



# Informal care in Europe

Exploring Formalisation, Availability and Quality

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*April – 2018*



*Social  
Europe*

**EUROPEAN COMMISSION**

Directorate-General for Employment, Social Affairs and Inclusion  
Directorate A — Employment and Social Governance  
Unit A.4 — Thematic Analysis

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# **Informal care in Europe**

Exploring Formalisation, Availability and Quality

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Luxembourg: Publications Office of the European Union, 2018

ISBN: 978-92-79-86583-1

doi: 10.2767/78836

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## **EXECUTIVE SUMMARY**

Informal care forms a cornerstone of all long-term care (LTC) systems in Europe and is often seen as a cost-effective way of preventing institutionalisation and enabling users to remain at home. Most recent LTC reform packages have included important components focused on informal carers. A common trend is to introduce cash payments as support for people in need of LTC or directly to informal carers. These have often been motivated by a desire to offer care users more choice of their care package, but also in an effort to incentivise and support care provided by family or friends. This, however, means that distinctions between formal and informal care, paid and unpaid care are becoming increasingly blurred, which carries important implications for the role of informal carers and the quality of the care provided. The purpose of this study is to explore the range and meaning of policies which 'formalise' the role and status of informal carers in a subset of European countries. These schemes, either directed at carers specifically or indirectly through user policies, 'formalise' the caregiving role and, to varying extents, treats carers as recognized care providers. The study also attempts to shed light on the relevance of this policy trend for quality of informal care. The sample includes seven European LTC systems, representing the various LTC and informal care regime types. Evidence was gathered through a scoping of the literature and national reports, documents and legislation on LTC policies and legislation. The focus is on cash allowances, carers' assessments, training and legislation for informal carers and any studies including quality of informal care. The formalisation of informal care takes place either through payments and associated social security (pension and health insurance), training/certification of skills schemes and finally legislation (recognition of status and rights to being assessed as a carer). Within this category of policies there is a huge variation in design, regulation, implementation and outcomes. The more regulated schemes (UK, the Netherlands, France and Sweden) offers some protection for both vulnerable users and informal carers. Regarding quality, the study identified a conflict between governments' responsibility to ensure quality of the care they fund through public money, and the inherently private nature of the informal care relationship between carer and user. If informal care is indeed unpaid then, unless there are safeguarding or abuse concerns, the quality of that care is seen as a private matter. The level of regulation of cash payments is crucial for understanding the impact of such policy measures on the reshaping of the LTC system. Depending how payments are regulated, cash allowances can have very different effects on the formal-informal division of care. When the use of cash benefits is strictly regulated the aim tends to be to encourage a formal market and the complementary use of formal care services. On the other hand, unconditional cash benefits may create 'incentive traps', where informal carers are

encouraged to leave the labour market and end up in a dependency situation in relation to the family member who receives the benefit.

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## 1. INTRODUCTION

Informal care<sup>1</sup>, also known as unpaid care or family care, constitutes a significant share of the total long-term care (LTC) provision in European countries. Estimates suggest that as much as 80% of all long-term care in Europe is provided by informal carers (Hoffmann & Rodrigues, 2010). The available estimates of the number of informal caregivers ranges from 10% up to 25% of the total population in Europe. The average varies significantly between countries, groups of countries and depending on how informal care is defined and measured. Informal carers are often women, either providing care to a spouse, parents or parents-in-law, and a large share is provided by people who are older than standard retirement age (Colombo et al., 2011). Informal care is likely to become even more important in the future due to demographic change, health care advances, LTC policy and cost-containment pressures leading to the favouring community care options over institutionalisation where possible (Riedel, 2012). This research note provides the most recent survey data evidence of the availability of informal care and discusses the processes under which informal care is becoming increasingly formalised and what this means for our understanding of quality of informal care, in a cross-European perspective.

Informal care forms a cornerstone of all LTC systems in Europe. It is has also been gaining increasing recognition in international policy circles as a key issue for future welfare policy. The European Pillar of Social Rights (2017) makes explicit the commitment to people providing care, including their rights to flexible working and access to care services. Long-term care as a whole is a key policy priority and many European countries have significantly reformed their LTC systems since the early 1990s. Yet, in the context of cost containment and increasing need, the financing of public support for LTC is a continuing challenge (Gori et al. 2016). On the one hand it is seen as crucial to avoid unnecessary, and expensive, hospitalisation or institutionalisation, while on the other hand many countries have stringent needs assessments before a user receives publicly funded LTC. In this context, the caring function of families remains the key type of care provision. Informal care is often seen as a cost-effective way of preventing institutionalisation and enabling users to remain at home. However, informal care is not cost-free either to individuals or to the state (Rodrigues et al., 2013; Pickard et al., 2017). The needs of carers and the impact of providing informal care on key life outcomes such as employment, health, and wellbeing are further being increasingly recognised in the academic literature and in national policies across Europe (Brimblecombe et al., 2018; Bouget et al., 2016). The

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<sup>1</sup> We use the term 'informal care' throughout, and discuss the use of terminology further in section 2.

protection of family carers' human rights, given their particular challenges has been explored in recent European work (ENNHRI, 2017).

Given the importance and policy prominence of informal care it is not surprising that the reform packages of many countries have included important components focused on informal carers. Informal care is becoming increasingly recognised as part of the LTC system and not simply as something that takes place in the private realm of the family and the home. As identified by Daly & Lewis (2000) and Ungerson (2003), a common trend in European countries is to introduce cash payments to support people in need of LTC. These have often been motivated by a desire to offer care users more choice in terms of their care package (Lundsgaard, 2005). Nevertheless Le Bihan (2012) argues that an important driver of cash for care schemes was to formalise the care provided by the family. Likewise, Ungerson argues that cash payments can form a "means of reinforcing intergenerational and intra-generational familial obligations" and that the traditional distinction between formal and informal care, between professional carers and unpaid family carers, is no longer fitting in the new context of reformed care systems (2005:51). There is a fair amount of research on cash-for-care policies (see for example Riedel & Kraus, 2016), their characteristics and structures, and the outcomes they produce, in particular in relation to carers employment, but little on what they mean for the future and sustainability of informal care and much less research on what they mean for the quality of informal care (Courtin, 2014).

In light of these recent policy developments and the importance of LTC reform for the sustainability of European welfare systems this research note zooms in on the state of informal care and informal care policy in Europe. The note aims to provide a snapshot of the availability/supply of informal care in European countries and to explore the range, meaning and implications of policies 'formalising' the role and status of informal carers in a subset of European countries. The focus is on policies which conceptualizes the carer as 'co-workers'<sup>2</sup> following Twigg and Atkin (1994): these schemes, either directed at carers specifically or indirectly through user policies, 'formalise' the caregiving role and treats carers as recognized care providers. This can take place through payments, contracting, training and other structures which support the ability of carers to provide quality care.<sup>3</sup> This process is further evident in legislation which 'formalises' the role, emphasises the importance of informal care and established legal rights for carers, such as the Care Act of 2014 in England where carers are made an

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<sup>2</sup> The conceptualisation can also be understood as that of 'co-clients', as further discussed in section 2.2.

<sup>3</sup> This is increasingly discussed a 'professionalisation' of informal care and can be seen as a parallel and sometimes overlapping process with the formalisation of informal care (see Baltruks et al. 2017).

explicit part of users' needs assessments and have the right to receive an assessment of their own (Care Act, 2014). Finally, where possible, the note includes the prominence attached in policy to quality of informal care and outcomes for carers and users. The note aims to answer the following questions:

- What is the current state of the availability of informal care in Europe?
- How do policies and legislation 'formalise' the character of informal care and aim to support and recognise the status of informal carers?
- What are the implications for quality of informal care?

These questions are of particular importance given the relevance of informal carers for the sustainability of LTC systems in Europe. There are potentially huge gains to be made, not only financial, although cost-containment continues to be at the forefront of the agenda, but on a human level; preventing carer breakdown, improving carer health, facilitating carers to continue in or return to employment, and ensuring that users are able to remain living at home for as long as they wish to while receiving high quality care. This note firstly draws on survey data evidence: descriptive data on availability of informal care, characteristics and outcomes for carers from the most recent cross-European survey available to date and the European Quality of Life Survey (EQLS) 2016. Secondly, the note analyses evidence gathered through a scoping of the literature and national reports, documents and legislation on LTC policies and legislation. The note will cover academic articles published since 2010, building on the evidence in the Triantafyllou et al. (2010) European overview paper which provides a baseline for many of the questions of this paper. We focus on seven European countries: Czech Republic, England<sup>4</sup>, France, Germany, the Netherlands, Spain and Sweden. This note draws on this already collected evidence, and contributes novel information in the survey data analysis, as well as the framing of informal care policies and their potential impact on quality of care.

## **2. BACKGROUND**

This section briefly sets out the background to the questions this note seeks to explore. Firstly, the conceptualization of informal care is discussed before turning to the theoretical framework underpinning the analysis of formalisation of informal care in the seven countries. A discussion on how to compare LTC systems and informal care across countries follows. Finally, we briefly touch on the literature on carers outcomes mainly in terms of health and wellbeing, which provides a useful understanding for the discussion of the quality of informal care below (section 6).

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<sup>4</sup> We focus on the policy and legislative environment in England, while the survey data and certain references do refer to the United Kingdom. The LTC systems of the countries of the UK differ significantly and legislation and political decision-making in relation to LTC are devolved.

## **2.1 Understanding informal care and informal care policy**

The definition of “informal care” employed for the purpose of this note is broad. We take informal care to include any care or help provided to older people (family or otherwise), care provided to working age adults, young people and children with disability as well as people living with mental health problems. Different countries have different conceptions of what an informal carer is, and we take care not to exclude any understanding of informal care. There is a lack of standard definition on which to base inclusion criteria for empirical research and hence studies include varying groups, depending on for example co-habitation and amount or type of care provided (Molyneaux, 2011). Furthermore, the definition of who is seen as an informal carer defines access to any services offered by governments and will have important repercussions for the support carers receive. A facet of the definition problem is that cultural underpinnings, for example related to whether the obligation for relatives to provide care is part of national law (Courtin et al., 2014) and normative and cultural expectations about caring and about gender roles, determine what people think of as informal care. Furthermore, Arber and Ginn (1990) argue that families and households are characterized by all sorts of altruistic and reciprocal behaviour that would not typically constitute ‘informal care’. They argue that what defines informal care is that these are ‘extra’ activities go beyond the ‘normal’ helping activities within the household (Arber and Ginn, 1990; further discussed in from Rutherford & Bu, 2017).

The confusion regarding the conceptualisation of informal care leads to issues when it comes to measuring the prevalence of informal care. Generally this is done through surveys, or as for example in England and Wales, through the decennial Census. Van den Berg and Spauwen (2006) advocate a diary-based time-use approach to measure the provision of informal care and argue that the distinction between support with activities of daily living (ADLs), instrumental activities of daily living (IADLs) and housework activities is important. Even when attempting to identify informal carers in the simplest most inclusive way possible; through questions such as ‘do you help anyone’, cultural differences may mean that carers do not self-identify. They see their ‘helping’ activities as a normal part of life and their duties to the family. From a comparative perspective confusion, or inappropriate comparisons, arise due to differences in culture, legislation, long-term care policy and the extent to which people tend to live in multigenerational households. How informal care is understood in the national context influences care assessments and whether the presence of an informal carer is taken into account when allocating formal services.

Current LTC policy also result in confusion in terms of terminology. As mentioned at the beginning of this note, informal care is often referred to as unpaid care, or family

care. All three terms carry connotations that are not always true for the phenomenon we are trying to describe. In particular, the cash for care policies at the focal point of this note, mean that caring may no longer be unpaid. Even though spousal care is the most common relationship, caring is also provided by neighbours, friends or relatives and these do not fit directly within the ‘family category’. According to the OECD (2005), the ‘unpaid’ facet of care is no longer generally applicable and emphasis should instead be placed on the informal nature of the relationship between care recipients and carers.<sup>5</sup> This is however also muddled in some LTC systems, for example the inclusion of informal care into the overall care package subject to employment contracts in the Netherlands, as discussed further below (Da Roit, 2012). Under these circumstances there is little material difference between an informal and a formal care provider.

As discussed above, LTC policy is increasingly recognising informal carers and provide services benefiting informal carers. Defining what a service is for informal carers is complex as carers are often not the direct recipients of services. Services which support carers are often channelled via the user and their needs. The type of schemes covered in this note can be both direct (i.e. provided to informal carers) and indirect (provided to users but benefiting carers), but it is still useful to set this against the framework by Twigg and Atkin (1994). The framework aims to cover the universe of services potentially provided for informal carers, including the policy environment in which the services are provided. Three levels of support are defined (see Figure 1).

**Figure 1 Theoretical framework – categorisation of informal carer policies**

Degree of incorporation	↑	1. Specific carer support (care allowance, counselling, information, respite care, training)	Often small-scaled and focused. Some cash system are now at national level	Scope of the scheme	↑
		2. Help that is a “by-product” (cash-for-care directed at user)	Mainstream services		↓
	↓	3. National policies and legal entitlements (identification and needs assessment processes, legal entitlements to social security while caring)	Global level of service system		↓

Source: Adapted from Twigg and Atkin, 1994 (original contribution) and Courtin, 2014 (adaptation)

The first level includes services which are provided to directly support informal carers, for example counselling, respite care or training services. The services included at the

<sup>5</sup> Therefore, live-in migrant care workers are usually classified as formal carers, as they fulfil their role as carers in a professional relationship with care recipients.

second level influence the caregiver as a “by-product of the services aimed at the cared-for person” (Twigg and Atkin, 1994). Cash allowances and cash-for-care is a typical example of such a policy, which can often be used to either pay an informal carer or purchase formal care services. Similarly, personal assistance and certain home care services, even though they are directed at the user, also benefit the carer. The third dimension covers the potential impact the LTC system has as a whole has on the ability of carers to provide care, for example getting a carers’ assessment, or structures supporting combining caregiving and employment. Twigg and Atkin argue that these levels vary in terms of the extent to which support is designed with the carer in mind and in terms of the scope of support – ranging from support provided at the local or employer level to national policies which accounts for the complex and often fragmented offer of support services for informal carers.

## **2.2 The carer as ‘co-worker’ and the ‘formalisation’ of informal care**

We begin this section by disentangling Twigg’s conceptualisation of the carer as a “co-worker”, and what we mean by ‘formalisation’ of informal care and how these ideas seem to align. Through this, three facets (discussed in sections 5.1 to 5.3) of LTC policy are identified which contribute to this reconceptualisation of informal care and these form the themes for the scoping of the literature below.

Julia Twigg’s seminal work on how carers are perceived help make sense of informal carers’ relation with social care services (1989) and the extent to which these formalise the role of informal carers. Given the increasing recognition of informal carers, this understanding is crucial for how informal care policy is constructed and what support is made available. Twigg distinguishes between carers as resources, as co-workers and as co-clients. She does so to “draw out some of the tensions in policy that relate to informal care”, primarily related to the ambiguous position of informal carers in LTC systems. Carers as ‘co-workers’ are found in a system where formal care provision works in cooperation with informal care. Family and friendship relations are “semi-professionalised” and brought into the formal system. Carers as ‘resources’ relies on the fact that the vast majority of care is provided informally. It represents “the ‘given’, the taken-for-granted reality against which services are structured” (Twigg, 1989: 56). This model focused on the user and the informal carer is simply a, however vital, background to the user’s situation. The informal carer’s interests are not of importance and the duties are mainly seen as a family responsibility. Finally, carers as co-clients tends to be present in relation to the highest intensity carers and those that are the most likely to suffer adverse effects of the caregiving situation. However, carers’ status as clients is always secondary rather than full ‘co-clients’.

The implications for policy and practice of intervention in the 'co-worker' model is firstly, to maintain and enable informal care and secondly, to ensure the quality of the care offered. Carer morale is seen as a key factor and represents an "intermediate outcome on the way to the final outcome of increased welfare for the dependent person." (Twigg 1989:59). Twigg argues that the position of informal care in the 'co-worker' model is a "slightly uneasy intermingling between the formal and informal sectors" and even though informal care is distinct from formal care services, it has become the object of social service support (1989:61). A further tension identified by Twigg is between ensuring the continuance of caregiving on the one hand and supporting carers to increase their well-being on the other. The 'formalisation' policies which are the focus of this note draw on the categories outlined above, in particular the 'co-worker' category. What defines these policies is that they move the emphasis on caring from something that is done without formal support, remuneration or official status to a 'situation' where the carer is not expected to care simply out of obligation, at any cost, but rather forms a recognised piece of the care jigsaw puzzle.

This note will mainly focus on the 'formalisation' of informal care, but in doing so also engage with policies which represent moves toward a more professionalised role for informal carers in European countries. These policies (found within category 1 and 3 in figure 1) include social insurance contributions and training or peer support (discussed in section 5.1.2 and 5.2 below). The debate about the 'professionalisation' of informal care stems partly from discussions of professionalisation of the social care workforce overall. Baltruks et al. argue that professionalisation can start by providing informal carers with the possibility of paying social insurance/national insurance contributions so that they can build up towards their pension while providing care, as well as providing them with training or peer support groups. Establishing formal training and qualifications that recognise practical skills and experience that are acquired in an informal context is a further route of professionalisation (2017).

### ***2.3 Comparative analysis of informal care policy***

Comparative welfare research traditionally takes its starting point in the welfare regime typologies defined by Esping-Andersen (1990), or, when discussing LTC, typologies based on the characteristics of health care systems, i.e. tax funded or social insurance based (see Wendt et al., 2009). These typologies, if we bear in mind that they are simplifications of reality, provide an informative backdrop against which to select our cases and interpret our findings. As table 2 shows, the countries surveyed in this research note reflect the classical Esping-Andersen welfare typologies, with the addition of Spain in the 'Latin Rim' typology, and the Czech Republic as a 'new' EU

Member State (2004) and an example of the 'Post-communist European' typology<sup>6</sup> (Fenger, 2007). Table 2 further illustrates the different approaches to health and LTC financing systems among the countries as well as the range of spending on LTC as a proportion of GDP.

**Table 1 Comparing LTC systems and welfare regimes**

	Welfare regimes <sup>1</sup>	Informal care regime type <sup>2</sup>	Health and LTC financing	% of GDP spent on LTC <sup>3</sup>
Czech Republic	Post-communist European*	N/A	Health insurance Tax funding for LTC + user charges	1.4
France	Conservative (E-A)	4	Health insurance Tax funded universal LTC (some private LTC insurance)	1.9
Germany	Conservative (E-A)	3	Social insurance (health and LTC)	1.1
Netherlands	Conservative (E-A)	2	Social insurance (health and LTC + some tax funding)	4.3
Spain	Latin Rim **	1	Tax funded universal/	0.7
Sweden	Social Democratic (E-A)	5	Tax funded universal health LTC universal but income related	3.2
England	Liberal (E-A)	2	Tax funded universal LTC means tested	1.2

Note: <sup>1</sup> (E-A) Esping-Andersen 1990, \* Fenger 2007, \*\*Arts & Gelissen 2002, as the original categories created by Esping-Andersen did not include southern and eastern European countries. <sup>2</sup> Informal care regime type – see Bettio and Plantenga (2004) <sup>3</sup> OECD data 2014.

These regime types do not fit as neatly when comparing the role of informal care across countries, although they provide an understanding of the welfare policy context. Several studies have explored how to understand regime types, taking into account informal caregiving, and Strauss et al. (2017) provides a survey of these typologies. Bettio and Plantenga's (2004) five care models identified in European countries are focused on the role of the family and distinguish the relative weight given to the family and informal care in the LTC system. Much has changed since the publication of their paper in 2004, but the typology is still informative. The first type

<sup>6</sup> Most of these typologies are focused on Western European countries and tend to see central and eastern European countries (CEE), many of which joined the European Union in the 2000s, as one separate group. Fenger critiques the literature and offers a typology of CEEs (2007). Fenger (2007) defines the "Former-USSR type" (including Belarus, Estonia, Latvia, Lithuania, Russia and Ukraine) which in terms of total government expenditures resembles the conservative type, scores lower on all other governmental programmes variables than the Western European types. The biggest difference can be found in levels of trust in these countries. The "Post-communist European type" (including Bulgaria, Croatia, Czech Republic, Hungary, Poland and Slovakia) resembles the "Former-USSR" type but has had higher economic growth and inflation, somewhat higher social well-being and more egalitarian.

assigns all caring responsibility to the family, informal care is quite common and formal care services are underdeveloped (Spain). The second type regards LTC as a collective responsibility, however, informal care still plays a substantial role. These countries tend to have a high supply of residential care (United Kingdom and the Netherlands). In the third type again informal care plays an important role, but here the cost for care is compensated by collective arrangements (Germany). The fourth type is denoted by medium levels of residential care as well as of informal care (France). The latter types, except type 2, tend to include countries from the conservative welfare regime type, which traditionally value the family and family care before formal care services. The countries of the fifth group take a universalistic approach, where formal care services are well developed and care is not seen as a responsibility of the family (Sweden). These typologies, and the LTC policy tradition in each country helps explain the type of cash-for-care scheme and any other informal care related policies that have developed and importantly, what implications and challenges they are likely to face.

#### **2.4 Informal carers outcomes**

Key carers' outcomes include health, well-being, and employment (for a detailed discussion see Brimblecombe et al., 2018). Here we focus on carers' health and wellbeing, or in other words, physical and mental health, as these outcomes are important predictors of the quality of the care situation (discussed further in section 6) and crucially the availability and sustainability of caregiving. A considerable literature has provided insights into the relationship between caregiving and physical and mental health outcomes and while the findings are mixed, the consensus remains that, at least under certain conditions, mainly linked to intensity of the care provided, caregiving has negative impacts on physical as well as mental health.

Informal caregiving is argued to have all the features of a chronic stress experience; it creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance (Vitaliano et al., 2003). The literature on effects of caregiving has therefore constructed a logic model which assumes that caregiver distress leads to depression which in turn makes caregivers more susceptible to illness, all potentially leading to an early death (Schulz & Sherwood, 2008). Although researchers have demonstrated the predicted effects for isolated components of this model, they have not shown how illness progresses sequentially or how one condition, such as depression, leads to changes in health habits or physiology (see Bertrand et al., 2012: 2). The empirical evidence is not

completely consistent across individual health, mental wellbeing and mortality effects, for example recent studies have found that carers indeed tend to live longer than non-carers (see O'Reilly et al., 2015). However, it is clear that the character, intensity, duration, and strain of the caregiving situation matter significantly (Brown & Brown, 2014). Depression and mental health are key outcomes both as factors leading to institutionalisation of the user (Coehlo et al., 2007) and due to the risk of affecting future health behaviour and consequently mortality effects. These outcomes have also been shown to matter for the quality of the caregiving relationship as we discuss further in section 6.

### **3. DATA AND METHOD**

The first part of the empirical analysis provides survey data evidence from the European Quality of Life Survey (EQLS) 2016. The purpose of the survey data analysis is to provide an overview of the availability, or supply, of informal care across Europe and the types of indicators which can be used to measure informal care. The EQLS 2016 is the most recent data available on the availability and character of informal care across Europe. The survey includes 33 countries – the 28 EU Member States and 5 candidate countries (Albania, the former Yugoslav Republic of Macedonia, Montenegro, Serbia and Turkey) and close to 37,000 people. We follow the survey data evidence with a discussion of future supply of informal care and the data needed for better understanding informal care across Europe.

The second part of the analysis draws on a scoping of literature, policy documents and legislation in relation to the 'formalisation' of informal care. The aim of the scoping study<sup>7</sup> part of the research note is to explore what is known about how various policies work to 'formalise' informal care and, where there is evidence, what the outcomes might be. Preliminary searches identified that there is a wealth of empirical studies on the availability of informal care, the relation with employment and formal care, and outcomes for carers in terms of health and wellbeing. Less studies were found which focused on how LTC policy affect the situation and understanding of informal care. Searches were carried out during late 2017 and early 2018 for primary research, literature reviews and other types of resources such as reports, policy documents and legislation. We then undertook conceptual and thematic analysis to summarise the review findings. Table 2 outlines the search terms and criteria used.

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<sup>7</sup> Scoping reviews are an increasingly popular method to map the body of literature on a given topic in a timely, transparent and rigorous way (Pham et al. 2014). A scoping study is useful as a way of summarising and disseminating research findings as well as clarifying a complex concept and may be particularly relevant to disciplines with emerging evidence. There is however calls for a greater consistency in how scoping reviews are carried out (Peters et al. 2015, Tricco et al. 2016) and we have followed the Arksey and O'Malley (2005) approach.

**Table 2 Outline of scoping process, search terms and criteria**

Search terms	Informal care, cash-for-care, cash benefits, unpaid care, family care, Europe, choice and informal care, country name* informal care
Inclusion criteria	English language articles and data, mainly published after 2010.
Exclusion criteria	Studies related to care of healthy children, outcomes in terms of employment, health and wellbeing – unless related to quality of care.

Source: authors' own

## **4. AVAILABILITY OF INFORMAL CARE IN EUROPE**

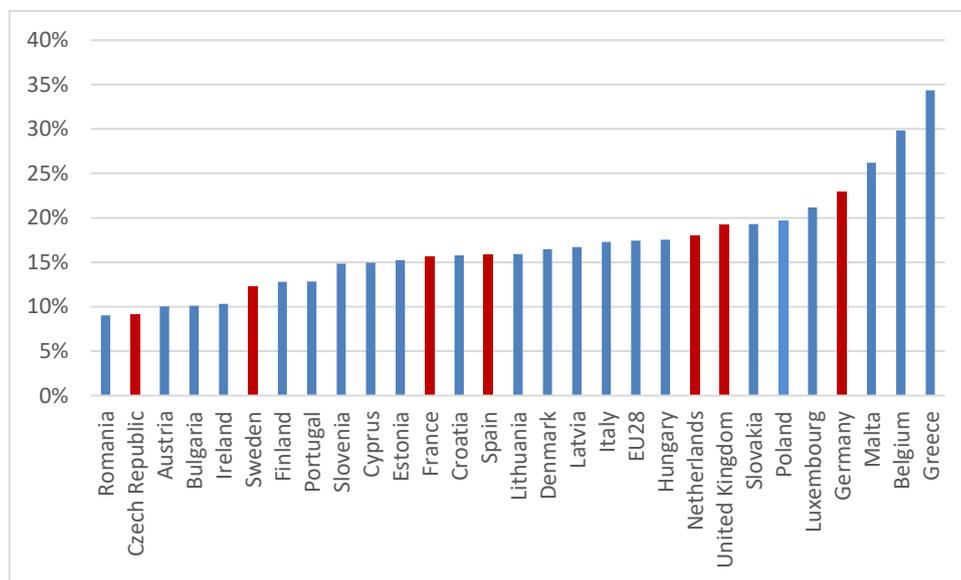
### **4.1 European Quality of Life Survey**

This section discusses the most recent evidence of the availability of informal care in European countries, their social situation and interaction with formal care services. This is followed by a discussion of estimates and drivers of future availability. As Rutherford & Bu (2017) caution, the data on informal care is collected through self-identification as carer or care receiver, either by the carer or the user, and hence the response depends on how these questions are interpreted by different respondents. Care providers and recipients may perceive their shared caring relationship differently (see Brimblecombe et al., 2017). The EQLS data is focused on provision of care and the EQLS question from which the information in the figures and tables below is drawn from reads (Q42) "In general, how often are you involved in any of the following activities outside of paid work?" ranging from "never" to "every day". For the purpose of this note we have included care which takes place once per week or more. Firstly, we must note that this is a 'low' threshold for defining someone as an informal carer compared to other studies, where often carers are only included if they provide care more than 20 hours per week. We also note that it is only the carers who respond to the question and little is known about the person they care for.

In figure 1 the percentage of the population who provides informal care at least once a week as a proportion of the total population aged 18 or above is shown. The countries that we focus on in this study have been highlighted in red. Figure 1 shows a remarkable variation in self-reported informal care provision across Europe. The highest prevalence is found in Greece, where over 30% self-report as informal carers. The lowest rate, found in Romania, is less than 10%. The figure shows the spread of informal care prevalence across the countries used as case studies for the purpose of this research note. Germany has the highest rate at around 22%, while the Czech Republic has the lowest rate at around 12%. This discrepancy may have something to do with the way that the question is asked: it is possible that people in the Czech

Republic are less likely to respond positively due to cultural or policy related factors. The Germany LTC system heavily emphasises informal care as a key component, and the cash-for-care system through which informal carers are paid is one of the schemes with the highest take-up in Europe (Da Roit & Le Bihan, 2010). On the other hand, the Czech system has been heavily reliant on residential care which may partly explain the low number of carers. The number for Sweden is among the lowest as we would expect due to the highly formalised LTC system. Interestingly the rate found in the EQLS for United Kingdom is close to 20%, which is much higher than the rate of around 12% found in the Census for England and Wales of 2011, although the Census is filled out as a postal questionnaire, which may explain part of the difference.

**Figure 2 Informal carers as a % of total population, EQLS 2016**



Source: EQLS 2016, figure adapted from EQLS Overview report (see Eurofound, 2018 forthcoming)

Further exploring the same informal care variable, table 3 shows us the percentage of the population who self-report as carers, for men, women and divided by age categories. In general the picture is dominated by female carers. In all countries except for two more women than men provide care, and the largest difference between men and women is found in Belgium, where 13% more women provide care. Similarly in the Netherlands and Greece, 10% more women than men provide care. On the other hand, in the Czech Republic, as many men as women provide care. These difference may partly be due to differences in female labour market participation which generally is higher in Eastern European countries. In the Czech Republic the rate is 52% and has been traditionally high, at 52% in 1992. On the other hand in Belgium and Greece the rates of female labour market participation are 48 and 45% respectively, however up from 37 and 36% in 1990. This may explain the low overall rate of informal care in the Czech Republic, as well as the need for men to provide more care.

Table 3 also shows informal carers as a proportion of three age categories; 18-34, 35-64 and 65+. Here there are less differences between the countries. The distribution in the UK and Sweden are fairly even between the categories, whereas Germany and the Netherlands are defined by more carers over the age of 35. In general the least carers are found in the 18-34 category; the only exception is Spain where there are more carers in the young category than in the old (65+) category. This may be due to lack of employment opportunities for the young in Spain after the financial crisis which resulted in large youth unemployment.

**Table 3 Informal carers as a % of total population, EQLS 2016**

Country	Total	Male	Female	18-34	35-64	65+
Czech Republic	9%	9%	9%	6%	11%	9%
France	16%	13%	18%	11%	18%	14%
Germany	23%	20%	26%	12%	28%	24%
Netherlands	18%	13%	23%	10%	23%	17%
Spain	16%	13%	19%	14%	19%	11%
Sweden	12%	10%	15%	12%	14%	10%
United Kingdom	19%	16%	22%	18%	20%	19%
Austria	10%	8%	12%	4%	11%	15%
Belgium	30%	23%	36%	25%	33%	30%
Bulgaria	10%	8%	12%	8%	12%	8%
Croatia	16%	13%	18%	14%	19%	11%
Cyprus	15%	10%	20%	11%	18%	13%
Denmark	16%	13%	20%	6%	21%	18%
Estonia	15%	14%	16%	14%	17%	14%
Finland	13%	10%	16%	6%	16%	13%
Greece	34%	29%	39%	33%	35%	34%
Hungary	18%	17%	18%	8%	25%	13%
Ireland	10%	9%	11%	6%	13%	8%
Italy	17%	16%	19%	12%	20%	18%
Latvia	17%	13%	20%	11%	19%	17%
Lithuania	16%	11%	20%	9%	22%	10%
Luxembourg	21%	19%	23%	16%	26%	14%
Malta	26%	25%	27%	19%	33%	21%
Poland	20%	18%	21%	7%	26%	20%
Portugal	13%	9%	17%	8%	17%	10%

Romania	9%	8%	10%	5%	11%	9%
Slovakia	19%	22%	17%	16%	24%	11%
Slovenia	15%	13%	16%	8%	17%	19%
EU28	17%	15%	20%	13%	20%	17%

Source: EQLS 2016, adapted table from overview report (Eurofound 2018, forthcoming). Q46 defined as respondent cares for disabled or infirm relatives, neighbours or friends at least once a week.

Table 4 shows the distribution of carers by employment status and focused on working age carers. This gives us interesting information from two perspectives. Firstly, if we compare the proportion of informal carers as a percentage of people of working age to the percentage informal carers of the total population, for most of the countries the rate is lower for working age people. The only exception is France where 16% of the overall population are informal carers compared to as much as 26% of working age people. In the Czech Republic the percentages are exactly the same, indicating that the informal care responsibilities are spread evenly throughout the population. Secondly, when comparing whether or not carers are in employment we again find distinctive difference between the countries. In all countries except the Czech Republic carers of working age are more likely to be employed than unemployed. The most noticeable difference was found for France where 18% of the population are employed carers of working age compared to 8% of the population being carers not in employment.

**Table 4 Informal carers as a % working age people (18-64), by employment status**

	Non-carers	Working carers	Carers not in employment	All carers
Czech Republic	91.5%	3.6%	4.9%	8.5%
France	73.9%	18.3%	7.8%	26.1%
Germany	94.4%	3.6%	2.1%	5.6%
Netherlands	90.7%	6.3%	3.0%	9.3%
Spain	87.6%	6.6%	5.8%	12.4%
Sweden	95.7%	3.6%	0.7%	4.3%
United Kingdom	86.3%	8.9%	4.8%	13.7%
Austria	94.9%	2.6%	2.5%	5.1%
Belgium	81.0%	10.8%	8.2%	19.0%
Bulgaria	92.3%	3.0%	4.7%	7.7%

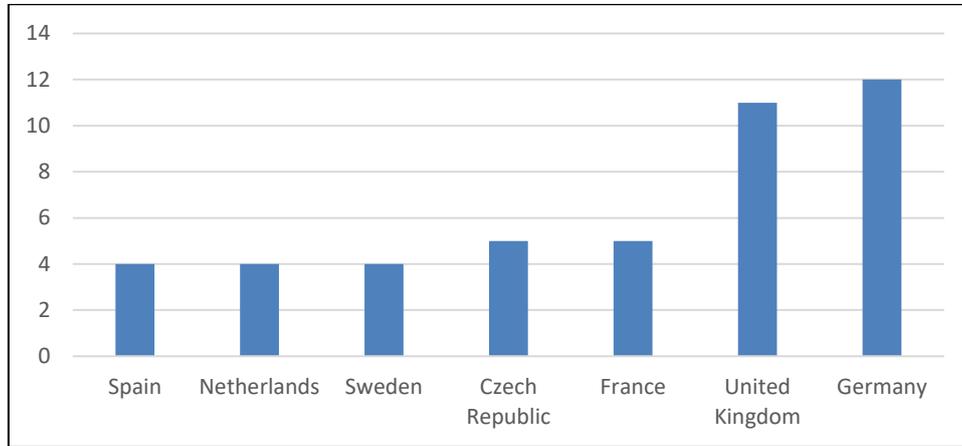
Croatia	87.1%	7.2%	5.7%	12.9%
Cyprus	88.6%	5.4%	5.9%	11.4%
Denmark	92.9%	4.9%	2.2%	7.1%
Estonia	88.1%	7.2%	4.7%	11.9%
Finland	89.9%	7.3%	2.7%	10.1%
Greece	90.4%	3.1%	6.5%	9.6%
Hungary	92.5%	4.1%	3.4%	7.5%
Ireland	86.3%	6.2%	7.4%	13.7%
Italy	89.5%	5.8%	4.7%	10.5%
Latvia	78.0%	14.8%	7.2%	22.0%
Lithuania	85.5%	9.6%	4.8%	14.5%
Luxembourg	85.2%	11.5%	3.4%	14.8%
Malta	86.4%	4.8%	8.8%	13.6%
Poland	89.0%	5.1%	5.9%	11.0%
Portugal	93.1%	3.6%	3.3%	6.9%
Romania	83.9%	10.4%	5.7%	16.1%
Slovakia	91.3%	5.3%	3.4%	8.7%
Slovenia	86.9%	8.3%	4.8%	13.1%
EU28	87.8%	7.5%	4.8%	12.2%

Source: EQLS overview report. (Eurofound 2018, forthcoming) Q.46: respondent cares for disabled or infirm relatives, neighbours or friends at least once a week, working age people (18-64), by employment status and country (%)

A key issue in terms of the availability of informal care is the willingness of carers to provide care, and importantly whether they are willing to provide care at the intensity (i.e. the number of hours or difficulty of tasks) required. Figure 3 shows the percentage of the population who would like to spend *less* time on caregiving tasks for the countries of our sample. Notably, both in Germany and the United Kingdom more than 10% of carers would like to spend less time on caregiving activities. This is twice the number of any of the other countries of our sample. This may be due to underfunding of formal care services in the UK and the cash-for-care policy in Germany which has strong financial incentives for relying on informal care rather than formal care services. Strong familistic values are also traditionally present in Germany, and it may be that given the changing labour market requirements, for

example increased female labour market participation, this is slowly changing and creating tension.

**Figure 3 % of people who would like to spend less time on caring for disabled or sick relatives or friends, by country EQLS 2016**



Source: EQLS 2016, data from the online data visualisation tool and adapted by author.

#### **4.2 Future projections of informal care**

As discussed above, many European countries are planning to reform their long-term care systems. Given the current reliance on informal care, understanding the possible future availability of informal care is particularly important when reforming LTC systems. Cash-for-care and other cash allowances are argued to incentivise the provision of informal care, however, there is currently no research on whether this works. Analysis of the possible future availability of informal care is however challenging given the many, sometimes conflicting, processes of societal change which influences informal care demand and supply. This note seeks to discuss the main drivers of change and report evidence from recent studies offering projections of future informal care (see Pickard, 2015; Pickard & King, 2012) for a representative set of European countries.

In order to understand current or future informal care availability it is useful to separately consider the demand for informal care and the supply of informal care and the key factors with influence each. Firstly, demand for informal care is projected to increase due to population ageing in Europe. Age is a key predictor of difficulty to carry out activities of daily living (ADLs) such as eating, bathing, dressing, toileting and transferring (mobility). The way need is defined in projection models significantly affects the results. Two main processes affecting the supply of informal care. Firstly, projected increases in care by spouses or partners are primarily due to projected reductions in male mortality rates and a likely fall in the number of widows. Secondly, care for older people from their adult children may be affected by the future

availability, ability or willingness of children to provide care. This in turn can be affected by demographic and socio-economic factors such as the projected decline in people with no surviving children, the decline in co-residence of older people with their children, the continuing rise in labour market participation by mid-life women (Pickard, 2015; Pickard & King, 2012).

Specific estimates are sensitive to the usual uncertainties of making projections. However, Pickard & King (2012) predict that demand for informal care by older people will exceed supply and by 2060 there will be a deficit of approximately 20,000 caregivers in the Netherlands, 400,000 in Germany, and over a million caregivers in Spain. The 'care gap' is particularly large in Germany and Spain. This reflects the heavy reliance on informal care in the long-term care systems in these countries. The 'care gap' in all countries studied is projected to grow throughout the period of study. A key reason why the supply is unlikely to keep pace with demand can be found in underlying demographic trends – the numbers of older people, especially the oldest old, are rising faster than the numbers in the younger generation (Pickard, 2015). A key challenge in making robust projections for future informal (and formal care) stems from lack of reliable data. To better understand informal care in the future we need access to longitudinal data (see Pickard, 2015), data which links the carer and care recipient (dyads), preferably also in cases when the carer and care recipient are not co-residing. Further, data which links caring activity to the formal services on offer and how these work together would be highly policy relevant. Comparative data along these lines would offer opportunity to draw lessons across countries, however care is required in careful understanding of the details and sometimes tiny but very significant difference in how formal services are offered and paid for.

## **5. THE FORMALISATION OF INFORMAL CARE IN EUROPE – POLICY AND LEGISLATION**

This section surveys policies which contribute to the conceptualisation of informal carers as 'co-workers', and the 'formalisation' of informal care, covering policies in the seven countries: Czech Republic, England, France, Germany, the Netherlands, Spain and Sweden. The themes which guide the scoping of the informal care literature are facets of policy and the relationship between the carer, the user and the state which works to create a formalised caregiving situation. These themes are – and it will be evident that these are applicable to any type of formal work – *payments* (preferably regular and predictable), an *employment contract and social security* (i.e. being protected by regulation), *training and validation of skills*, and finally broader *legislation* which recognises the importance of the role and offers assurance of a certain minimum standard of rights. We do not aim to provide a thorough account of the

systems in these countries, but rather draw out the defining characteristics under the three key themes; cash benefits, carers' assessments, training and informal carers' recognition in legislation.

The characteristics of the formalisation processes in the seven countries are outlined in table 4. The countries are defined by various combinations of formalising processes or aspects as discussed in relation to figure 1.

### **5.1 Cash for care schemes and cash benefits**

Cash for care schemes, as discussed above, have spread across the various welfare regimes and LTC system types during the past 15 years (OECD, 2011; Pavolini & Ranci, 2008). The purpose of these types of policies has been argued to offer choice, independence, and flexibility (Le Bihan & Martin, 2012) while containing costs. The schemes are however very different in several respects. The conditions regulating who receives money and what needs and means assessments are required differ across countries, varying from freely disposable cash transfers to highly regulated and tightly controlled transfers conditional upon the employment of regular paid carers. Cash benefits have been advocated as a means of empowering individuals in need of care because such benefits help broaden opportunities of choice (Riedel et al., 2016). The outcomes for carers and users of the cash schemes are however unpredictable and difficult to research comparatively due to the large variation in the schemes.

Cash allowances which can be used to pay informal carers can either be given *directly* to the informal carer for their work – with or without an employment contract – or given to the cared-for person, who can in turn use funds to remunerate their family caregiver (*indirect support for informal care*). The latter, indirect financial support, is the most common approach in Europe, and in the countries of our sample we find it present in the Czech Republic, Germany and France (Hubíková, 2017; Wija, 2015; Da Roit & Le Bihan, 2010). England, the Netherlands, Spain and Sweden on the other hand provide both indirect and direct financial support (Courtin et al., 2014; Casanovas et al., 2017). In countries where the support is indirect, studies often emphasise the lack of control over whether the payment reaches the informal carer at all, for example in the Czech Republic (Křížová et al., 2016) and Germany (Arntz & Thomsen, 2010). Direct support in the form of a carer allowance is generally associated with conditions such as income (means test), relationship with the user, level of disability of the user and, relatedly, the intensity of the informal care provided.

**Table 5 Characteristics of ‘formalisation’ of informal care in our sample of countries**

	1. Specific carer support	2. “by-product” (cash-for-care directed at user)	3. National policies and legal entitlements	Cash recipient	Amount/ level of income replacement	Employment contract	Social security benefits	Carers assessments	Training for informal carers
Czech Republic	No	Yes	No	User	Low level	No	Yes	No	Very little
France	No	Yes	No	User	Some income replacement	Yes	Yes	No	Yes
Germany	No	Yes	No	User	Set amounts depending on need	No	Yes	No	Yes
Netherlands	Yes	Yes	Yes	User	Medium income replacement	Yes	Yes	No	Yes
Spain	Yes	Yes	Yes	User	Low level	No	Yes	No	Some
Sweden	Yes	Yes	Yes	User/Carer	Equivalent to formal care worker wage	Yes	Yes	No	Yes
England	Yes	Yes	Yes	User/Carer	According to care package	No (possibly but not mandated)	Yes	Yes	Yes

Source: author’s own. The first three columns relates to the theoretical model in Figure 1.

The size of the care allowances varies significantly across the countries but as a general rule it is too low to replace income in a meaningful way. It is in many cases significantly lower than the cost of institutional and home care services (Riedel & Kraus, 2016) and for example in the Czech Republic, the allowance represents around one third of the payments received by formal home care worker (Wija, 2015). In Sweden on the other hand, carers are employed as 'formal' care workers and given a salary, which is taxable, of similar size as what a regular care worker receives. It is however important to note that currently very few informal carers become employed 'family carers' and the numbers have dramatically dropped since the 1970s (Sand, 2014). In England there are three different schemes of cash payments that can be channelled towards informal carers and these vary significantly in the amount paid. The direct payments or personal budgets is a sum of money calculated to cover the user's care needs as paid on the market. This tends to be at minimum wage level, but can, depending on the size of the care package amount to a significantly larger sum than the other cash benefits available to carers. These are carers allowance and attendance allowance, both paid at a rate of around £60 per week, however under specific conditions. The French APA (Allocation personnalisée d'autonomie, translated as the "Personal autonomy allowance") is paid as a voucher and is relative to the user's income. People with high income (above €2495 per month) will pay 90% of the care cost (in 2014), whereas people with an income of less than €800 will get 100% of the value of the care package paid through public funds (Brugiavini, 2017). The German cash benefit is calculated in relation to the needs of the user at three levels and is about 30% lower than the value of in-kind formal services. A market for private LTC insurance is emerging as a way of supplementing the cash payments (Nadash & Cuellar, 2017). Many low income LTC users in Germany also receive social assistance payments to supplement the payments through the main LTC system (Nadash & Cuellar, 2017). Similarly in the Netherlands the personal budget in cash is worth around 25% less than the equivalent formal services (Da Roit, 2012). In Spain the cash benefit for informal carers is provided without any restriction at an amount determined based on the needs of the user (Casanova et al., 2017). Spain has however struggled with funding of the LTC system since the reform in 2007 and not all types of services are offered across the board.

### **5.1.1 Regulation of cash schemes**

We find noticeable differences in terms of the regulation of the cash-for-care schemes. The rules range from cash benefits paid to the user with no control over whether the carers receives any money (Czech Republic) to the carer signing a formal employment contract with either the user (France and the Netherlands) or with the municipality (Sweden). Table 4 provides an overview of the types of regulation present in our seven countries.

**Table 6 Regulation of cash-for-care schemes in the seven European countries**

Type of cash benefits	Countries
Employed by municipality as a carer	Sweden
Employed by the user with contract	France, Netherlands
Paid to the user, channelling cash benefit towards informal carer(s)	Germany, Czech Republic
Paid directly to informal carer	England, Spain

*Note: author's own. Several countries offer more than one type of cash benefits. The table is focused on the most common cash scheme in each country.*

Apart from Sweden, where the carer becomes a formal employee of the local municipality, the arguably most stringently regulated system is the French APA. The French cash benefit is paid out exclusively to finance a specific care plan determined by a team of professionals. This team includes health and social care workers employed by the French local authorities. The level of payment depends on the needs of the recipient and can only be used to finance the care activities defined as necessary by the professionals and included in a 'care plan' (Le Bihan, 2012). Similarly in the Netherlands, family members and even spouses can be paid through the personal budget, subject to an employment contract (Da Roit, 2012).

In the English system the three cash benefits are different in terms of regulation: the direct payments/personal budgets can be used to pay non co-residential carers (and if 'necessary' co-residential, but the law is set against that). Carers' allowance is paid directly to the carer if the person they care for is themselves receiving certain disability related benefits (for example attendance allowance), if the carer is providing care for at least 35 hours a week, and if they earn less than £116 a week. Likewise, attendance allowance can in theory be channelled towards the household income or the informal carer. Finally, carers can receive a direct payment themselves – if they need care/support – but this has to be agreed through a carer's assessment as discussed further below (Pickard et al., 2018). The Spanish system offers one type of cash benefits for informal carers. The aim is to financially support informal carers, without applying any restrictions in terms of usage. The amount depends upon the intensity of care required by the care user (Casanova, 2017).

### **5.1.2 Social security**

As European governments have begun to recognise the role of carers in the provision of care, the social protection rights of informal carers in terms of pension credits, health insurance and reconciliation of employment and caring have started to appear. The countries of our sample have engaged with this issue in various ways. For the small number of carers in Sweden who are employed by the municipality, full social security

coverage is in place as the salary paid is taxed through the general taxation system (Sand, 2014). In the Czech Republic informal carers of a care recipient with significant needs (level 2 out of 4) can be credited for their care in the pension insurance system and receive health insurance (Baríková, 2011). Equally, in Spain informal care support is fully integrated into the overall system of social protection through a social security compensation of 74 euros/month paid by the state (Casanova et al. 2017). The inclusion into social security is often tied to a certain intensity of informal care provided. For example, in Germany pension and accident insurance contributions are paid for informal carers if they are not in full-time paid work and are providing 14-plus hours care per week. If a carer in England is receiving the means-tested carer allowance they receive pension credits at basic state pension level. In the Netherlands and France no social security for informal carers is available (Da Roit, 2012; Le Bihan, 2012).

## **5.2 Training and validation of carers' skills**

The majority of countries provide some type of training for carers, however the quality and availability varies significantly and the voluntary sector often plays a large role in the provision of training (Bouget et al., 2016). Even though training is sometimes offered as part of the cash-for-care schemes discussed above, it is not the rule. Regardless, training and validation of skills contributes to the formalisation of informal care.

The TRACK project, which aims to develop new training pathways for informal carers, found that the current state of training opportunities for informal carers in Europe are fragmented and that little has been well documented (TRACK, 2016). The TRACK report found four types of training schemes present in European LTC systems: professional vocational training open to informal carers; training developed within the health sector; training developed by Civil Society Organisations (CSOs), and training developed by CSOs, specifically targeted at female carers. The comprehensiveness of training seems to correspond to the general spending of the LTC system.

Bouget (2016) as well as Courtin et al. (2014) found no evidence of training for informal carers in the Czech Republic but argued that training is well developed in Germany, Sweden and the UK (where the focus is on training provided by voluntary organisations). In Sweden, group courses on specific topics offered by the health care sector directed at carers of people with stroke, dementia or diabetes. Municipalities on the other hand offer courses and sessions on self-awareness (TRACK 2016). The debate on training in Sweden has been focused on the tailoring of training to suit different target groups; age, gender and ability. Further examples of training schemes from the countries surveyed in this paper are AMWAHT in the Netherlands which aims at empowering migrant informal caregivers by training them to work as a group and peer support other groups of informal

caregivers. In the Netherlands a further example is the guided self-help course 'Mastery over dementia' which albeit struggling with high drop-out rates reached a wide variety of caregivers, including among those aged 75+ (Pot, et al., 2015). The UK has a range of training initiatives, one of the most prominent being the 'Caring with Confidence' scheme and a range of local initiatives. Spain, among other countries not in our sample, utilise the ECVC "Elderly Care Vocational Certificate" which is an e-training programme for formal, informal and migrant carers of older people. This is based on the pre-existing e-learning curriculum developed by the LdV ECV project ([www.ecvleonardo.com](http://www.ecvleonardo.com) in 2005-2007) and is supplemented with work experience at elderly care providers.

Regarding validation and certification of caregiving skills the TRACK report finds that existing training rarely include a formal validation or certification process. Validation could be valuable to certain carers, in particular carers who face difficulties returning to the labour market after a, in particular longer, spell of informal caregiving. The TRACK report also found that certification should allow for flexibility in the learning situation and not be too demanding on carers (2016). The relevance of certification/validation and training more broadly is particularly strong for working age carers. The question is whether the cash for care models discussed in this report work to bridge the boundaries between informal care and formal labour market participation. And, whether payment and in particular employment contracts help retain a sense of connection to formal work on the part of informal carers. There is however little evidence on formalisation of the skills acquired in informal caregiving as potential assets for future employment.

### **5.3 Carers assessments and legislation**

This final theme in the literature on LTC policy which formalises informal care falls within the global care policy category of the theoretical framework (see figure 1). It includes national level policies which provide for carers' assessments and other national strategies and assurance of informal carers rights in national legislation.

A key way of recognising carers and formalising their role is to provide an assessment, either together with the user or separately, that takes into account the needs of the carer and devises support where needed. This recognises the needs of carers as intertwined but also independent of the user's needs. Systems to locate informal carers through the national health and social care systems are in place in England, France, the Netherlands, and Sweden (Courtin, 2014). Carers' assessments have been available in England since 1995, however there are still gaps in the frequency of which assessments are carried out and only a minority of carers actually receive one. Sweden have a similar process in place. In the remaining countries, informal carers are identified *via* the person they care for, e.g. when the latter's care is discussed with their general practitioner or with local

social services. Assessing the carer separately is not in general a common practice across Europe.

In England, the Netherlands, Spain and Sweden national policies and legislation targeted at informal carers are present. England can be seen as a front runner in this regard; the first national strategy for carers was launched in 1999. It was enhanced in 2008 by the national plan "Carers at the heart of 21st century families and communities" and then replaced in 2010 by a new carers' strategy titled "Recognised, Valued and Supported: Next Steps for the Carers Strategy", which aimed to raise the profile of carers and improve their support services (Molyneaux, 2011). These have recently been followed by The Care Act (2014), where under section 10 (which came into force in April 2015), councils in England must carry out an assessment of a carer of an adult where it appears that the carer may have need for support. Previously, carers needed to be providing a substantial amount of care on a regular basis to qualify for an assessment. The legislation in England is a significant development for carer's rights and recognition because it gives carers a right to assessment and services independent of/regardless of any assessment/provision for person with care needs (Yeandle, 2016). The Spanish reform of 2007 (Ley De La Dependencia) provides a strong and explicit recognition and support of the role played by informal carers and is unique in comparison to other LTC policy in the Mediterranean countries (Casanova, 2017). In the Netherlands the Dutch Social Support Act from 2007 made informal carers an explicit party of LTC provision and the responsibility of local authorities and similarly in Sweden, since 2009 it has been the duty of municipalities to offer support to informal carers.

## **6. INFORMAL CARE QUALITY AND OUTCOMES**

The conceptualisation and measurement of the quality of informal care is one of the least researched areas in the LTC literature (Courtin et al., 2014; Gori et al., 2016). The focus of this note – the formalisation of informal care – carries important implications for the how we understand quality and who is responsible for the quality of care provided by informal caregivers.

This lack of research may stem from the conflict between governments' responsibility to ensure quality of the care they fund through public money, and the inherently private nature of the informal care relationship between carer and user. If informal care is indeed *unpaid* then, unless there are safeguarding or abuse concerns, the quality of that care is seen as a private matter (see Nies et al., 2010). Formalisation of informal care and the informal care related policies set out in this note changes that dynamic significantly, not only due to the link with provision of training for informal caregivers, but importantly, due to the fact that informal care in cash-for-care schemes can become publicly funded

and in some cases regulated (as in for example the Netherlands). One could argue that it becomes in the interest of the funder, i.e. the state, to engage with the quality of the care provided. Ensuring sustainability and quality can both act as a cost-containment tool and to prevent users deteriorating prematurely and needing institutionalisation or extensive formal home care provision. Quality, supported through training or equipment, and appropriately designed formal (often preventative) care provision reduce the risk of carer breakdown, and again the need for more extensive formal care services. As discussed below, both the empirical evidence and the theoretical underpinnings of the concept of quality of informal care are lacking in the literature and this is a key area for future research.

Conceptualising quality of informal care is made difficult by the challenges of defining quality of LTC provision as a whole. Quality is to some extent an 'experience good' and quality (beyond pure safeguarding) is partly about meeting users' preferences for their care. Many countries therefore focus on process measures instead of outcomes for measuring quality of formal care. A large literature deals with quality assurance in LTC. For example, Nies et al. list a set of prerequisites for ensuring quality: shared vision of stakeholders, aims of quality management, clear responsibility, aspects of service delivery to be addressed, costs and cost-effectiveness and involvement of staff and users (2010). All of the examples listed in Nies et al.'s report can be applied to the informal/formal care situation and in particular when the informal care situation is in some way formalised in the ways outlined above.

On the other hand, quality of informal care is often understood as the basic ADL needs of the user being met (see Christie et al., 2009). This is a limiting approach given the intricate nature of the intimate relationship of informal caregiving. Likewise, Christie et al. argue that quality goes beyond determining whether the care recipient needs for assistance (ADLs) are routinely satisfied. Instead potentially harmful behaviour (PHB), adequate care, and exemplary care (EC)<sup>8</sup> are empirically distinct dimensions of quality of care and should be incorporated into analysis (2009). A European report from the WHO however highlighted that a growing number of older people experience mental and physical abuse and suggested that the most common perpetrators are informal caregivers, and that co-residency is a particular risk factor (Sethi et al., 2011). Strained carers are more likely to be abusive, and anxiety and depression are particularly

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<sup>8</sup> Potentially harmful behaviour are actions on the part of caregivers which can include screaming, threatening with nursing home placement, hitting, slapping, handling roughly that can be detrimental to the care recipient without being severe enough to warrant social services or legal intervention. Exemplary care on the other hand is the extent to which caregivers consistently demonstrate sensitivity to psychological need for respect and pleasurable activities. Both of these concepts can take place at the same time as adequate (in terms of ADLs) care is provided (Christie et al. 2009).

important risk factors for abusive behaviour (Cooper et al., 2010). Abusive behaviour on the part of the care recipients was also found to be a risk factor. Carers of users with dementia who were forced to start providing care tend to experience more anxiety and abusive behaviour on the part of the user. Both of these aspects were found to predict admission into residential care (Camden et al., 2011). This all suggest that poor quality informal care, and essentially safeguarding of users with the majority of care provided by informal carers, can be prevented by early identification and intervention to support carers who are suffering from stress, anxiety or depression (Courtin et al., 2014).

Certain aspects of the cash-for-care systems are explicitly or implicitly directed at ensuring quality. For example the 2010 Carers (Equal Opportunities) Act and the 2014 Care Act in England include assurances for carers needs for education, training and support. Also the Netherlands and Germany include informal care in users' needs assessments, and in Germany courses are offered to informal carers through the health insurance funds, through which LTC insurance is channelled. Both of these approaches are driven by the fact that carers are paid, and in the case of the Netherlands, employed as part of the publicly funded LTC provision. None of the countries surveyed in this note however have a robust monitoring or evaluation system in place to measure quality of informal care. This is likely due to the delicate nature of the issue – it would be difficult to systematically inspect and assess the care provided by informal carers in a sensitive and non-intrusive manner (Courtin, 2014).

Identifying carers who are struggling is a challenge, and even more so given the finding above that few of the countries surveyed know anything systematic about informal carers – even though they may be paid through public money. Cross-European data can offer some insights into the level of strain and quality of life of informal carers. Table 5 provides the most recent cross-European evidence on the social and economic situation of informal caregivers from the EQLS survey (described above). Table 5 shows how carers, working carers, as well as carers not in employment, fare on key indicators capturing a challenging life situation. Carers are more likely to have fair or poor health (as compared to good or very good health), they are more likely to have difficulty making ends meet and carers not in employment are highly likely to be in the lowest income quartile. Similarly, carers not in employment are more likely to feel lonely, score higher on the perceived social exclusion index (see details in note to table 6) and have a lower overall life satisfaction. Carers, both working carers and carers not in employment, are more likely to feel that the value of what they do is not recognised. Carers who are not in employment are more likely to be providing high intensity care which is another predictor of difficulty.

**Table 7 The social and economic situation of regular carers of working age (18-64), EU28, %**

	Non-carers	Working carers	Carers not in employment
In fair or bad health	22%	27%	41%
Having difficulties making ends meet	38%	44%	54%
In lowest income quartile	25%	26%	45%
Feel lonely more than half of the time (in previous two weeks)	10%	14%	17%
Feel the value of what they do is not recognised by others	19%	26%	28%
Social exclusion index	2.1	2.2	2.4
Life satisfaction	7.2	7.1	6.5

*Source: EQLS 2016. The perceived social exclusion index refers to the overall average score regarding the four statements – 'I feel left out of society', 'Life has become so complicated today that I almost can't find my way', 'I don't feel that the value of what I do is recognised by others', 'Some people look down on me because of my job situation or income' – where 1 = 'strongly disagree' and 5 = 'strongly agree'.*

## 7. DISCUSSION

The note has addressed one of the principal policy trends in European LTC systems over the past 15 years; that is, policies which recognise and to some extent 'formalise' the role of informal carers. This takes place either through payments (cash allowances, cash for care policies), social security (pension and health insurance), legislation (recognition of status and rights to being assessed as a carer), statutory employment related rights and training/certification of skills schemes. Within this category of policies this note has identified a huge variation in design, regulation, implementation and outcomes. Key themes have been identified through the scoping of the literature on informal care policy related to the formalisation trend, which have implications for carers' outcomes and should be taken into account when formulating policy. These are the level of income replacement and whether social security is available to carers; the level of regulation of cash benefits; the impact of cash benefits on family relations, and the level of engagement with quality of informal care.

Income replacement during caregiving and social security contributions, in particular pension contributions, are interrelated facets which are key to avoiding caregiver poverty over the life course. The former captures the situation during the caregiving stint, while the latter protects against long-term financial impacts. Many caregivers do continue to

work alongside their caregiving duties and hence do not solely rely on the level of income replacement through cash for care schemes and cash benefits. These are however generally far from sufficient: the levels of cash payments are often at least 25% lower than what is spent on formal care services and often equate to well below minimum wage for the carer (Sweden is an exception). Further, access to LTC support across Europe is often means-tested or income related. This, and the low level of cash benefits, means that it is critical to ensure that social support is in place when there are cases of financial hardship, such as for example in Germany. Likewise, social security contributions being paid during caregiving, including access to pensions and health insurance, shields informal carers from financial difficulty over the life course following a shorter, or more so, a longer stint of caregiving. Pension contributions and where relevant, health insurance contributions are covered in some countries but generally only above a certain threshold of caregiving.

Implications of the lack of adequate income replacement over carer's life course are particularly noticeable for female caregivers. Women tend to have a weaker attachment to the labour market to begin with, and more often work part-time over long periods of time to provide care for children and other family members. The repercussions in terms of access to sufficient pensions can be considerable. Rummery argues that the cash schemes, and in particular the low level of income replacement, reinforces gendered inequalities through "trapping" women in expectations of providing care, while not sufficiently compensating them for the value of the care they provide (2009: 642). Haberkern et al. similarly expects cash for care schemes to reproduce and increase gender inequality in the provision of informal care (2015).

The level of regulation of cash payments is crucial for understanding the impact of these policy measures on the reshaping of the LTC system (Le Bihan, 2012). Depending on how cash payments are regulated, cash schemes can have very different effects on the formal-informal division of care. When cash benefits' use is strictly regulated (such as in The Netherlands and France) the aim tends to be to encourage a formal market and the complementary use of formal care services while assuring that the informal care component of the care package meets the needs of the user, without 'overloading' the carer. On the other hand, unconditional cash benefits, while being easy to access and arguably the most 'freely' available support to carers across the board, may create 'incentive traps', where informal carers are encouraged to leave the labour market and end up in a dependency situation in relation to the family member who receives the benefit (Lundsgaard, 2005). The more regulated cash benefits schemes (UK, the Netherlands, France and Sweden) offers some protection for both vulnerable users and informal carers. This can however be set against the power of the state to control what

we can argue are private, intimate caregiving relationships between family members or even spouses.

The policy types discussed in this note have important impacts on the family and family relations in relation to caregiving. The broader LTC literature identifies trends of 'de-familialisation', i.e. formal care services taking over caregiving responsibility from the family, and 're-familialisation', where the family 'takes back' caregiving responsibility from the state. The former arguably found in Mediterranean countries where the family has traditionally had a strong role and the largely underdeveloped formal care systems have more recently been growing in importance – however constrained by cost containment pressures (see Bettio & Plantenga, 2004, regime type 1 in section 2.3) and the latter in Scandinavian countries where traditionally strong formal services are inviting more family care (Bettio & Plantenga, type 5). The increasing emphasis on cash for care and cash benefits changes this relationship, in ways which vary significantly depending on LTC system. In France for example, the cash allowances are contingent on a link with formal care services, and the main effect of care allowances is one of "familialising" or "re-familialisation". Similarly, in the Dutch system, which traditionally relies on formal services, the move to 'formalised' cash payments represents a strengthening of (traditional) family obligations and a 're-familialisation' of care (Kremer, 2006). In Sweden the shift towards more reliance on informal carers is on the other hand more tied to lower subsidies of formal care services and formal care services relying on informal carers for tasks that would previously have been covered (Sand, 2014). This can be seen as an imposed familialisation. Spain is an interesting case in this sense, as the policy reinforces an already strong focus on the family. In all the countries surveyed in this note, the context of cost containment and the emphasis on cash payments has, despite the broader trends discussed above, overall reinforced family obligations and responsibility to provide care.

In terms of family relations, it has been argued that cash allowance policies may bring about a range of potentially difficult dynamics within families, related to formally employing or being employed as a family member carer. The character of relationships can change when someone becomes de facto employee and employer and equally it can be challenging when a family member becomes financially dependent on the other family member (Glendinning, 2009). As discussed, the cash benefits are often channelled through the user, with little actual income protection for informal carers. Given the possible negative effects in terms of family relations of 'formalising' caregiving it is important to pay attention to what impact this may have on the quality of care. Findings reported above, including the risks of abusive behaviour stemming from

difficulties in the caregiving relationship, need to be incorporated into any caregiving policy.

Training and skills validation is one of the most variable facets of LTC policy overall, and particularly in relation to cash benefits. Only in Netherlands are carers receiving a cash allowance routinely offered training. Training can be beneficial both to users and carers, firstly as quality of care is likely to improve, but also as carers can learn to work in a way which protects their ability to continue caregiving. Examples include managing lifting and moving, mobility and managing challenging behaviour. Further, Le Bihan (2012) finds that many informal caregivers do not only provide care under cash-for-care systems but also take on a significant management role. This can mean liaising with formal care services (regardless of whether these are paid out of pocket or publicly funded) and in some countries recruiting, supervising and paying unregulated and/or migrant workers providing care. In the latter situation the quality of the care delivered can be highly variable, as can the working conditions of the migrant or unregulated carers (Da Roit, 2010). This generally also applies to informal carers, little is known about quality of care provided or the working conditions of informal carers.

As discussed throughout, quality of informal care is a key area for further research. There are challenges as regulating and improving or supporting quality of informal care has inherent tensions. On the one hand informal care is a key facet in the European wide policy aim of 'ageing in place' and hence high on the priority of governments seeking cost-containment. On the other hand informal care is seen as something that is uniquely within the private realm, something that is done by choice and out of feelings of kinship. The 'co-worker' (Twigg & Atkin, 1994) type policies, such as cash-for-care, disrupt the latter understanding. When care is publicly funded, even if it is provided by a family member, one can argue that the funder, i.e. the government, has a responsibility in ensuring the quality of the care provided. Support for assuring quality (for example through training, peer support, equipment or complementary formal care services) can help prevent carer breakdown or significant deterioration in users which in the long run can delay or prevent institutionalisation altogether. The continuing role of formal care services cannot be emphasised enough: even though users often tend to prefer a family caregiver to receiving formal care (Chappell & Blandford, 2008), community care services have been found to have a significant preventative effect in terms of avoiding carer breakdown and delaying user institutionalisation (Pickard, 2015). Measures in support of family carers, on top of and beyond cash benefits, are needed to alleviate the burden of care and ease the trade-off between care giving and employment. These are for example day care, respite care, domiciliary and community care and counselling and training.

## **8. CONCLUSIONS**

The findings of this note suggest that formalising informal care through cash payments, legal rights, social security, and training opportunities can have important beneficial effects on informal carers and the users that they care for, as well as work to incentivise caregiving overall. These policies can help support the sustainability of the caregiving situation by recognising the informal carer's needs as early as possible, as well as offering supportive services on an ongoing basis. Importantly, it has been shown that informal care, as well as community care, have significant preventative properties in terms of avoiding or delaying institutionalisation.

The need for LTC services, formal and informal, is set to increase over the coming decades due to the ageing population of Europe. Depending on the extent to which formal care services are available and publicly funded, the future role of informal care is set to remain very important. It has however been shown that the future availability of informal care is uncertain due to the demographic changes and it has been estimated that there will be a large deficit of carers by 2060 (see Pickard & King, 2012). Unless significantly more funding (either public funds or private spending/insurance) is allocated to formal care services the European LTC systems may face significant increases in unmet need. Therefore the support and enabling of informal carers should be seen as a key policy goal in relation to LTC in Europe in the coming decades.

Keen attention must be paid to the balancing act between the protective aspects of regulation, transaction costs and the potential it has to exclude carers from any cash/services at all. More specific data, including longitudinal data on carer/user dyads and details on formal care service utilisation is however needed in order to capture effects of policy in a meaningful way, particularly if the aim is to compare and monitor the outcomes of LTC systems. Finally, given that formalised informal care is mainly publicly funded, we argue that the governments' responsibility for quality of the care provided should be further explored. Respect for the private realm needs to be maintained, while seeking innovation in new approaches to understanding and ensuring the quality of the care provided by informal carers.



## 9. BIBLIOGRAPHY

- Arber, S. and Ginn, J. (1990). The meaning of informal care: gender and the contribution of elderly people. *Ageing & Society*, 10, 4, 429-54
- Arksey H, O'Malley L. (2005). Scoping studies: Towards a Methodological Framework. *International Journal of Social Research Methodology*, 8, 1, 19-32.
- Arts, W., and J. Gelissen. (2002). Three worlds of welfare capitalism or more? *Journal of European Social Policy* 12 (2):137-158.
- Arntz M and Thomsen, S, (2010). The social long-term care insurance: a frail pillar of the German social insurance system. CESifo DICE Report
- Baltruks, D.; Hussein, S.; Lara Montero, A. (2017). Investing in the social services workforce. Brighton: European Social Network.
- Baríková, J. (2011). Long-term Care in the Czech Republic. On the Threshold of Reform. In: Österle, A. (eds.): *Long-term Care in Central and South Eastern Europe*, Frankfurt a.M. [u.a.]: Peter Lang, pp. 81-105.
- Bertrand, R.M. et al., (2012). Caregiving and cognitive function in older women: evidence for the healthy caregiver hypothesis. *Journal of aging and health*, 24(1), pp.48-66.
- Bettio, F., & Plantenga, J. (2004). Comparing care regimes in Europe. *Feminist Economics*, 10(1), 85-113.
- Brown, R.M. & Brown, S.L., (2014). Informal Caregiving: A Reappraisal of Effects on Caregivers. *Social Issues and Policy Review*, 8(1), 74-102.
- Brugiavini, A. Carrino, L. Orso, C. Pasini, G. (2017). *Vulnerability and Long-term Care in Europe: An Economic Perspective*. Springer
- Bouget, D., Spasova, S. and Vanhercke, B. (2016). Work-life balance measures for persons of working age with dependent relatives in Europe. A study of national policies, European Social Protection Network (ESPN), Brussels: European Commission.
- Brimblecombe, Nicola and Pickard, Linda and King, Derek and Knapp, Martin (2017). Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for. *Health and Social Care in the Community*, 25 (2). pp. 435-446
- Brimblecombe, Nicola, Fernandez, Jose-Luis, Knapp, Martin, Rehill, Amritpal and Raphael Wittenberg (2018). Review of the international evidence on support for unpaid carers. Forthcoming in *The Journal of Long-Term Care*
- Camden, A., G. Livingston, and C. Cooper (2011). Reasons why family carers and the outcome for the person with dementia: Results from the CARD study. *International Psychogeriatrics*, 2011. 23(9): p. 1442-1450.
- Care Act 2014 (c.23), London: The Stationery Office (TSO). <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>
- Casanova, G G. Lamura & A. Principi (2017). Valuing and Integrating Informal Care as a Core Component of Long-Term Care for Older People: A Comparison of Recent Developments in Italy and Spain, *Journal of Aging & Social Policy*, 29:3, 201-217
- Chappell, N. & Blandford, A., (2008). Informal and Formal Care: Exploring the Complementarity. *Ageing and Society*, 11(03), p.299.
- Christie, J., Smith, G. R., Williamson, G. M., Lance, C. E., Shovali, T. E., & Silva, L. C. (2009). Quality of informal care is multidimensional. *Rehabilitation Psychology*, 54(2), 173-181.

- Coehlo, D.P., Hooker, K. & Bowman, S., (2007). Institutional placement of persons with dementia: what predicts occurrence and timing? *Journal of family nursing*, 13(2), pp.253-77.
- Colombo, F., Llana-Nozal, A., Mercier, J., and Tjadens, F. (2011). *Help Wanted? Providing and Paying for Long-Term Care*. Paris: OECD Publishing.
- Cooper, C., et al., (2010). The determinants of family with dementia: Results of the CARD study. *Journal of Affective Disorders*. 121(1-2): p. 136-142.
- Da Roit, B. (2012). The Netherlands: the struggle between universalism and cost containment. *Health & social care in the community*, 20(3), 228-237.
- Da Roit, B., Le Bihan, B. (2010). 'Similar and yet so Different: Cash-for-Care in Six European Countries' *Long-Term Care Policies*, *Milbank Quarterly* 88(3): 286-309
- Daly M. & Lewis J. (2000). The concept of social care and the analysis of contemporary welfare states. *British Journal of Sociology* 51 (2), 281-298.
- ENNHRI (2017). European Network of National Human Rights Institutions "We have the same rights – the human rights of older persons in long-term care in Europe. June 2017
- European Foundation for the Improvement of Living and Working Conditions. (2018). *European Quality of Life Survey Integrated Data File, 2003-2016*. [data collection]. 3rd Edition. UK Data Service. SN: 7348, <http://doi.org/10.5255/UKDA-SN-7348-3>
- Eurofound (forthcoming), *European Quality of Life Survey 2016 – Quality of life, quality of public services, and quality of society*, Publications Office of the European Union, Luxembourg.
- European Pillar of Social Rights (2017). *The European Pillar of Social Rights in 20 principles*. European Commission, Brussels.
- Esping-Andersen, G. (1990). *The Three Worlds of Welfare Capitalism*, Cambridge: Polity Press.
- Fenger, H. M. (2007). Welfare regimes in Central and Eastern Europe: Incorporating post-communist countries in a welfare regime typology. *Contemporary issues and ideas in social sciences*, 3(2).
- Glendinning, C (2009.) *Cash for care: implications for carers*. Geneva Association Health and Ageing Newsletter. pp. 3-6.
- Gori, C, Fernandez JL and R. Wittenberg (Eds.) (2016). *Long-Term Care Reforms in OECD Countries*, Policy Press
- Haberkern, K., Schmid, T., & Szydlik, M. (2015). Gender differences in intergenerational care in European welfare states. *Ageing & Society*, 35(2), 298-320.
- Hoffmann, F., & Rodrigues, R. (2010). *Informal carers: who takes care of them? POLICY BRIEF APRIL 2010* European Centre for Social Welfare Policy and Research, Vienna
- Hubíková, Olga (2017). *A Double-Edged Tool: the Czech Care Allowance from the Perspective of Family Caregivers' Situation*. *Czech & Slovak Social Work*. 2017, Vol. 17 Issue 1, p23-37.
- Křížová, E Hana Janečková, H, Běláček J (2016). *Family Carers' Perspectives on Integrated Community Care in the Czech Republic* *Central European Journal of Public Health* 2016; 24 (4): 289-296
- Lundsgaard, J. (2005). *Consumer Direction and Choice in Long-Term Care for Older Persons*. Paris: OECD
- Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2011). Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing & Society*, 31(3), 422-437.

- Nies, H., Leichsenring, K., Veen, R., Rodrigues, R., Gobet, P., Holdsworth, L., & Hammar, T. (2010). Quality Management and Quality Assurance in Long-Term Care European Overview Paper. INTERLINKS project European Overview Paper.
- Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence Based Healthcare*. 2015;13(3):141-6.
- Pham MT, Rajic A, Greig JD, Sargeant JM, Papadopoulos A, McEwen SA. (2014). A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Res Synth Methods*. 5(4):371-85.
- Pickard, L., King, D., Brimblecombe, N., and Knapp, M. (2015). The Effectiveness of Paid Services in Supporting Unpaid Carers' Employment in England. *Journal of Social Policy*, 44(3): 567-590.
- Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society*, 35: 96-123
- Pot, A. M., Blom, M. M., & Willemse, B. M. (2015). Acceptability of a guided self-help Internet intervention for family caregivers: mastery over dementia. *International psychogeriatrics*, 27(8): 1343-1354.
- Riedel, M. (2012). Financial support for informal care provision in European countries: a short overview. *Health and Ageing Newsletter*, 27: 1-4.
- Riedel, M., & Kraus, M. (2016). Differences and similarities in monetary benefits for informal care in old and new EU member states. *International Journal of Social Welfare*, 25(1): 7-17.
- Rodrigues, R., K. Schulmann, A. Schmidt, N. Kalavrezou, M. Matsaganis. (2013). The indirect costs of long-term care. Research note 8/2013, European Commission
- Rummery, K. (2009). A comparative discussion of the gendered implications of cash-for-care schemes: markets, independence and social citizenship in crisis? *Social Policy & Administration*, 43(6): 634-48
- Rutherford, A & F, Bu. (2017). Issues with the measurement of informal care in social surveys: Evidence from the English Longitudinal Study of Ageing. *Ageing and Society*, 1-19.
- Sand, A-B. (2014). Det handlar också om tid och pengar" Anhörigomsorg, försörjning, lagar. Nationellt kompetenscentrum anhöriga. *Kunskapsöversikt 2014:2*
- Schulz, R. & Sherwood, P.R. (2008). Physical and mental health effects of family caregiving. *The American journal of nursing*, 108(9): 23-7.
- Sethi D., et al., (2011). European report on preventing elder maltreatment, WHO Regional Office for Europe: Copenhagen
- Triantafyllou , J., Naiditch , M., Repkova , K. et al. (2010). Informal Care in the Long-Term Care System. European Overview Paper. Athens, Vienna: European Commission.
- Tricco AC, Lillie E, Zarin W, O'Brien K, Colquhoun H, Kastner M, et al. (2016). A scoping review on the conduct and reporting of scoping reviews. *BMC Med Res Methodol*. 16(1):15.
- Twigg, (1989). Models of carers: how do social care agencies conceptualise their relationship with informal carers? *Journal Social Policy*. 18(1):53-66.
- Twigg , J., Atkin , K. (1994). Carers perceived. Policy and practice in informal care. Buckingham: Open University Press.
- Ungerson C. (2003). Commodified care work in European labour markets. *European societies* 5(4): 377-396.
- Ungerson C. (2005). Care, work and feeling. *The Sociological Review* 53, 188-203.

Van den Berg, B & P Spauwen (2006). Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. *Health economics*, vol. 15, issue 5: 447-460

Wija, P. (2015). Formal and informal long-term care and the role of family carers. *European Journal of Mental Health*, 10(2).

Yeandle, S. (2016). Caring for our Carers: An international perspective on policy developments in the UK. *Juncture*, 23(1): 57-62.

Vitaliano, P.P., Zhang, J. & Scanlan, J.M., (2003). Is Caregiving Hazardous to One's Physical Health? A Meta-Analysis. *Psychological bulletin*, 129(6): 946-72.

Wendt, C. Frisina, L. Rothgang, R. (2009) Healthcare system types: A conceptual Framework for Comparison. *Social Policy and Administration*, 43(1):70-90.

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