. On the one hand, dementia has also been specifically recognized in the assessment of needs – 25 hours per month of care needs are automatically awarded to those diagnosed

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3 Benefits can be topped-up by the regions, which have the responsibility for the development of long-term care services.
4 This refers to the more medicalized home care provided under the National Network of Integrated Care, while the capacity of (social) home care under the Ministry of Social Affairs has actually increased significantly (Statistics of the Portuguese Ministry of Social Affairs, accessed on 21th December 2017).
with dementia – and benefits have also been increased with inflation after a lengthy period where they had been kept frozen. Similarly, as of 2018, the asset contribution levied on users to access institutional care (Pflegeregress) will be abolished, which is likely to improve the affordability of (and probably also increase the demand for) this form of care. On the other hand, the eligibility threshold of the first two levels of care for the long-term care allowance (Pflegegeld) has been raised: from 50 and 75 hours, respectively, to 60 and 90 hours in 2011 and further to 65 and 95 hours in 2015. Taken together, these two levels account for nearly 50% of total beneficiaries of the allowance, with the majority of these users using the allowance to compensate informal carers rather than purchasing services (Sozialministerium, 2016).

### 3.2 Developing semi-residential services and services in the community

Bulgaria, Latvia and Czech Republic have all witnessed moves towards increasing capacity in home care provision, often as part of broader efforts of de-institutionalization of long-term care (Sowa-Kofa and Wija, 2017). Although home care services have increased in all three countries, a key aspect in the development of ‘ageing in place’ – defined here as the ability to live in one’s own home and community independently – has been an emphasis on supporting and incentivizing informal care provision through mostly cash benefits. This is part of the process of re-familialization of care, which has seen a greater deal of responsibilities for the provision of care in the community being transferred to families. In this sense, ageing in place has been pursued not so much through the development of services but by informal care provision. For example, in the Czech Republic, informal care provision has been incentivized by increasing the amount of cash benefits (Sowa-Kofa and Wija, 2017): as of 1st January 2018, the amount of the highest level of the Czech long-term care allowance is to be increased by approximately 45% for those beneficiaries receiving informal care at home.

In an attempt to spur the development of home care services, the Austrian Federal and the Regional Governments set up the LTC Fund (Pflegefonds) in 2011, with earmarked funds to create additional services and subsidise already existing ones (the Federal Government contributes with 2/3 of the funds for the Pflegefond) (Rodrigues, Bauer and Leichsenring, 2017). The Fund had a total of €1335 million assigned to it by 2016 and has in the meantime been extended to 2018. In addition to this, Austria has enacted legislation to regulate and legalize migrant 24-hours carers, which were previously operating in the grey market of care. As part of this reform, users may now claim a means-tested benefit to help pay for the costs of hiring 24-hours carers (e.g. social contributions owed). Finally, in both Austria and the Czech Republic, nursing homes are instructed to accept only residents above a certain need threshold to improve targeting of this type of care to users with higher needs (Colombo et al., 2011).

Germany has experimented with an innovative concept of ‘share housing’ (Ambulant Betreute Wohngemeinschaften), which is comprised of a normal apartment or house rented together by a group of users (or managed by a provider) who share the living space and receive care services from an external provider (Doetter and Rothgang, 2017). The housing and care service provision components are kept separate and the rationale is to provide users with greater freedom in determining their care and daily routine, while living in an environment and surrounding that more closely resembles a standard living arrangement. This solution has now been mainstreamed into the regional regulations and an estimated 4% of beneficiaries of home care now use this type of housing/care (Doetter and Rothgang, 2017).

Given the devolved nature of the Spanish long-term care system, many of the initiatives developed to enhance semi-residential care and services in the community have had a more regional or local scope. These include the delivery of services that go beyond those defined and provided under the 2006 Dependency Law, such as personal
assistance and home help (Guillen et al., 2017). While the Dependency Law favoured the provision of in-kind benefits, and had only foreseen their replacement by a cash equivalent to pay for informal care as the exception, currently about 1/3 of benefits are provided in cash (Peña-Longobardo et al., 2016).

Another dimension of the development of benefits that allows for ageing in place, are care leave schemes aimed at carers of working age. France has a number of different care leave arrangements for care, the longest of which (Congé de proche aidant) allows for paid leave periods of up to 3 months to care for dependent relatives (total leave period is capped at 12 months over the lifetime). Germany has also introduced in 2015 a Care Leave Allowance (Pflegeunterstützungsgeld), which although more generous in length (its duration is up to 24 months) is paid as a loan provided by the employer or the state that needs to be paid back by the employee (Schmidt, Fuchs and Rodrigues, 2016). However, some of the care leave schemes, such as the Austrian Longer Care Leave arrangement (Pflegekarenz) are dependent on the agreement by the employer.

Figure 2: Overview of care leave arrangements for long-term care in Austria, Germany and France
Notes: Each axis refers to one dimension considered crucial in determining the generosity of a specific care leave model: maximum duration (upper axis), payment (right axis), circle of eligible relatives or others (lower axis), and definition of minimum care need for which a leave is granted (left axis). The larger the rectangle in a specific dimension in a given country, the more generous the regulation is with regard to that dimension.

3.3 Better integration of health and long-term care

Integrated care in Germany has mostly taken place through local initiatives that seek to establish linkages between providers (e.g. the Gerinet Leipzig or the Dortmunder Modell – see Leichsenring et al., 2015) and provide information to users, who in the German context are empowered to make decisions about the provision of care. Since 2008, regions have been able to establish Care Support Centres (Pflegestützpunkte) which aim to provide guidance to users about the existing care solutions and providers, but also to enhance collaboration between providers. More recently, care consultants in these centres have been provided with additional training and requirements in order to improve the consultation process and help address the great geographic variation in the quality of consultations that characterized the operation of Care Support Centres thus far (Doetter and Rothgang, 2017).

As in Germany, efforts to improve integration of health and long-term care in Austria have consisted mainly of local initiatives and have lagged behind in comparison with the healthcare sector where integration (of health care only) has been more prominent. Among the locally implemented initiatives are the experiment carried out in two Austrian regions (Upper Austria and Styria) to divide the region into districts that are then allocated to single providers responsible for providing integrated care within the borders of those districts, as well as example of approaches to joint-working in palliative care (Rodrigues, Bauer and Leichsenring, 2017). Currently there seems to be no evidence that these initiatives were mainstreamed.

In France, there are two main recent programs seeking to improve the coordination of health and long-term care specifically for the older population, albeit none of them is yet fully implemented in the whole country (Bihan and Sopadzialy, 2017). The PAERPA (Personnes âgées en risque de perte d’autonomie) has a strong preventing focus and aims to reduce avoidable hospitalization, improve autonomy and ageing in place for older people (aged 75 and older). It functions as a care pathway to support GPs and care professionals in improving the wellbeing and independence of users.

The other initiative recently created consists of case management with a single entry point (the initiative is called Méthode d'action pour l'intégration des services d'aide et de soins dans le champ de l'autonomie), which includes individualized care plans and sharing of information between providers. Initially developed for people with Alzheimer (under the acronym MAIA), this initiative has now been extended to older people with complex care needs.

As for Spain, efforts to integrate care provision have mostly consisted of coordination initiatives at a higher level involving the health and social care public administration in each region, often under the guise of strategic plans (Guillen et al., 2017). In Portugal, the National Network of Integrated Care has sought to operate with multi-disciplinary teams, particularly in home care, and it includes also discharge management and referral and assessment teams, which are presently operating in all

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hospitals and major primary health care centres across the country (Administração Central do Sistema de Saúde, 2017).

4 Discussion and learning

The process of needs assessment and eligibility in the countries surveyed has evolved between two opposing driving forces. On the one hand, the assessment processes have sought to provide an answer to growing and shifting needs resulting from an ageing population. The evolution of the German needs assessment criteria from a rather strict physical disability-focused to a broader concept that includes cognitive and psychological impairments is a case in point. In particular, long-term care systems seem to be responding to the increasing relevance of dementia and related conditions among the older population. The same can be said of the steps taken by countries such as Spain or the Czech Republic, to recognize long-term care as a social risk and to bring it firmly under the umbrella of the public social protection system – in effect promoting at least in appearance the partial de-familialization of care.

On the other hand, however, changes to the eligibility criteria or processes have also reflected efforts to contain or target benefits to those more in need by tightening eligibility criteria. The increase in the eligibility threshold of the Austrian Pflegegeld and the discussion surrounding it is a good example of the issues at stake: whether providing benefits from a lower level of care needs is a way to have needs assessed from early on and may therefore have a preventive effect and result in savings for the system. Unfortunately, little to no evidence exists on whether provision of benefits to lower level of needs is cost-effective (for an example, see Forder et al., 2017). For Latvia, Cyprus, Bulgaria, Malta and Portugal, public expenditure ratios suggest that further investments in care provision loom in the future in order to address potential unmet needs of their older population.

The ‘asset-resource’ assessment of needs (exemplified by the English example), which considers social capital and available resources in the community to care for older people can be seen as reflecting both forces described above. It can be argued that it empowers users and takes a broader view of their needs and available resources to tackle these (which may include access to mainstream services such as cinema). At the same time however, it offers clear scope for a transfer of costs back to users and communities under the guise of mobilization of social capital (of which informal care is a manifestation).

A significant share of the countries included in this Peer Review carry out the assessment of needs using standardised instruments (see Table 2 above). This could have the advantage of providing more transparent information to users as to the conditions under which they can access long-term care. It is not clear however, how participatory the assessment process is in many cases (i.e. whether users may define their own needs and how best to address them).

There is a marked consensus about the need to prioritize ageing in place and many of the countries in this Peer Review have taken steps to allow dependent older people to be cared for in their own homes. The evidence base for the cost-effectiveness of home care is not unequivocal however, as it seems to depend on the level of care needs (residential care may be more cost-effective for higher needs (Colombo et al., 2011)) or type of intervention (for example, certain types of behaviour and carer support for people with dementia (Clarkson et al., 2017), or assisted living technology (Graybill, McMeekin and Wildman, 2014) seem to be more cost-effective).

However, it seems that ageing at home has mostly taken the form of a re-familialization of care, by shifting the responsibility for care to families (Ranci and Pavolini, 2015). In countries which have the option to provide cash benefits, the build-up of home care services has been slow, as families find it more affordable to
internalize the provision of care or outsource it to migrant carers (Simonazzi, 2008). While informal care is often the preferred option of care by users, this re-familialization is not without its costs, especially given the limited availability of respite care across Europe (Hoffmann, Huber and Rodrigues, 2013). Existing evidence suggests that high intensity care (i.e. in number of hours) can have a significant negative impact on the probability to be employed and on wages earned, particularly for women (Heitmüller and Michaud, 2006; Viitanen, 2010). Similar negative outcomes are found for health, especially mental health; with variables such as co-residency, being an older spouse carer and intensity of care being particularly correlated with adverse outcomes (Schulz and Beach, 1999; Schulz et al., 2001; Colombo et al., 2011). In this respect, recent measures implemented by countries such as Austria and Germany, aimed at expanding the possibilities for working age carers to take a leave related to long-term care, are a welcomed policy development. Still, existing evidence points to a very low take up rate – around or below 2% of the eligible population – for these care leave arrangements (Schmidt, Fuchs and Rodrigues, 2016). Among the reasons pointed for the low take-up rates are stigmatization of workers with caring responsibilities (France), complexity of the application procedure (France), low replacement rates or benefits that are provided as a loan to the employee and not as a social benefit (Germany).

In countries such as Austria (Germany to a less extent), migrant carers play an important role in providing care to (usually) high needs users in their homes. The Austrian policy reform, which led to the regulation of what was essentially a grey market of 24-hours migrant care provision, shows some promise in terms not only of regulating migrant carers but also tackling quality and asymmetric information (Schmidt et al., 2016). Users receive a subsidy to offset part of the cost of paying 24-hour carers, but the latter must also comply quality standards regarding their qualifications and training (Rodrigues, Bauer and Leichsenring, 2017), which can be seen as a move towards improving the quality of this particular form of home care.

Similarly to the development of home care, improving the coordination between health and long-term care is also a clear policy goal in most of the countries included in this Peer Review. The barriers to integration of health and long-term care are multiple and by now well documented (for a discussion see Leichsenring et al., 2015). Where the evidence is still lacking is whether integrated care is cost-effective, which in part stems from the fact that integrated care includes a wide range of initiatives and degrees of integration (e.g. financing, care delivery, exchange of information). Existing studies seem to indicate that integrated care can significantly improve the outcomes of some groups of patients (particularly those with more complex care needs), but often at higher costs (Nolte and Pitchforth, 2014; Flanagan, Damery and Combes, 2017), although the data and methodological robustness of many studies are weak. For many of the countries included in this Peer Review, user choice is a prominent feature of their long-term care systems (e.g. Germany, Austria, Czech Republic), which could also add to the difficulties of integrating health and long-term care (Leichsenring et al., 2015). Against the backdrop of user choice, most of the initiatives surveyed consist of case management and sharing of information, with much less emphasis on improving incentives and financial governance to achieve better outcomes.

5 Conclusions

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 of 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, several challenges remain. Fiscal sustainability of public expenditure on long-term care will be an issue for some countries in the future – how to keep costs manageable. For others the challenge is of achieving ‘social sustainability’ – recognizing needs and providing the public funding that is currently lagging behind. There are encouraging signs in terms of strengthening the integration of health and long-term care, with integration initiatives focused around particular (more complex) conditions showing greater promise. There remains however, much to do to improve the experience of users along the continuum of care. Informal carers have also witnessed an increase in their rights and benefits, but this has come also with much greater responsibilities for providing or at least managing the care of their dependent relatives. This carries with it a very strong gender and socio-economic dimension. However, the diversity of care arrangements in Europe provides at the same time fertile testing ground for devising, scaling up (between countries) and adapting innovative ways to address long-term care issues. This mutual learning process is already evident in some of the initiatives or discussions taking place across Europe (e.g. the Slovenian discussion around which of the several European models of long-term care financing to adopt) and should be strengthened in the future.

6 List of references


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