

The challenging roles of informal carers

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Challenging context

There are different approaches to responding to the growing long-term care needs of ageing populations across the UNECE region. Societies rely to a varying extent on the unpaid labour of informal carers who cover an estimated 70 to 95 percent of all care needs. While informal unpaid care saves public spending on formal care services, the reliance on informal care has many hidden costs. If not adequately supported in their role, informal carers can face negative impacts on their health and well-being, and be forced to reduce or quit employment - putting themselves at risk of poverty and social exclusion. The challenges associated with informal care not only affect carers themselves but society at large: intensive informal caregiving can result in higher demand and costs for health care as a consequence of its negative impact on the physical and mental health of carers, reduced labour market participation and consequently higher risks of poverty and social exclusion.

Suggested strategies

- develop a clear definition of informal care and informal carers at the national level
- raise awareness about the challenges of informal long-term care, assess the needs of carers, and give families real choice between alternative care arrangements
- acknowledge informal carers as co-producers and as co-clients in the care process, train professional carers to cooperate with informal carers and train informal carers to build their skills
- provide access to care leaves and flexible working arrangements and promote supportive work cultures
- improve the availability of community-based services such as flexible home care, day-care, and respite care
- minimize and simplify administrative procedures to improve access to services and benefits
- improve access to information about available support and services, including psychological support
- ensure income security and social protection for informal carers, including health care, pension contribution and accident insurance

Expected results

Adequate support and social protection for informal carers will enhance choices, health and well-being and reduce the risk of social exclusion.

With good practice examples from:

Belgium, Canada, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Malta, Serbia, Slovenia, Slovakia, Sweden, Switzerland, Ukraine, the United Kingdom of Great Britain and Northern Ireland, and the United States of America.

This policy brief addresses **Commitments 1, 2, 4, 5, 7, 8, 9 and 10 of the Regional Implementation Strategy of the Madrid International Plan of Action on Ageing; Goals 1, 2 and 3 of the 2017 Lisbon Ministerial Declaration; and SDGs 3, 5 and 10.**



United Nations

Introduction

The number of older people with care or support needs is on the rise across the UNECE region. While there are efforts to expand formal long-term care services to respond to this growing demand, informal care forms the backbone of long-term care (LTC) provision across the UNECE region. There is diversity in the way long-term care provision is organised and financed across the region as well as with regard to the status, recognition and support provided to informal carers. Although informal carers cover an estimated 70 to 95 per cent of all care needs,¹ they are often called the ‘invisible workforce’ in long-term care systems as they are rarely registered or counted and their status as informal care provider is often not formally recognized. The majority of informal care is provided by women.²

By covering for the gaps in both short-term and long-term formal care provision, thus “co-producing” care services alongside professional service providers, informal carers help prevent or delay the need for institutionalization of people in need of care or support and are enabling them to remain living at home.³

It is challenging for informal carers to cover short-term care needs for a family member, neighbour or friend. It becomes even more demanding the longer this activity has to be performed, especially when informal carers might themselves be of advanced age and care recipients themselves. Policy measures are needed to address the growing need for care in a way that prevents strain on families and caregivers and protects their health and well-being. Public policies need to ensure that informal carers will not be forced to reduce or give up paid employment, face social exclusion and ultimately be caught in a poverty trap.

This policy brief focuses on informal carers who provide long-term informal care to older persons. It addresses the policy challenge to support informal carers in a multifaceted way, identifying key challenges faced by informal carers and policy strategies to address them.

What is informal care and who is an informal carer?

There are diverse definitions of informal carers in national and regional legislation. The term informal carer is often used inter-changeably with the term ‘family carer’. Some notions of ‘informal carers’ therefore tend to exclude paid, but non-professional carers providing care in private households. Others focus only on those providing informal care to older people with care needs.⁴

In France, the *Act on adapting society to an ageing population* introduced an extended definition of informal carers in 2015. According to this law, the definition of an informal carer (“*proche aidant*”) of an older person losing autonomy refers to “any person who is cohabiting or having a close and stable relationship with the person in need of care, and who is helping frequently and regularly, on a non-professional basis, to accomplish all or a part of the activities of daily living”.⁵

In Italy, regional law of the Emilia-Romagna region defines an informal caregiver as “a person who voluntarily and free of any charge takes care of a person with care needs who allows him/her to do so”. The care may involve assistance with housekeeping, mobility, accessing services and social relations.⁶

¹ Hoffmann & Rodrigues, 2010; Schneider et al., 2016; European Commission, 2018; <https://www.carerscanada.ca>.

² Bettio and Verashchagina, 2012; Schulz & Tompkins, 2010; Glendinning et al., 2009; Ungerson, 1997.

³ OECD, 2011; European Commission, 2018.

⁴ See OECD, 2011; Mestheneos and Triantafillou, 2005; Glendinning et al., 2009; Birtha & Holm, 2017.

⁵ <https://www.legifrance.gouv.fr/eli/loi/2015/12/28/2015-1776/jo/texte>.

⁶ Regional Law n. 2, 28th march 2014. Regulations concerning the recognition and support of the family caregiver (a person who voluntarily provides care and assistance) <http://sociale.regione.emilia-romagna.it/documentazione/norme/leggi/successivi-il-2010/lr-2-2014-1>.

For the purpose of this policy brief, informal care is defined as *all non-professional care provided – by choice or by default – by family members (next of kin), friends, neighbours or other persons caring for people with long-term care needs at all ages, usually in private households*. Informal carers are important co-producers of long-term care. At the same time, they are themselves in need of being recognized as informal carers and to be provided with material and non-material support.

Who provides informal care?

Everybody is likely to become an informal carer at some point over one's life course.⁷ It is possible to distinguish between different care relationships in informal care: (a) adults of working age who are caring for older parents, family members, neighbours or friends; (b) individuals of pension or higher age who are caring for their partner, family members, neighbours or friends; (c) youth caring for their parents or grandparents or other family members; and (d) paid non-professional caregivers who are replacing or complementing care provided by the family.

According to European surveys, about 40-55 per cent of informal carers are adult next-of-kin (daughters, sons, in-laws), depending on the country, 20 to 45 per cent are partners. Siblings, friends or neighbours are also providing unpaid care and the majority of unpaid care is provided by women.⁸

Although informal care is usually unpaid, there is a growing number of paid informal carers who are replacing or complementing informal care provided by family members. This group is to a large extent composed of women, based on permanent or temporary migration, with or without qualification, and remunerated under various forms of legal regimes.

Box 1: The rise of live-in migrant carers in the UNECE region

Live-in migrant care workers are increasingly employed as caregivers for older adults. This phenomenon can be observed in particular in the Mediterranean countries, where live-in migrant carers are coming from Eastern Europe (Romania, Ukraine), Asia (Philippines) or Latin America. In Austria and Germany, personal carers are migrating from neighbouring Central European Countries (Czechia, Poland, Slovakia). Furthermore, there are 'domino effects' across the entire UNECE region, with personal carers generally moving into the closest country offering higher income, even in the informal household economy. Altogether it can be estimated that there are more than 4 million migrant personal carers - mostly women - who are providing care in private households across the UNECE region.⁹ This is in addition to the high number of migrant care professionals being formally employed in receiving countries.

Prevalence of informal care provision

Data on informal care are scarce. National and international surveys that have tried to shed light on informal care have faced the challenge of defining thresholds in terms of time and types of activities that qualify as informal care and were confronted with the difficulty that many people who are supporting a person in need of long-term care do not define or perceive themselves as being carers. With these limitations in mind, survey data indicate that 10 to 20 per cent of the population aged 50 and over are caring informally on a weekly basis or more for a person in need of care (Figure 1).

The European Social Survey based on data from 20 countries showed that on average, one in three adults (34.3 per cent) between the ages of 25 and 75 provided informal care and one in thirteen (7.6 per cent) did so for a minimum of 11 hours a week (see Figure 2). The largest group of caregivers are women between the ages of 50 and 59. Women are 33 per cent more likely than men to provide care, and 60 per cent more likely to provide intensive care.¹⁰

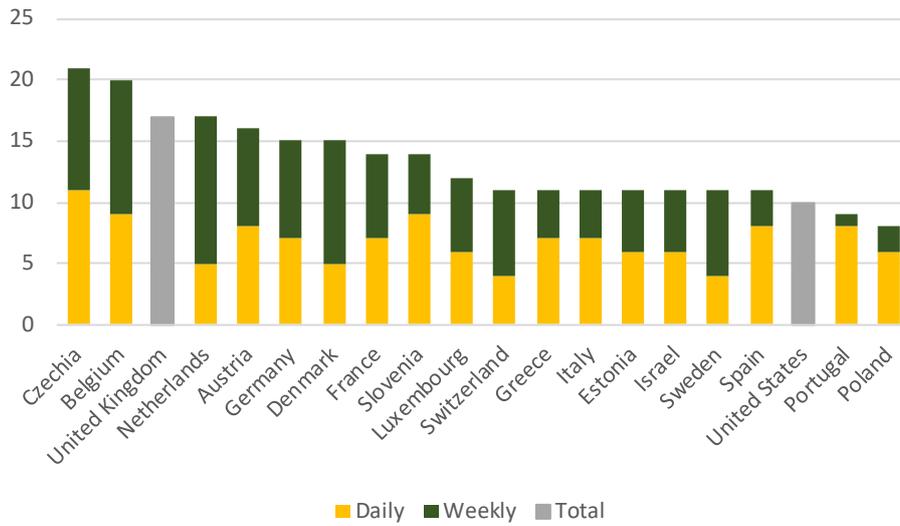
⁷ OECD, 2017; see also Eurofound 2018; ILO 2018; for the US see Schulz & Tompkins, 2010.

⁸ Bettio and Verashchagina, 2012; Schulz & Tompkins, 2010.

⁹ Estimates based on Schmidt et al., 2016; da Roit et al., 2013; Shutes & Chiatti, 2012.

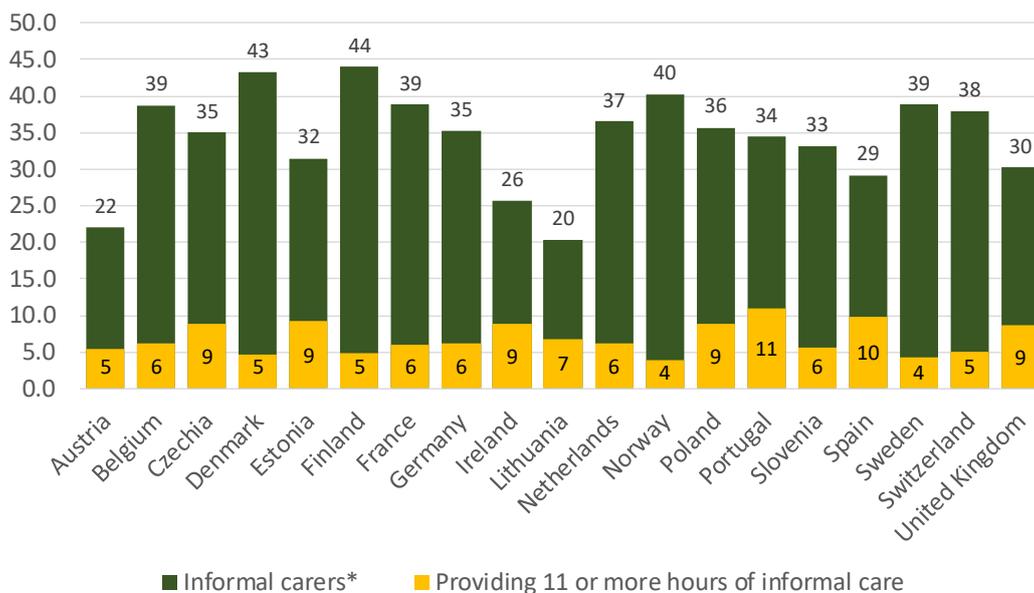
¹⁰ Verbakel et al., 2017. Comparative knowledge on informal carers in EU Member States is largely based on data collected in the Survey of Health, Ageing and Retirement (SHARE) or from the European Social Survey (2014) special module on the social determinants of health.

Figure 1
Share of informal carers among the population aged 50 and over, 2015



Source: Wave 6 of the Survey of Health, Ageing and Retirement in Europe (2015), wave 7 of the English Longitudinal Study of Ageing (2015), wave 12 of the Health and Retirement Survey for the United States (2014).
Note: The definition of informal carers differs between surveys; United Kingdom refers to England.

Figure 2
Prevalence rate of informal carers by country in per cent, 2014

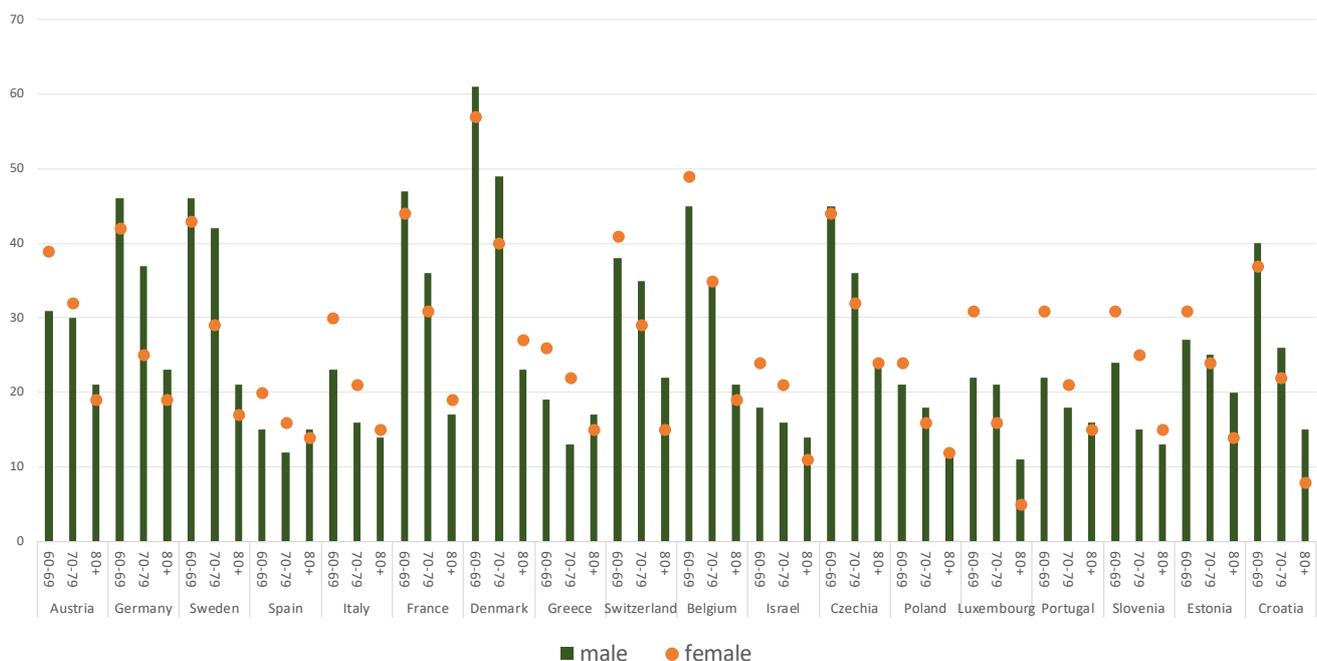


Sources: Verbakel et al., 2017; ESS Round 7: European Social Survey Round 7 Data (2014), Data file edition 2.0. Norwegian Social Science Data Services, Norway – Data Archive and distributor of ESS data for ESS.
Note: *) Question: Do you spend any time looking after or giving help to family members, friends, neighbors or others? Intensive caregivers (more than 11 hours per week) are marked in yellow.

Due to changing family patterns, rising mobility and the increased participation of women in the labour market, it is likely that fewer people will be available to provide informal care in the future. Declining fertility rates, delayed childbearing and smaller numbers of siblings imply that future cohorts of potential care givers will be smaller than current ones. This means that the probability for each individual to become a carer at one point during his or her life-course will further increase, thus altering the characteristics of informal care.¹¹ For instance, already over the past decades, the average age of informal carers has risen together with the general rise of chronological age at which the need for long-term care occurs.

Another change might occur regarding the gender balance of informal carers. The large majority of informal carers is female, i.e. at least 75 per cent in the USA¹² and around 55-60 per cent in Europe.¹³ Yet it is important to note that the gender balance in informal care changes across the life course. Men are less engaged in informal care at working age. Even as young pensioners they engage less in care provision than women in most countries. In some countries and especially in the oldest age groups, however, a greater share of men act as informal carers, in particular for their spouses. This trend, illustrated in Figure 3, is likely to continue with converging life-expectancy between men and women, and increasing gender awareness.

Figure 3
Prevalence rates of informal care to older people, by sex and age groups (60+), 2015
(Household-standardized)



Source: WHO/Europe, 2018; based on data from SHARE (wave 6)

Figures 2 and 3 also show that fewer people provide daily and intensive care in countries with stronger formal long-term care systems. While informal carers in Southern and Eastern European countries need to provide support with activities of daily living (ADL), informal carers in the Nordic countries provide support with ‘instrumental activities’ (IADL) such as shopping and leisure activities, complementing formal care services provided. These different roles of informal carers are rooted in the different cultures of care and the division of care responsibilities between the State and the family in the different long-term care regimes that have developed in the UNECE region.

¹¹ Pickard & King, 2012.

¹² <https://www.ioaging.org/aging-in-america>.

¹³ Verbakel et al., 2017.

The roles of informal carers in different care regimes

Different backgrounds of informal carers, their personal situations and their (past and present) relation with the person being cared for lead to a differentiated set of needs and interests.¹⁴ The diverse institutional, political and cultural contexts further condition the situation of informal carers.

Cultures of care

The roles of informal carers, related policy challenges and potential support mechanisms in the UNECE regions are therefore dependent on specific cultural and ethical environments, as well as on the type of welfare regime in which the different groups of informal carers are living. Traditional values and ‘family ethics’ remain embedded in personal identities, everyday life, moral foundations and the general legal framework across the different jurisdictions within the UNECE region. At the societal level, this is reflected by policies that continue to strengthen or even reinforce the roles and responsibilities of the family in caring for older adults either by law or by means of financial (dis-)incentives.

Long-term care regimes

Four ideal-types of LTC regimes have been distinguished.¹⁵ ‘Universal’ care regimes are characterized by an early acknowledgement of LTC as a social risk and related endeavours to extend the formal care system with individual rights and a reduction of family responsibilities (Nordic countries, the Netherlands). This so-called ‘defamilisation’ of care has taken place much later and to a rather restricted degree in care regimes with a pattern of ‘Mixed solidarity’: in countries such as Austria or Germany some specific rights such as respite care or (limited) care leave have been introduced since the 1990s, LTC services were expanded and the moral obligation to provide care was reduced. ‘Family-based’ LTC regimes in Mediterranean countries are only slowly moving in this direction, while in many Eastern European countries – the ‘Emerging’ care regimes - informal carers are still waiting to become formally recognized as co-producers of LTC, who are also in need of support.

Informal carers in universal care regimes are entitled to more state-provided support than those living in family-based and emerging care regimes. In Sweden, for example, the social welfare boards in municipalities are required by law to provide support and respite services to persons caring for next-of-kin with long-term care needs. The support for informal carers primarily aims to reduce their burden and risk of ill health and to improve their quality of life. Table 1 contextualizes the key policy challenges for informal carers by groups of countries (care regimes).

Challenges faced by informal carers

The role of an informal carer can be very challenging. Many assume this role unprepared and may not have a real choice when they become a carer. This may be due to their legal or moral obligation to provide care, the lack of formal, alternative care arrangements, or simply because information about such alternatives is missing.

There are also significant hidden costs of informal care to carers.¹⁶ These include the opportunity costs of lost earnings, careers and pension entitlements, as well as the health consequences of the physical and psychological burden experienced. Without adequate support, informal care can put carers at risk of poverty, ill-health and social isolation.

In 2017, COFACE Families Europe consulted over 1000 family carers across 16 countries about the challenges they faced.¹⁷ Table 2 provides an overview of challenges that were identified during this consultation. The extent to which informal carers are affected by these challenges depends on the care regime in which they live, on the stage of life during which they become an informal carer, and on the options and choices they have in their given context.

¹⁴ Naiditch et al., 2013.

¹⁵ See, for instance, Schulmann et al., 2019; Lamura, 2007; Nies et al., 2013.

¹⁶ Rodrigues et al., 2013.

¹⁷ Based on Birtha & Holm, 2017; see also National Academies, 2016.

Table 1
Long-term care regimes as a context and basis for support for informal carers

	<i>Universal</i>	<i>Family-based</i>	<i>Emerging</i>	<i>Mixed solidarity</i>
Country examples	Sweden, Denmark, Netherlands, Norway	Spain, Italy, Greece, Portugal	Armenia, Latvia, Lithuania, Poland, Republic of Moldova, Russian Federation, Slovenia, Ukraine	Austria, Belgium, Canada, Germany, France, Switzerland, United Kingdom, United States
Demand for LTC	high	high	medium	high
Acknowledgement of LTC as a social risk	before 1980	since 2000	partly still pending	since 1990
Extent of informal care provided	medium	high	high	medium/high
Status of formal care services and facilities	high	low	low	medium
Primary legal obligation to provide care	State	family (spouse, children)	family (spouse, children)	mixed
Moral obligation of family to provide informal care	medium-low	high	high	medium
Formal recognition of the status as 'informal carer'	specific rights and direct entitlements for informal carers	obligation, but only derived, indirect rights depending on entitlements of relatives in need of LTC	established in some countries	specific rights

Sources: Schulmann et al., 2019; Nies et al., 2013

Table 2
Challenges faced by informal carers

<i>Lack of recognition & risk of social exclusion</i>	<i>Reconciling care with work and personal life</i>	<i>Adequate income and social security</i>	<i>Access to community-based services</i>	<i>Access to information and training</i>	<i>Health and well-being</i>
Low social recognition	Lack of time	Financial problems, costs of care	Lack of access and support	Lack of knowledge	Mental or emotional stress and exhaustion
Social isolation	Difficulty to balance care with professional and/or personal life	Lacking income support	Lack of temporary and flexible services	Lack of skills	Physical burden
Lack of representation and political voice	Social isolation and loneliness	Lack of social insurance	Lack of affordable and high-quality services	Bureaucratic hurdles	Negative impact on social relationships

Sources: Inspired by Birtha & Holm, 2017.

Lack of recognition and risk of social exclusion

Overall, the recognition of informal carers' work and of its value is very low, both by society, but also by their families and immediate circles. Despite filling large gaps in formal long-term care provision, informal carers are rarely considered as co-producers of social services, despite their developing a wide range of skills and being experts by experience. The voice and representation of informal carers should be strengthened to raise awareness on the problems linked to the caring role.

Incompatibility of care, employment and personal life

Carers who are trying to combine employment and informal care are particularly challenged by repercussions on their professional and personal life. Providing informal care is often very time consuming and leaves little time for informal carers to fulfil professional activities or meet their own or other family members' personal needs. Informal care has an impact not only on the quality of life of the informal carer, but also on other family members. Many informal carers who have to juggle professional and care responsibilities decide to leave paid employment due to the stress deriving from work and care and the lack of appropriate support measures in place.¹⁸ It is also challenging for informal carers to return to the labour market as many workplaces lack the flexibility that would allow reconciling work with often unpredictable care duties.

Income and social security

As a consequence of the hidden costs of care and the lack of appropriate income support, informal carers can face significant financial problems. The necessity to reduce or even quit employment results in a loss of income, and subsequently entails reduced pension entitlements and other negative financial consequences. Financial burden is sometimes escalated by expenses related to the special needs of the person with care needs (e.g. orthopaedic devices, therapies), or the cost of adaptations required to make the living environment more accessible.

Access to community-based services

Accessible, affordable, tailor-made and high-quality support services in the community are much needed measures to relieve informal carers from the burden of undertaking most care duties alone. The lack of available temporary and flexible services (e.g. respite care) or more permanent formal care provision that would complement informal care (e.g. in-home nursing, or day-care services) present a significant problem for informal carers, resulting in feelings of loneliness and strain. There can be many unnecessary bureaucratic obstacles and required paperwork to access support services or to prove the entitlement to benefits, often deriving from the lack of coordination between different authorities and service providers, as well as rigid procedures.

Need for information and training

A challenge for informal carers is lacking information about their entitlements (e.g. care leave), benefits (e.g. income support or assistive devices) and support services (including counselling or respite care) that are available to them when they become carers – often all of a sudden, with no time to prepare. Unless there is a central contact point, finding information can be time consuming and authorities may provide conflicting information. As many informal carers are entering their new role unprepared, access to training to help them deal with the challenges of informal care and self-management as a carer is needed.

Negative impact of informal care on health and well-being

Informal carers often experience mental stress and physical exhaustion related to their caring role. The often rapidly deteriorating condition of the person with care needs puts relatives under a lot of stress and anxiety, in particular as the duration of care is in most cases hardly foreseeable. Counselling and psychological support to informal carers could therefore play a key role in recognizing early signs of burnout and depression.

Providing informal care can entail physically demanding tasks such as lifting someone out of bed. Informal carers often lack the necessary fitness due to their own advanced age or as a result of suffering from a chronic illness. Consequently, informal carers may need social and/or health care themselves and support with care tasks.

¹⁸ Eurofound, 2015.

Policy strategies to support informal carers

Acknowledging the contribution of informal carers

There are a number of ways in which informal carers can be supported by national and local governments. This section presents policy strategies implemented in the UNECE region. Table 3 provides an overview of diverse measures that have been put in place to respond to the specific needs of informal carers.

A clear definition of informal care and of the status of informal carers at national level is an important step in acknowledging the unpaid contribution by informal carers as it forms the basis of formal entitlements relating to financial support, employment regulations and respite care services. Informal care provision and the situation of unpaid carers needs to be better understood to provide the support needed. Research, awareness raising and education on informal care among the general public and health and social care professionals can contribute to a greater acknowledgement of informal carers as co-producers of social services.

Awareness-raising on informal care in Czechia

In Czechia there is still a very low level of awareness of the demanding character of informal care. The term itself is unfamiliar and many informal carers have never identified themselves as such. To raise awareness both among the general public and among informal carers and other stakeholders such as employers, social services, local administrations and care receivers, a new multi-layered government-funded project has been brought under way to gather knowledge and data for national and local administrations, so that evidence-based policies and measures can be suggested, communicated and implemented.

Activities include analytical and research activities, as there are very little data on the topic. This includes baseline research on the numbers of informal carers and their categorization; experiences and needs of both current and former informal carers; attitudes and awareness of the general public. The project further includes awareness raising events; the preparation of information materials such as practical guides for informal carers and for local administrations; conceptual roadmaps and finally the preparation of a strategic document tackling the key issues on informal care. Finally, certified educational seminars are organised in regions and towns for informal carers and professionals working in social services, municipal administration and labour offices.

The project is financed by the Operational Programme Employment. All activities and outputs are continually consulted with the Ministry of Labour and Social Affairs.

Source: Information provided by the Czech Ministry of Labour and Social Affairs. See also: <http://www.fdv.cz/pecujici> (Czech language)

Enabling informal carers to reconcile care responsibilities with employment

Informal carers require both time and flexibility when trying to reconcile employment and other responsibilities in their personal lives with often unpredictable care requirements. In a number of countries informal carers have a statutory entitlement to time off from employment – ranging from a few days to several months. Such care leave enables working carers to take time to coordinate care arrangements or to provide care themselves for a limited period of time while remaining in employment.

Flexible working arrangements, such as the possibility to reduce working hours or to work from home can be instrumental in enabling working carers to remain in employment when faced with care responsibilities. As such arrangements are largely provided at the discretion of employers, the sensitization of managers to the needs and challenges of informal carers can yield positive results towards more employee-oriented and supportive workplace cultures.

Care leave entitlements vary in length and conditions across the UNECE region. In Canada, working carers can take compassionate care leave for up to 28 weeks within a 52-week period to provide care and support to a family member who has a serious medical condition with a significant risk of death within a 26-week period, as attested by a medical certificate from a medical doctor or nurse practitioner. Leave may be divided in shorter periods, of at least one week each. The 28 weeks of leave can also be shared between two or more employees to provide care and support to the same family member.

Table 3
Legal, social and political support measures addressing the needs of informal carers

<i>Challenge</i>	<i>Type of support measure</i>	<i>Examples</i>
Lack of recognition and risk of social exclusion	Defining the status of informal carers, rights and responsibilities	FIN - Act on Informal Care Support provides statutory right to 2 days of respite per month for informal carers FRA – Act on adapting society to an ageing population extended definition of informal carers ITA – Regional law in Emilia Romagna recognizing informal carers SWE – Social Services Act’s makes provisions for support for informal carers
	Raising awareness about the challenges of informal carers	BEL– Training of professional care givers on support for informal carers CZE- Awareness-raising project on informal care
Reconciling care with work and personal life	Care leave entitlements	CAN – Compassionate care leave FRA – Caregiver leave; Family solidarity leave
	Flexible working arrangements	CAN - Labour Code reform introduced a right to request flexible work arrangements
Adequate income and social security	Cash benefits for carers (care allowances), social security contributions, employment of carers (level of home helpers)	CAN – Employment Insurance, Caregiving Benefits IRL – Carers’ Allowance LUX – Long-term care insurance: cash benefit for a dependent person to be used for home care SVK–Carers’ Allowance
Access to services in the community	Home-based /respite care	FIN – Family care services at home to enable time off for informal carers MLT – Carer at Home scheme/Respite at Home service USA – The Lifespan Respite Care Program
	Funding of services to enhance availability	BEL – Personal Assistance Budget SVK – Cash benefits for Compensation of Severe Disability USA – Alzheimer Disease Programs Initiative provides grants for community-based services supporting people living with dementia and their caregivers USA – National Family Caregiver Support Program
Access to information and training	Information and counseling for informal carers	DEU – Hotline for informal carers FIN – ‘Omatori’ one-stop-shop support centre for informal carers GBR – Digital resource for Carers
	Training for informal carers	BEL – ‘Alternative’ project to train informal caregivers SRB – Training program for informal carers SVN – Program for informal carers’ training and self-organizing in local communities USA - Financial literacy and preparedness training
Health and well-being	Faciliate social relationships, peer support and self-help	BEL – Young Caregivers’ Support Platform DNK – Education program for self-management skills for relatives of people living with Dementia UKR – Self-and mutual help groups of informal carers of people with dementia

Source: Compilation based on policy examples shared by members of the UNECE Working Group on Ageing

Care leave for informal carers in France

The familial solidarity leave (*congé de solidarité familiale*) is open to “every employee whose ascendant, descendant, brother, sister, or person sharing the same home, suffers from a life-threatening pathology or is at an advanced or terminal stage of a serious and incurable affection”. It allows the employee to suspend their professional activity to care for someone losing autonomy, for a period of three months (renewable). It cannot be deferred or denied by the employer. During this time, the caregiver can benefit from the daily home support allowance (*allocation journalière d’accompagnement à domicile, AJAP*), payable by social security. The caregiver leave (*congé de proche aidant*) is designed for the care of an infirm relative or a relative coping with a loss of autonomy. Caregivers can ask their employer to temporarily interrupt their professional activity, while keeping their position and rights in the company. This leave can last up to three months (except if there is a collective agreement) and can be renewed. It is however not compensated by the employer.

New legislation adopted in May 2019 to promote the recognition of caregiving aims to promote the use of caregiver leave through compensation and more business negotiations. It also seeks to secure the social rights of the caregiver by standardizing the situations across different social security schemes, by putting in place a system or relay with social or medico-social services, by issuing a caregiver’s card to identify them (especially with health professionals), and by developing a caregiver’s guide and web-based information and guidance.

Source: Information provided by the French Ministry of Solidarity and Health

Flexible working arrangements that allow workers with care responsibilities to alter their work schedule, working time or work location are important in helping carers flexibly juggle their work and care roles and personal lives. In Germany, working carers have the possibility to take part-time care leave over a period of up to 24 months while continuing to work a minimum of 15 hours per week.¹⁹

European Union Directive on work-life balance for parents and carers

The European Union Directive on work-life balance for parents and carers, adopted on 20 June 2019, introduced the entitlement to 5 days of carers’ leave per year for workers providing personal care or support to a relative or person living in the same household and extended the right to request flexible working arrangements to working carers (it previously applied to working parents). While many EU Member States already have measures in place that go beyond these provisions, the Work-Life Balance Directive can nevertheless be considered an important step in recognizing informal carers.

Source: http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=uriserv:OJ.L_.2019.188.01.0079.01.ENG.

Providing informal carers with an adequate income and social security

There are a number of ways in which informal carers can be financially supported. This can be done through an attendance allowance that is paid to the care recipient to purchase social and health care services (e.g. AUT, DEU, ITA, LUX). As the allowance becomes part of the household budget it can be seen as an indirect acknowledgement of the family carer’s engagement. In other countries (e.g. CZE, GBR, IRE, TUR) ‘care allowances’ are directly paid to the carer.

As these rather low benefits often cannot provide an adequate income, some governments have established the possibility for carers to get employed by the municipality, usually with a wage similar to a formal home helper (e.g. FIN, SWE), thus extending the traditional definition of informal care.

In order to ensure social security coverage for informal carers measures need to be put in place to ensure that informal carers are able to maintain/obtain access to health, pension and accident insurance. Some countries acknowledge informal carer’s contributions by covering their contributions to social pension insurance (e.g. AUT, DEU, LUX).

¹⁹ UNECE, 2017. Box on the Law on Improved compatibility of family, caring and career – Germany in Policy Brief on Ageing No. 19.

Carer's allowance in Slovakia and Ireland

In Slovakia, informal carers of persons with severe disabilities can receive a care allowance. The carer must be older than 18 years and capable of providing care, must have the consent of the person they are taking care of, and must have legal capacity. A beneficiary of care allowance may be concurrently employed, but the income of this person is monitored. Beneficiaries of old age pension may also be recognized as informal carers. Income and property of the care receiver is also monitored.

The amount paid as care allowance is currently approaching the amount of net minimum wage. Carers who are pensioners receive a flat rate of approximately 50 per cent of this amount in addition to their old age pension. The care allowance increases if the person cared for is a child. Attending school and/or enjoying other social services does not prevent persons living with a disability from benefitting from the care allowance.

The contribution is provided from the state budget on the principle of discretion. Informal carers do not have the status of employees; however, the state covers their health and social insurance contributions.

In Ireland, a means-tested carer's allowance, is paid to informal carers to provide full-time care. Since 2017, this allowance is paid for an additional 12 weeks after the death or entry into long term residential care of the care recipient as it was recognised that when a carer's caring role ends, the carer requires a transition period during which they can adapt to and plan for their life post-caring.

Source: Information provided by the Slovak Ministry of Labour, Social Affairs and Family. For more information see <https://www.employment.gov.sk/en/family-social-assistance/severe-disability>; Information for Ireland provided by the Irish Department of Health. For more information on the carer's allowance see <http://www.welfare.ie/en/Pages/ca.aspx>

Employment insurance family caregiver and compassionate care benefits in Canada

The Employment Insurance Family Caregiver benefit helps addressing the needs of Canadian families and covers situations where individuals are temporarily on leave to provide care and support to a family member with a critical illness or injury. Caregivers can access up to 15 weeks of benefits to provide care to a critically ill or injured adult or up to 35 weeks of benefits to provide care to a critically ill or injured child. The EI Compassionate Care benefit provides up to 26 weeks of income support to eligible caregivers, when a family member has a serious medical condition and a significant risk of death within a 26-week period. When multiple caregivers share an employment insurance caregiving benefit, they may do so at the same time or one after another.

Source: Information provided by Canadian Department for Employment and Social Development

Family foster care in Finland

There are approximately 1,250 informal caregivers within the South Karelia Social and Health Care District's (Eksote). Most of them take care of an older family member. Caregivers are entitled to have three days off per month. They can choose to use family foster care of older people (FFC), free of charge, to enable this.

Family care has greatly changed in just a few years. There are now more family foster carers available and the FFC model is being implemented throughout the Eksote region. Family care can be provided at the care recipient's own home by so-called travelling family carers or at the family foster carer's home. Additionally, long-term FFC has been launched in December 2018.

FFC is a suitable form of service when the care receiver has a disability, illness or feels unsafe. It is granted based on the customer's life situation and the need for support, guidance and care. When considering FFC, the customer's wishes, the opinions of family members as well as the skills of the family carer in relation to the care receiver's needs are taken into account.

FFC offers individual care and supervision and is designed to flexibly serve the needs of the customer. It also offers stimulating environment, security, positive and intimate relationships and participation in family life on equal terms.

There are several ways to implement FFC. Travelling family carers support caregivers by participating in their daily life (cooking, nurturing, rehabilitating and spending time with the person cared for). This option is especially suitable for people with memory disorders as they do not have to leave their own home.

FFC is arranged, supported and supervised by the municipality. A commission agreement including rights and responsibilities is made between the municipality and the family foster carer.

Source: Information provided by the Finnish Ministry of Social Affairs and Health. <http://www.eksote.fi/sosiaalipalvelut/perhehoito/Sivut/default.aspx>

Access to services

Informal carers need quality, flexible and accessible formal care services in the community to redistribute some of the care tasks and to have time to pursue other activities. Day care services and home care assistance are examples of community-based services that enable informal carers to have time for employment or personal lives. UNECE Policy Brief on Ageing No. 20 on ‘Innovative social services and supportive measures for independent living in advanced age’ and No. 15 on ‘Innovative and empowering strategies for care’ provide examples of such services.²⁰ Formal care services can also support informal carers with tasks they do not have the capacity to carry out to ensure a high quality of care for care recipients.

Direct cash benefits paid to persons with care or support needs enable them to choose and purchase the type of support service they want to use. In the Walloon Region of Belgium, the so-called ‘Personal Assistance Budget’ was recently introduced to give persons with disabilities the possibility to access formal support from personal assistants in their own home and to depend less on informal care.

Access to respite care services are particularly important in cases where informal care is provided full-time and care recipients require 24/7 presence and support.

Respite care programmes in Malta and the United States

Since 2017, the ‘Respite at Home’ service in Malta provides formal carer support in the home of older persons by a qualified carer, to relieve the informal carer from the burden of care. The Respite at Home service is implemented at national level and offers support with activities of daily living such as bathing and dressing, for older persons with dementia, or other cognitive impairment and support needs. Each client is assessed or reviewed by a multi-professional team that decides on the frequency and delivery of respite care based on the needs of the family.

In the United States, the Lifespan Respite Care programs are nationally-funded coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs implemented across different regions of the country. Since 2009, the United States Congress has allocated approximately 2.5 million US dollars per year to implement these programmes to enable States to develop respite infrastructures through a variety of approaches, including: environmental scanning to understand available respite programmes and family caregiver needs; marketing and outreach campaigns to educate family caregivers about respite care and how to access services; training of volunteer and paid respite care providers to increase the availability of respite services; partnering with communities of faith to develop respite programmes; developing or enhancing state-wide databases of respite care programmes, services and information to improve access for family caregivers; and developing and implementing person-centred respite service options, such as vouchers.

Source: Information for Malta provided by the Ministry of Family and Social Solidarity, see <https://activeageing.gov.mt/Elderly-and-Community%20Care-Services-Information/Documents/INF%20-%20RespiteAtHomeEN.pdf>; Information for the United States provided by US Department for Health and Human Services, for more details see <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

Protecting the health and well-being of informal carers

Caregiving can negatively impact the mental and physical well-being of informal carers. In addition to reducing the overall burden of care through the provision of formal care services and respite care mentioned above, it is important to assess the overall care situation as well as the needs of carers so that services and support measures can be better tailored and that the “burden of care” remains manageable. This might in some cases involve moving care recipients to residential care. There is evidence that carers’ burden is often reduced after the transfer of the care recipient to a care home. It should however be underlined that even after such a change of setting informal carers continue to fulfill their role, though with less intensity and with different tasks.²¹

Informal Care Act – Finland

In addition to providing a minimum of two days of statutory respite care services to informal carers, the Finnish Informal Care Act makes provisions on coaching, training and welfare and health checks for carers, which the municipality must organize if needed. The content of health examinations, coaching and training is determined by the individual needs of the caregiver and the requirements of the caring situation.

Source: Information provided by the Finnish Ministry of Social Affairs and Health, see also <https://stm.fi/en/social-services>

²⁰ UNECE 2018; UNECE 2015.

²¹ Nagl-Cupal et al., 2018.

The provision of informal care for persons with dementia is particularly challenging. The World Health Organization (WHO) in its Global action plan on the public health response to dementia 2017-2025 identified support for dementia carers as one of its seven action areas. To support dementia carers, WHO developed ‘iSupport’, a knowledge and skills training programme for carers of people living with dementia. It includes how to deal with behavioural changes such as memory loss and getting lost, providing support with everyday activities such as eating and drinking, and managing one’s own physical and mental health. The manual is available in an online format and in an offline version.²²

National education programme for relatives of persons living with dementia in Denmark

The implementation of the national programme ‘Learn to thank you every day as relatives’ (“*LÆR AT TACKLE hverdagen som pårørende*”) aims to support relatives of persons living with dementia or other long-term diseases to take care of themselves as many relatives develop physical or mental health problems. Through weekly interactive training sessions, relatives share their experiences and build their skills to be able to better tackle stress, potential social isolation and prevent becoming physically or mentally ill themselves. The national implementation of the education programme is carried out by the Danish Committee for Health Education in 98 municipalities between 2018 and 2021 and the project is financed by the Danish Government.

Source: Information provided by the Danish Ministry of Health, see also <http://patientuddannelse.info/3809.aspx> (in Danish)

Self-help groups for informal carers in Ukraine

Self- and mutual help groups have been set up for families caring for people with dementia in 9 cities in Ukraine by the civil society organisation Turbota pro Litnih v Ukraini. The aim of the project is to provide informal carers with access to information on dementia care, and to allow them to socialize, take a break from care giving and share their experience with others. Each group consists of 20-30 members and is followed by five trained volunteers. The groups meet on a fortnightly basis. They come to the meeting points to communicate with their peers, to ask practical help from each other and/or to offer help to each other. The volunteers organize consultations from professionals on request of the group members, invite lecturers or trainers, find useful information and manage joint activities.

Source: Information provided by Turbota pro Litnih v Ukraini

The number of young carers is on the rise, with severe consequences for mental health and well-being.²³ Adolescent or young carers are often thrown into caring tasks without being prepared and experience the challenges of informal caregiving in connection with other developmental challenges. Their specific situation calls for greater attention. The opportunity to exchange with peers who face similar challenges can be of significant support to young informal carers.

Peer support for young carers in Belgium

The Young Caregivers Association in Belgium has around 60 members and meets 3 to 4 times a year to reflect on ways that are best to support young people who provide informal care to their relatives. The group is also raising awareness among health and youth sector professionals on the needs of young carers by creating a support platform dedicated to young caregivers. One of the objectives of the platform is to share information and strengthen skills of young people with care responsibilities.

Source: Information provided by Wallonie - Bruxelles International, see also <https://www.jeunesaidantsproches.be>

²² iSupport is available online at <https://www.isupportfordementia.org/en>. The offline version is available here: https://www.who.int/mental_health/neurology/dementia/isupport_manual/en/

²³ See BMASK, 2015; <https://me-we.eu/>; <https://eurocarers.org/young-carers/>

Access to information

There are a number of ways in which relevant information on caregiving, available support services, entitlements and benefits can be made available to informal carers – online, via telephone or through service centres.

In Finland, for example, a one-stop-shop support centre for informal carers “Omatori” was established in the South-Savo region. The centre gathers over 70 services ranging from information and counseling to preventive services that are accessible for informal carers at one place.²⁴

Information services for informal carers in Germany, the United Kingdom and Switzerland

Since 2011, the German Federal Ministry of Family Affairs, Senior Citizens, Women and Youth operates a counseling hotline (“*Pflegetelefon*”) for family caregivers where information and advice can be obtained about all aspects of nursing care, including information about the right to benefits, assistance at home, respite, or counseling services among others.

A ‘Digital Resource for Carers’ was developed by Carers UK to offer carers the best digital products and online resources (such as the ‘Jointly’ app) hosted on a single webpage, creating a comprehensive support resource for carers. The Digital Resource can support prevention and help carers before they reach crisis point by offering them two e-learning courses, targeted information, the opportunity to build networks of support and to understand the financial support available, develop coping strategies for physical and emotional pressures, improve personal resilience and manage care more effectively.

In Switzerland, the Federal Office of Public Health has created a database of services, projects and measures that provide support for caregivers. People interested in knowing more about ongoing projects or wishing to develop new services can find best practice models online, using various search criteria (for example, age of the person in need of support, type of intervention, type of provider).

Sources: Information for Germany provided by the German Federal Ministry of Family Affairs, Senior Citizens, Women and Youth, see also: www.wege-zur-pflege.de. Information for the United Kingdom provided by the Department of Health & Social Care in the UK, See also: <https://www.carersuk.org/help-and-advice/technology-and-equipment/jointly>. Information for Switzerland provided by the Swiss Federal Social Insurance Office, see also <https://www.bag.admin.ch/bag/fr/home/strategie-und-politik/nationale-gesundheitspolitik/foerderprogramme-der-fachkraefteinitiative-plus/foerderprogramme-entlastung-angehoerige/modelle-guter-praxis-suche.html>

Building skills for informal care

Training can help informal carers to acquire the necessary knowledge and skills for care provision and can enable them to protect themselves from burnout and other negative impacts of caring on their physical and mental health. Such training is essential to ensure the status of informal carers as co-workers in long-term care, to define more precisely the cooperation with professionals and, consequently, to improve the quality of care.

In most countries in the UNECE region, there is not yet a national framework for the provision of training to informal carers. Such programs are offered mainly by non-profit organizations, for example in Austria, France, Germany, and Spain. In the Walloon Region of Belgium, a European training reference system for caregivers and family carers of people with loss of autonomy and special needs was created and tested, along with France, Italy and Spain.²⁵ In Serbia, the Red Cross is implementing a two-day training programme for informal carers that covers practical skills (e.g. bathing patients in bed), communication skills (e.g. communicating with persons diagnosed with dementia) and awareness raising on how to seek help, or assistance, or how to deal with the emotional burden caused by providing care.²⁶

²⁴ Information provided by the Finnish Ministry of Social Affairs and Health, see also: www.omatorille.fi.

²⁵ Information provided by Wallonie-Bruxelles International, See also: https://www.aviq.be/handicap/AWIPH/collaboration_internationale/Alternative/alternative.html.

²⁶ Information provided by the Serbian Red Cross.

Training and self-organizing of informal carers in local communities in Slovenia

The Anton Trstenjak Institute of Gerontology and Intergenerational Relations has developed and implemented a community-based training programme for informal carers. The contents include social and health aspects of caring such as understanding of and communication with the care receiver, skills for home care, care for carers' own health, knowledge on prevalent age-related diseases, palliative care, death and grieving, information about respite care possibilities and institutional care, and psychosocial situation management. During the training, participants have the opportunity to learn from local and national experts and institutions related to caregiving. Some topics are presented by local community nurses, physiotherapists, doctors, formal carers from the local home care centre etc.

Training for family and other informal carers consists of ten weekly learning sessions that are attended by 15-25 family carers and carried out with a method of active peer learning from shared experience and expertise. In the course of the training programme, participants develop personal relationships. At the end of the training programme they are therefore encouraged to continue with monthly meetings in "local relatives' groups", which based on the principle of self-help groups. The Anton Trstenjak Institute provides expert support to leaders of these self-help groups. Furthermore, it organizes regular meetings of leaders from all over Slovenia where they exchange experiences and discuss topics such as: awareness raising, informal carers' rights and equal opportunities. In 2018, the Anton Trstenjak Institute, together with informal carers, organized the first national conference on informal care in Slovenia.

The programme is co-financed by Ministry of Labour, Family, Social Affairs and Equal Opportunities and by Municipalities as part of the Network of intergenerational programmes for quality ageing.

Source: Information provided by the Slovene Anton Trstenjak Institute of Gerontology and Intergenerational relations, see also <http://www.instantontrstenjaka.si/eng/gerontology.asp?section=1673&subsection=1674>

Strengthening the financial literacy and preparedness of family caregivers in the United States

Time spent as a family caregiver can have devastating consequences on financial solvency. To support family caregivers, the Administration for Community Living /U.S. Administration on Aging established the 'Strengthening the Financial Literacy & Preparedness of Family Caregivers Program'. The programme aims to improve the financial education and skills of family caregivers. It seeks to ensure on the one hand their own financial well-being and on the other hand to better equip them to handle financial matters for the persons they care for. First implemented in 2018, it is a three-year competitively awarded grant programme to provide training to informal carers across the United States.

Source: Information provided by the US Department for Health and Human Services

Political representation of informal carers

Representation and political participation of informal carers is important to raise awareness about their contribution and their needs to obtain social recognition of their role and improved conditions. Representative organizations of informal carers at local and regional level play an important role in disseminating information about existing types of support for informal carers and by directing recommendations for improvement towards political decision-makers. Many of these organizations run peer support groups that are helpful platforms for sharing experiences, skill-building and learning about different coping strategies. The International Alliance of Carer Organizations has started to bundle advocacy organizations worldwide to advance programmes, policies, and legislation that support caregiver well-being, to facilitate the exchange of good practice and to provide assistance to countries interested in developing family carer organizations.²⁷ Similar goals are pursued by national organizations in Canada, Israel and the United States as well as in many European countries. The Brussels Caregiver Association for example supports informal caregivers by bringing together informal carers, promoting peer support and developing a web platform for caregivers where they can access and share information and good practices. The Association receives financial support by the French Community Commission of the Brussels-Capital Region. At the EU level, informal carers are represented by several non-governmental organizations that carry out advocacy work and regularly publish reports relating to informal carers, e.g. Eurocarers, AGE Platform Europe, COFACE Families Europe and other organizations that specifically address the challenges of caregivers for persons with mental illness (EUFAMI) or of caregivers for persons with rare diseases (EURORDIS).²⁸

²⁷ <https://internationalcarers.org/>

²⁸ See <https://eurocarers.org/>, <http://www.coface-eu.org>, <https://www.age-platform.eu/>, <https://www.eurordis.org/>, <http://eufami.org/>

Conclusion

This policy brief has highlighted key issues to be addressed to support informal carers in their challenging roles across the UNECE region. Going forward, systematic and comprehensive support measures for informal carers need to be included in developing integrated, person-centered and sustainable long-term care systems that provide quality care to those who need it.

Specifically, the following is recommended:

- To improve the status and recognition of informal carers, it is necessary to develop a clear definition of informal care and informal carers at the national level, to raise awareness about the challenges of informal long-term care, and to give families real choice between alternative care arrangements. This entails assessing the needs of informal carers at both individual and societal level.
- To alleviate the strain on informal carers while also recognizing and supporting them in their fundamental role of providing care, professional carers need to be better trained to cooperate with informal carers, and formal care services need to acknowledge informal carers as co-producers and as co-clients in the care process.
- To facilitate the reconciliation of employment, informal care and personal life, it is necessary to provide access to care leaves, flexible working arrangements and supportive work cultures and to improve the availability of community-based support services such as flexible home care, day-care, and respite care. Bureaucratic and administrative procedures need to be minimized to improve access to services and benefits.
- It is important to provide better access to information about available support and services, including psychological support, and to build the skills of informal carers through training.
- To combat inequalities and to avoid that informal carers, including live-in migrant care workers, get penalized for their work it is necessary to ensure income security and social protection, including health care coverage, pension contributions and accident insurance.

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Checklist: The challenging roles of informal carers

Main areas	Areas of implementation	Key elements
Recognition of status and inclusion	Definition of status	<ul style="list-style-type: none"> • Formal definition and recognition of informal care and informal care status
	Political representation	<ul style="list-style-type: none"> • Awareness raising about the contribution and needs of informal carers • Recognition of and financial support for carers associations
	Needs assessment	<ul style="list-style-type: none"> • Comprehensive assessment of carers' needs (individual level) • Research on carers' needs (societal level)
Reconciling work, care and personal life	Care leave	<ul style="list-style-type: none"> • Entitlements to take time off
	Flexible work arrangements	<ul style="list-style-type: none"> • Part-time employment options • Flexible work schedules
Adequate income and social security	Financial support	<ul style="list-style-type: none"> • Care allowances
	Social protection	<ul style="list-style-type: none"> • Social insurance contributions
		<ul style="list-style-type: none"> • Pensions contributions
		<ul style="list-style-type: none"> • Health & accident insurance coverage
Employment	<ul style="list-style-type: none"> • Employment of informal carers by municipality (level of home helpers) 	
Community-based services	Access to services	<ul style="list-style-type: none"> • Home care assistance • Day-care and respite care services
	Affordability and choice	<ul style="list-style-type: none"> • Cash benefits to purchase services
Information and training	Information, counselling and training	<ul style="list-style-type: none"> • Hotlines
		<ul style="list-style-type: none"> • Resource centres
		<ul style="list-style-type: none"> • Building skills of informal carers
Health and well-being	Health promotion	<ul style="list-style-type: none"> • Build self-management skills of informal carers to reduce negative impact of informal care on health and well-being
		<ul style="list-style-type: none"> • Peer support programmes