Investing in the mental wellbeing and resilience of informal carers and long-term care workers

through the identification, evaluation and promotion of good practices across Europe

Well Care

Report on analysis of legislation, policies, care frameworks and funding schemes

October 2024

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Table of contents

Glossary

Long-term care (LTC)
Long-term care includes a broad range of personal, social, and medical services and support that ensure people with, or at risk of, a significant loss of intrinsic capacity (due to mental or physical illness and disability) can maintain a level of functional ability consistent with their basic rights and human dignity (WHO).
Long-term care is provided over extended periods of time by family members, friends or other community members (also called informal carers) or by care professionals.
Formal long-term care aims to prevent, reduce, or rehabilitate functional decline and it can be provided in different settings, such as home care, community-based care, residential care, or hospital care.

Long-term care (LTC) workers
Qualified nurses and personal care workers, either employed by a LTC provider (in home or residential settings) or directly by the care recipient/family (i.e. live-in carers, mainly in home settings). The latter also includes migrant care workers. LTC workers are also called formal carers.

Informal carers
Persons who provide – usually – unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework.

Formal homecare
Long-term care provided in an individual recipient's home, by a professional long-term care worker.

Live-in carer
Domestic care worker who lives in the care recipient's household and provides long-term care.

Executive Summary

The present document *D4.1: Report on analysis of legislation, policies, care frameworks and funding schemes* is a public deliverable of the WELL CARE project, developed within *WP4: Policy analysis, evaluation and recommendations* at month 9 (September 2024).

How do policies, legislation, care frameworks and funding schemes impact on the mental health of those who provide long-term care? What is the role for long-term care in our societies? Why should we care about carers? These are the main questions this Report explores.

As partners in the EU-funded WELLCARE Project, we argue that long-term care (LTC) deserves greater political attention and that the mental health of both informal carers and long-term care workers should be high on the agenda of the European Union (EU) and EU countries. Taking concrete actions to support the mental health of long-term care workers and informal carers will ensure the fulfilment of fundamental rights and crucial European values, such as the right to receive accessible, affordable, good quality long-term care; gender equality; and the right to health, which includes the right to mental health. In addition to the human rights argument, taking action to support the mental health of both informal carers and long-term care workers will allow EU countries to address urgent challenges they are facing, related to the sustainability of long-term care systems, opportunity costs of reliance on informal carers, and the costs related to increasing mental health problems in our societies.

In line with a mental health in all policies approach, actions to improve the mental health of informal carers and long-term care workers must go beyond the individual and address the broader socio-economic determinants of mental health. In the case of LTC workers, comprehensive actions are required to address psychosocial risks (such as high quantitative demand, high insecurity about working conditions, high emotional demands, high work-life conflicts, low control, low recognition, low social support, third party violence) at the source, by changing and/or improving the working conditions. Similarly, for informal carers, a comprehensive, preventative approach requires States to strengthen the accessibility of good quality LTC services (in order to ensure that care is a choice) and to address risks related to informal carers' health and wellbeing (physical and mental), poverty, social exclusion and work-life balance conflicts.

This report provides the reader with an overview of the legislation, policies and care frameworks for the mental health of informal carers and LTC workers, at EU level and at national/subnational level in the five partner EU countries (Germany, Italy, The Netherlands, Slovenia and Sweden). The data collection and analysis are based on desk research and consultations with key stakeholders. The Report builds on the combined expertise of the project consortium and partnerships, on mental health, informal care, LTC provision for older people and people with disabilities.

If the need to step up efforts to prevent mental health problems of both informal carers and care workers is increasingly recognised, it is now time to translate the recent commitments into concrete actions. What is needed is a fundamental re-valuing of the care professions and working conditions which match the crucial role of carers in our societies. Professional care work must be adequately paid, rewarded and represented. Informal care work must be recognised at its true value. Public authorities must strive for a better balance between formal and informal care. Informal care should complement formal care, not the reverse, and no one should be overwhelmed by a high-intensity caregiving role they did not choose.

The risks faced by carers in terms of mental health must be identified as a public health matter, and adequate support tailored to their needs should be made available to all of them. Informal carers need to be recognised as a key partner within care, where their role is based on choice and where they are proactively empowered, to enable them to thrive and combine care with, for example, a fulfilling personal life and paid employment.

How the issues are addressed will shape the future of LTC, affecting both the people who provide it, as well as those who receive care. The WELL CARE project will offer concrete tools for policymakers to take action, which must be driven by a strong political will. Achieving better recognition of the value of care, in general, is also essential for building gender-equal, inclusive, and resilient societies that are prepared for future challenges.

Introduction

Population ageing is increasing the demand for long-term care, as a decline in functional ability and the need for long-term care are associated with older age. Across the EU, informal carers account for almost 80 % of long-term care. Relying heavily on informal care will not be sustainable and formal care needs and pressure on public budgets are expected to increase.

Deinstitutionalisation, or DI, represents the shift from institutional to community-based care and focuses on providing individual support to people so they can live independently in the community (1). DI has gained prominence within Europe's policy agendas on long-term care (2), including an emphasis on helping people at home, rather than in residential settings. However, this effort has not been accompanied by adequate formal home-based support provision. Across the EU, only a quarter of households with people with disabilities receive formal home-based long-term care services (3), hindering their right to live independently in the community as stated by Article 19 of the UN Convention on the Rights of Persons with Disabilities. The shortage of adequate formal home-based care leads to several adverse consequences. It can cause avoidable institutionalisation or insufficient care and poor quality of life for those in need of care, as well as extensive engagement in informal care by family members and/or friends, with negative impacts on their life opportunities and mental wellbeing. Given the gendered dimension of care, this may translate into negative repercussions in terms of gender equality.

The COVID-19 pandemic shed light on the critical role of care workers in our societies. It also made visible the care sector's pre-existing structural weaknesses, such as staff shortages, poor working conditions, unequal funding in Member States, and the need to strengthen the resilience of the long-term care system (4).

These factors, together with privatisation/commodification of care, undermined the resilience of the care workforce and their ability to "bounce back" from the health crisis. At the same time, during the pandemic, the circumstances of informal carers were aggravated by the temporary unavailability of services and by the fear of contracting the virus. The Eurocarers survey of informal carers showed that 76.8% of respondents reported a negative impact on their mental health because of the health emergency (5). In some countries, policymakers recognised the particular situation faced by informal carers and introduced measures to support them. The work of formal and informal carers was put centre stage in policy debates related to working conditions, including issues of gender equality and work-life balance and quality of life. As stressed by the OECD (6), it is now time to go beyond the applause and translate the increased recognition of the value of care into concrete actions to support carers.

The health emergency and socio-political crisis caused by the COVID-19 pandemic, as well as the containment restrictions, evidenced the vulnerability of the general population to experience mental health problems and highlighted the relevance of broader factors, such as living in the height of a health crisis or lack of social contacts. As mental health problems also constitute a cost[1] for our economies, it is evident that there is a need to put in place broader actions, focused on prevention and in line with a mental health in all policies approach.

[1] The total costs of mental health issues – which include the costs to health systems and social security programmes, but also lower employment and worker productivity – are estimated to amount to more than 4% of GDP across EU countries, equivalent to over €600 billion per year. (Health at a Glance Europe 2018 report).

Against this backdrop, the EU-funded WELL CARE project aims to understand individual, contextual and organisational mechanisms behind the success of solutions for primary, secondary and tertiary prevention[2] of mental health problems among informal carers and long-term care workers.

In this context, the Report aims to provide an overview of the legislation, policies and care frameworks that address the mental health of informal carers and LTC workers, as well as providing recommendations on how to take action to support carers and build more resilience. The scope of the analysis is at EU level as well as at national and sub-national level, using as case studies the targeted project partner countries: Germany, Italy, the Netherlands, Slovenia, and Sweden.

This Report is based on a targeted consultation - via a questionnaire - of project partners and broader stakeholders within their respective networks, completed by information gathered by desk research by the lead author of this deliverable (Mental Health Europe). For the country snapshots, two sets of questionnaires were developed, related respectively to policies and legislation targeting informal carers and LTC workers, in the five project countries (see Annex 1). The latter questionnaire also included general questions on LTC country frameworks and funding regimes and was shared with the EU advocacy project partners, and consequently disseminated amongst their membership and broader partnerships. The questionnaire related to informal carers was circulated among the project partners from the five respective project partner countries. The data collection lasted approximately one month (end of March-end of April). A total of 12 responses was gathered. The information collected via the questionnaires was complemented by desk research and verified by the national project partners, who implemented a peer review role for their country snapshots.

Sections related to EU policy developments and overall conclusions and recommendations were based on desk research by Mental Health Europe, alongside exchange of knowledge with the EU advocacy partners in the project, so that their expertise (on disability, ageing, informal care and mental health) d informed the deliverable.

Section I sets the scene, by providing an explanation of the broader determinants shaping mental health (Chapter 1), followed by a state of play and an overview of risk factors and prevention measures in relation to the mental health of LTC workers (Chapter 2) and informal carers (Chapter 3).

Section II aims to outline the current EU policy climate with the core relevant policies, in relation to LTC (Chapter 1), and mental health (Chapter 2). It provides answers to the question on why the mental health of the project target groups of informal carers and LTC workers matters and the main entry points within the EU agenda.

Section III consists of a snapshot for each project country of LTC frameworks, funding schemes, as well as policies and legislation – at national, regional or local level- that may impact on the mental health of informal carers and LTC workers. The Conclusions bring together some key recommendations for policymakers at EU and national level.

This Report contributes to an understanding of the main issues at stake and reflects on potential solutions. A more in-depth analysis will be provided in the ensuing project work. A detailed analysis of country-level laws, policies, care structures, funding schemes and collective agreements, assessing their strengths and limitations, will take place later in the project and will inform five country profiles (D4.2), which will also include country-specific recommendations targeted at various stakeholders. Similarly, international and EU level recommendations will be the focus of a further targeted deliverable (D4.3).

[2] Primary prevention consists in addressing a risk at the source. Secondary prevention includes mitigation measures that aim to reduce the impacts of a risk that cannot be avoided at source. Tertiary prevention includes mitigation measures that address an illness or injury that has already occurred.

1. Section I: Mental health and wellbeing of LTC workers and informal carers

1.1. Mental health and its determinants

Mental health is "a state of well-being in which every individual realises their own potential, can cope with the normal stresses of life, work productively and fruitfully, and is able to make a contribution to their community" (WHO). Mental health and mental wellbeing are considered as synonymous.

Mental health is influenced by a variety of life events and transitions throughout the life course, as well as by broader social, economic, and environmental factors, which can impact positively or negatively on a person's wellbeing. These are called protective or risk factors. In this sense, the key to improving mental health is to prevent or minimise risk factors and to strengthen protective factors.

Resilience[3] - the ability to bounce back from adversity - can act as a buffer, counterbalancing the negative impacts of risk factors on mental wellbeing. Despite this 'ability' framing, it is important to emphasize that resilience is not an inherent quality of an individual (or of a community or even of health systems). It is rather a dynamic process and an outcome. People with resilience do not experience less distress, grief, or anxiety than other people. Rather, a resilient person uses healthy coping skills, takes advantage of resources available to them, whether internal or external, and asks for help when needed so they can best manage the situation they are facing. Research has highlighted the importance of considering not only an individual's internal resources, such as their coping skills and strategies, but also their social environments and the availability of resources within these environments[4]. It is important for decision-makers at all levels of society to support individuals' ability to access and utilise structural, socio-economic, environmental, and community resources conducive to resilience.

A comprehensive understanding of mental health and its socio-economic and environmental determinants sees a **mental health-in-all-policies approach** as essential to protect and improve mental wellbeing. In such an approach, actions are taken to address mental health within and beyond the health sector, with a strong focus on promotion and prevention. Policies in different areas (such as employment, income, social protection, among others) can impact positively on mental health, by strengthening protective factors and mitigating risk factors for mental health problems. Conversely, a lack of sufficient policy provisions or changes to policies (e.g., austerity measures) can adversely affect people's mental health and wellbeing.

1.2. Mental health of LTC workers: risk factors and prevention measures

1.2.1. State of play

When assessing the factors shaping mental health outcomes for LTC workers, the focus is mainly on psychosocial risks related to their work. Yet, it is important to consider that LTC workers are people – mainly women- who may also have caring responsibilities (childcare and/or LTC) in their private lives. This means that the distinction between LTC workers and informal carers is not so clear-cut, and the risk factors may add up.

Psychosocial risks (PSR) refer to aspects of the work organisation that might lead to negative physical, psychological or social outcomes. Psychosocial risks can result in stress, absenteeism, depression, burnout, harassment, parasuicide, and even suicide (EU-OSHA). It is important to understand and acknowledge that psychosocial risks are factors in the working environment, not intrinsic to an individual worker or related to their dispositions, attitudes, or health status. While the effects of PSR manifest at the

[3] Personal resilience can be defined as "the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional and behavioural flexibility and adjustment to external and internal demands" (APA 2023).

[4] Ungar and Theron, 2020, retrieved here: Risk and Resilience Factors During the COVID-19 Pandemic: A Snapshot of the Experiences of Canadian Workers Early on in the Crisis - PMC (nih.gov)

individual level as mental and physical health problems, the sources and factors are often found in employment conditions and in the way that work is organised. (7) This distinction is crucial for identifying the appropriate prevention measures.

According to WHO (7), the LTC sector is characterised by the following psychosocial risks: insecure working conditions (unpredictable working hours, workplace, work tasks and income); high quantitative demands (heavy workload because of understaffing, high patient/client- professional ratio, performance monitoring according to numerical goals vs quality of care); high emotional demands (e.g. stemming from dealing with functional decline or death of patients/clients); high work-life conflicts (working time arrangements that infringe on worker's work-life balance, e.g. changes in work schedules at short notice, lack of or low influence on management of shifts, lack of flexibility by management); low control over work tasks to be carried out; low recognition and rewards (inadequate income, undervalued professional knowledge, lack of continuous training and low promotion prospects); low social support (lack of physical space to meet colleagues, lack of peer support); psychological and sexual harassment, third party violence and job insecurity. Across Europe, the primary mental health risks care workers are exposed to are a high workload and time pressures, followed by care recipients with challenging behaviours (6).

1.2.2. The mental health of LTC workers in numbers

About two-thirds of registered or qualified nurses and personal care workers report being exposed to mental health risks, much more than average employees which lies at 43% (6). Workload and time pressure are the main sources of mental health risks for 31% of nurses and personal care workers and 19% of employees in general. Clients with challenging behaviours or, in the case of care workers, patients/ care recipients pose a mental health risk for 18% of nurses and personal care workers and 10% of employees in general. While violence or the threat thereof was considered the main source of mental health risk by only 4% of nurses and personal care workers, the level was 4 times lower among employees, at 1% (6). At the same time, Eurofound reported that 26% of LTC workers have been exposed to adverse social behaviours such as verbal abuse, 11% declared to have been threatened and 8% to have been humiliated, bullied or harassed during the month prior to being surveyed (8).

1.2.3. The specific challenges for paid home care workers and live-in carers

The situation is even more challenging in relation to home care. Job insecurity in home care is greater than in residential care. Permanent contracts are relatively common in the LTC sector, but these are clearly concentrated in residential LTC and are rarer in non-residential LTC. Besides temporary contracts, zero-hour contracts, self-employment, undeclared work and platform work are also less common in LTC than in other sectors, but more common in-home care than in residential LTC (8).

Home care – as it is currently designed – also makes it difficult to assess risks to ensure the health and safety of workers in the workplace. It is more challenging for employers to ensure the health and safety of workers in each home being visited. Higher self-employment in home care further complicates health and safety issues as there is no employer to ensure that protocols are followed (8).

A particularly vulnerable group of home care workers is constituted by formal carers – oftentimes women of migrant origins – providing LTC on a 24-hour live-in basis. They face particularly difficult working conditions, including low wages, unfavourable working-time arrangements, undeclared work, inadequate social protection, and non-compliance with essential labour protection standards and irregular forms of employment. The risk of migrant care workers being exploited can increase when the permission to stay in the country depends on their employment status such that they are dependent on their employer.

1.2.4. The effects of marketisation

Prior to the onset of the COVID-19 pandemic, LTC workers were already facing difficult working conditions, which could be associated with the marketisation of LTC. Austerity measures and the retrenchment of the welfare state demonstrated in the reduction of public spending on social services after the 2008 financial crisis paved the way for the outsourcing and commodification of health care services (9).

Marketisation is mainly based on outsourcing through public tendering, competition, and free choice of providers by service users, as well as the introduction of several techniques and practices typical to the private sector, now adopted via New Public Management, into the public sector. Not only do competitive tendering and profit-oriented strategies encourage cost-cutting, drive down wages and increase working hours, but market mentality has also fundamentally changed the nature of care work (10). In order to make care provision more 'efficient', the relationship-building aspects of care have largely been replaced with repetitive, standardised tasks which are to be completed as quickly as possible. Breaking down the profession in this way has gone "hand-in-hand" with an increase in part-time, zero-hour and temporary contracts, limiting worker access to social protection as a result. This system of organising care work also leads to higher psychosocial risks for LTC workers, and downplays the complex, emotional, physical, and psychological support aspects of the role (10).

1.2.5. Potential solutions

In relation to mental health at work, different levels of prevention can be identified. Primary prevention aims to eliminate risks at source, by changing the working conditions. Secondary prevention includes mitigation measures that aim to reduce the impacts of a risk that cannot be avoided at source (for example, skills training to deal with emotional demands and offering psychological support to workers) and tertiary prevention includes mitigation measures that address an illness or injury that has already occurred. Priority must be given to primary prevention actions, i.e. actions designed to eliminate the sources that give rise to the PSR factors in the first place (7).

Table 1 below clearly exemplifies what measures need to be put in place to address psychosocial risk factors among LTC workers (primary prevention measures are in black and secondary prevention measures are in blue).

The table below clearly highlights how psychosocial risks need to be eliminated by addressing the source, thus it is evident that the solutions are not so straightforward.

A comprehensive policy strategy is needed, consisting of different measures, ranging from increasing wages, supportive collective bargaining, fostering the leading role by governments vis à vis private actors, as well as combatting gender discrimination, increasing training requirements and public information campaigns. One solution is avoiding staff shortages reaching unacceptable levels by attracting workers to the sector. Men have the largest potential to reduce staff shortages in LTC. Unemployed and former informal carers may also be targeted, where appropriate. Another potential avenue is to address the insufficient recognition of LTC work. Improving pay is seen to be the first step, which can be achieved partly through more general minimum wages policies (as many of the low paid professions in LTC earn minimum wages or just above). However, the low income is exacerbated by many LTC workers working part time hours only. Many part time workers in LTC may be willing to increase their hours if working arrangements (working hours, predictability of their paid work schedule) allowed them to combine paid work with caring responsibilities of a family member/friend (8). Facilitating increased hours for those who want it is an avenue to improve working conditions of LTC workers.

It has been argued (10) that for care to be considered a public good, the commodification of care needs to be limited, or better yet, reversed. This will ensure a human centred approach, as opposed to a market driven approach (10).

Table 1. Workplace primary and secondary prevention measures for addressing psychosocial risk factors among LTC workers

Psychosocial risk factors	Psychosocial risk sources	Prevention measures
High quantitative demand	Excessive workloads	Safe staffing levels
High insecurity about working conditions	Frequent changes in work schedules, tasks, the number of hours worked and salaries	Limiting changes in working conditions that are not initiated by the worker
	Poorly managed organisational change	Involving workers and their representatives in decision making processes
	Ineffective communication	Promoting training on participative management (integrating the expertise of employees into company decision-making).
High emotional demands	Sense of powerlessness associated with not being able to fulfil tasks due to lack of resources	Adequate staffing and decreased patient-ratio.
	Lack of psychological and therapeutical support	Resources to cope with emotional demands, such as offering psychological support during working time and time off
High work-life conflicts	Long working hours	Decreasing patient ratios
	Changes in work schedules with short notice	Participatory management and decision making; scheduling considering caring responsibilities at home
	Law influence on management of shifts	
	Lack of flexibility by management	
Low control	Deskilling through job design that favours standardised tasks	Practising participatory management styles; transparent decision making
	Lack of influence over how the job is done	
Low recognition and rewards	Low salaries	Income that recognises qualifications, experience and job requirements
	Poor promotion opportunities	Valuing different care professions through recognition of professional competence derived from training and experience
	Undervalued/unrecognised expertise	
Low social support	Lack of support in carrying out work	Opportunities for peer support during shifts
Psychological and sexual harassment/Third party violence	Lack of zero tolerance culture regarding harassment and violence at the workplace	Establishing a clear policy; training directors and managers on harassment and violence prevention and providing reporting mechanisms and psychological support at the workplace

[Please note: this table is adapted from ETUI (2022), *Work-related psychosocial risks in the healthcare and long-term care - Sectors- Sources, factors, and prevention measures, ps 12-14*]

In relation to home care workers, a potential solution lies in the development of community-based services, where care is provided at centres in neighbourhoods rather than at home (8). Moreover,

regularisation of undeclared domestic LTC can be achieved by making regularisation easier and more attractive for both the worker and employer alike.

1.3. Mental health of informal carers: risk factors and prevention measures

In the EU, it is estimated that 52 million people provide informal LTC, and informal carers account for almost 80 % of long-term care (EIGE, 2023). A significant proportion of carers (42 % of women and 38 % of men) provide LTC daily. Most informal carers are of working age, under 54 years old (73 % of women and 75 % of men), which might impede their ability to maintain a healthy work–life balance (11). Some informal carers provide LTC to a family member/s and/or friend/s and have the additional responsibility of caring for their children under the age of 12. Furthermore, around 27 % of women and 31 % of men who provide LTC to a person/s close to them. also care for their own children simultaneously. Such dual caring responsibilities (sandwich carers) add to the challenges informal carers face as they endeavour to balance their caring roles with other aspects of their lives.

The mental health impacts experienced by informal carers who provide care on a regular basis are often complex. Informal carers may experience caring as constituting a source of intrinsic satisfaction, emotional fulfilment and a sense of purpose. However, in contrast, and especially where caring is of a high intensity and over prolonged periods of time, it is also more likely to lead to informal carers experiencing poorer mental and physical health and being at a much higher risk of depression compared to people who do not provide care (12).

Indeed, previous research has highlighted that providing informal care has all the features of a chronic stress experience: it causes physical and psychological strain over extended periods of time, it is characterised by unpredictability and uncontrollability, high levels of vigilance are required and caring can have a negative impact on a variety of life spheres of the informal carer, e.g., education, work, social inclusion and financial situation (leading to poverty). In addition to caregiving provision alone, it is recognised that the health status of the care recipient and other caregiving characteristics play important roles in the mechanisms through which caregiving impacts informal carers' health. For example, the affliction/illness experienced by the care-recipient can influence caregivers' health. In comparison to other diseases/conditions, caregiving for a loved one with dementia has been repeatedly reported to be especially impactful on informal carers' mental health. Caregiving features, such as the intensity of care provision is also an established contributor, with larger negative impacts experienced by informal carers when more intensive care is provided. As well, for those informal carers without any prior caring experience and/or training, and in situations where they are the sole care provider without any other sources of support, providing care to a family member or friend can also have a profound negative impact on their health and well-being (12).

1.3.1. The mental health of informal carers in numbers

Mental health problems are 20% higher among informal carers than among those who do not provide care and are especially pronounced in people who provide care more than 20 hours per week (high intensity care). Depression is one of the most common problems experienced by informal carers and it is suggested that a large number, in the range of 40% to 70% of all informal carers have some symptoms of depression, of which between 25% and 50% have symptoms of such severity that they meet the criteria of major depression. The presence of emotional stress and depression is high (from 30% to 40%) among informal carers of people living with dementia (13).

1.3.2. Potential solutions

Programmes to enhance coping skills of informal carers, as well as peer support group, psychological support and training can be provided as mitigation measures (secondary or tertiary prevention). These measures aim to support informal carers in their caring activities and to increase their resilience. However, a comprehensive preventative approach would address the risk factors by tackling the source, via primary prevention. The first measure would be to ensure the supply and accessibility of formal long term care services, so that informal care is a choice. Consequently, for those who have freely chosen to provide care, policies must be put in place to prevent informal carers from experiencing ill-health, poverty and social exclusion. This implies measures that allow carers of working age to combine paid work and care (without having to reduce working hours or drop out of the paid market altogether); financial remuneration and regular, quality respite care as perceived by both the care recipient and informal carer (Hanson, 2023). Addressing the barriers to accessing formal care services, improving work–life balance and supporting and empowering carers to have a life outside of caring are crucial for promoting gender equality, financial independence and the well-being of carers (and care recipients).

Gender and intersectionality in LTC

"Investing in care is an investment in gender equality and social fairness" – Helena Dalli, Commissioner for Equality (7 September 2022).

In the traditional gendered division of labour of the male-breadwinner model, care is considered women's work and the skills required for performing care work are incorrectly assumed to come "naturally" to women; moreover, informal care is not viewed as part of income-producing activities and is thus not valued in monetary terms. Gendered care norms downplay the skills needed to provide LTC and the wage levels required to attract skilled and motivated workers to the LTC sector, undermining recognition and valuation of care work (6).

Due to gendered social roles, stereotypes and power dynamics, women have historically shouldered most caring responsibilities. Even though LTC systems widely vary across EU countries, a persistent pattern can be identified: the disproportionate distribution of informal care duties to women's disadvantage. Most informal carers for older persons and/or persons with disabilities in the EU are women (62 %) (EIGE).

The disproportionate burden of care on women continues to have a significant impact on their lives and is a primary reason why women do not engage equally in the labour market and public life, with far-reaching consequences (6).

Therefore, to sustainably improve LTC workers' and informal carers' positions in society – and their wellbeing - it is not only necessary to better recognise care work in terms of increased status and remuneration, but also to tackle gendered care norms (6).

Moreover, when addressing gender, it is crucial to adopt an intersectional approach and consider the interaction of gender with ethnic origin and migration status. Otherwise, care policies risk addressing the interests of only one group of women, at the expense of other women (10). Indeed, even if the performance of care work, whether paid or unpaid, remains a gendered activity, care is distributed differently between women who can afford to outsource part of their unpaid care work, and women to whom this unpaid care work is transferred (10). In some countries, policies to increase women's participation in the paid labour market – in the absence of a formal provision of LTC services - have translated into women reducing their LTC responsibilities, relying on migrant women working as domestic carers, with the result of "women who replace other women in an activity that confirms itself as a female-only destiny" (14).

2. Section II: Mental health and wellbeing of informal carers and LTC workers on the EU agenda

2.1. Long-term care on the EU agenda: the European Care Strategy

"It is time to care about carers." – Dubravka Šuica, Vice-President for Democracy and Demography (2022)

Up until 2022, the engagement of the EU with care policy and carers has been incipient but rather fragmented. Unlike childcare, long-term care has barely been part of the EU policy discourse. It has often been limited to the work-life balance issue, although demographic ageing has been a concern for some time (10). Mainly, the European Commission, through the European Semester, which represents the annual cycle of reviewing the coordination of socio-economic and fiscal policies in the EU, has long recommended Member States to reduce the costs of their health and social care systems, including LTC.

The right to care was enshrined in the European Pillar of Social Rights (EPSR) presented by the EC in 2017. Specifically, Principle 18 recognises that "everyone has the right to affordable long-term care services of good quality, in particular homecare and community-based services". The EPSR also recognises the right to fair working conditions, although not specifically for the care sector, and the right of everyone to timely access to affordable, preventive and curative health care of good quality (principle 16), the right for persons with disabilities to live in dignity, and access services that enable them to participate in the labour market and in society (principle 17), the right to gender equality (principle 2) and work life balance (principle 9).

In 2019, the EU introduced the Work-Life Balance Directive, aimed at better supporting work-life balance throughout the life cycle for everyone, both parents and informal carers. It is guided by the recognition that the prevalent situation was detrimental in terms of quality of life for people endeavouring to combine paid work and care, and gender equality, as women tend to take on board most of the care responsibilities (15). Supporting the full participation of women in the labour market through improved work-life balance and a more equal sharing of care between genders is expected to have a positive impact on our economy. In relation to informal carers, the Directive introduced a carer leave and flexible working arrangements for people with caring responsibilities. It was a first sign of attention to the challenge faced by informal carers in combining paid work and care. The measures proposed were relatively timid and many limits have been highlighted by carers' organisations (16), such as: a strict definition of carer, a short leave, with no indication as to remuneration, the possibility for flexible working arrangements to be subject to conditions, as well as the fact that the Directive is purely for working carers. Yet, the Directive sets the minimum policy measures and Member States could potentially go further.

The health crisis caused by COVID-19 brought the work of formal and informal carers to the centre of policy debates related to working conditions, including issues of gender equality and work-life balance. Against this backdrop, in 2022, the European Commission presented the European Care Strategy and put care, both childcare and LTC, high on the EU agenda. The Strategy marks a paradigm shift, by taking care out of the private sphere and placing it on the public and political sphere. In this context, the Strategy recognises that care is a public good and that structural changes are needed to realise the rights enshrined in the EPSR. In addition to ensuring quality, affordable and accessible care services across the EU, the Strategy sets an agenda to improve the situation for both care receivers and carers (both formal and informal carers).

The Strategy has been defined as a "game changer", as it shifts attention in the care sector towards a sustainable and human rights-based care model. Putting care on the European agenda furthers and strengthens the actions of the social actors and policy makers who argue that needs for care and care provision should be an important political issue (10).

The European Care Strategy is accompanied by a Recommendation on access to affordable high quality LTC , proposed by the EC and adopted by the Council at the end of 2022.
In relation to LTC workers, the European Care Strategy and the ensuing Recommendation, encouraged Member States to support quality employment and fair working conditions in long-term care. Among the suggested measures, it urged promoting a national social dialogue and collective bargaining in LTC; supporting the development of competitive wages, adequate working arrangements and non-discrimination in the sector; promoting the highest standards in occupational health and safety, including protection from harassment, abuse and all forms of violence, for all LTC workers.
The Strategy and the Recommendation also encouraged Member States to improve the professionalisation of care and to address skills needs and worker shortages in LTC, in particular by building career pathways in the LTC sector, including through upskilling, reskilling, and skills validation.
The specific challenges faced by live-in care workers and domestic workers were also highlighted. The Council recommended Member States to establish pathways to a regular employment status for undeclared LTC workers and to explore legal migration pathways for LTC workers.
Similarly, the European Care Strategy encouraged Member States to ratify and implement the 2011 Domestic Workers Convention (No. 189) of the International Labour Organization, which lays down basic rights and principles, and required national competent authorities to take a series of measures with a view to ensuring decent working conditions for domestic workers.
The Council also considered the gender dimension of care, recommending Member States to tackle gender stereotypes and gender segregation and to make the LTC profession attractive to both men and women.
In relation to informal carers, the European Care Strategy and the Recommendation recognise that providing informal care can negatively affect carers' physical and mental health and well-being and is a significant obstacle to employment, particularly for women. It recommended that Member States establish clear procedures to identify informal carers and support them in their caregiving activities by: (a) facilitating their cooperation with LTC workers; (b) supporting their access to the necessary training, including on occupational health and safety, counselling, healthcare, psychological support and respite care, as well as supporting them in balancing paid work and care responsibilities; (c) providing them with access to social protection and/or to adequate financial support, while making sure that such support measures do not deter labour market participation.
Furthermore, Member States must ensure sound policy governance in LTC, by having in place a LTC care coordinator or another appropriate coordination mechanism supporting the implementation of this Recommendation at national level. Additionally, Member States should communicate to the Commission the set of measures taken or planned to implement it, within 18 months from the adoption of the Recommendation. To support Member States's efforts, the Commission will mobilise EU funding and technical support to promote national reforms and social innovation in LTC[5]. The Council welcomed the

[5] In order to support MSs in their efforts, the EC has set up the Flagship Technical Support Project to help health and social affairs ministries design and implement reforms in the areas of health, social care and LTC, aiming for better coordination between these sectors and integration of the different levels of care provision. The Commission has also established a European partnership on transforming health and care systems through research and innovation, and in April 2023 launched the first call for proposals for funding. In July 2023, the Commission established a new partnership with the World Health Organization (WHO) to strengthen access to and quality of LTC services, while offering support to informal caregivers, and set up the European social dialogue committee for social services seeking to improve working conditions, career development, skills and job attractiveness in the social services. The EU has pointed to already available funds that can be used to implement reforms in long-term care, including the Recovery and Resilience Fund which has a budget line for 'resilient health and care systems', the European Social Fund, but also the Cohesion Fund, European Social Fund, Fund for Regional Development, Rural Development Fund and others.

European Commission's intention to monitor progress in implementing this Recommendation in the context of the European Semester.

The European Care Strategy sets out for the first time an EU vision on LTC. It paves the way for the creation of a person-centred, community-based care and support system. It lays the foundation for a system that will respect the rights and dignity of persons in need of care and their carers, both professional and informal. The Care Strategy importantly recognises the synergies between formal and informal carers rather than viewing them as two completely disparate groups and calls for a strategic and integrated approach to care (integration between LTC and healthcare, or between informal care, home care, community based and residential care). It highlights the need to consider **care as a continuum**, to be addressed from a life-course approach, taking into consideration the **rights and wellbeing of all actors**: **persons in need of care, informal carers and care professionals**. While these are strong assets of the Strategy, the main concern is that the actual uptake of the Strategy lies at the national level. For the Strategy to deploy its full potential, it needs to be transposed through ambitious national LTC action plans. Hence, the call from civil society organisations, including some project partners, for these national measures to be 'appropriately funded, ambitious, time-bound, targeted and measurable to improve the affordability, accessibility and quality of care services'. The same stakeholders also call for open and transparent reporting mechanisms, by making the national actions plans publicly available on national or EU websites.

2.2. A comprehensive approach to mental health

"There is no health without mental health and there can be no European Health Union without equal and timely access to prevention, treatment and care for our mental health. Today marks a new beginning for a comprehensive, prevention-oriented and multi-stakeholder approach to mental health at EU level". - Stella Kyriakides, Commissioner for Health and Food Safety (2023)

In June 2023, the European Commission launched a Communication on a comprehensive approach to mental health, with the ambition to put mental health on a par with physical health and to leave nobody behind. This comprehensive approach looks at mental health across all policies to recognise the multifaceted risk factors of mental-ill health. Following this approach, concrete actions will cover a broad area of policies and include efforts to: promote good mental health through prevention; invest in training and capacity building that reinforces mental health across policies and improves access to care; ensure good mental health at work by raising awareness and improving prevention and address vulnerable groups by providing targeted support to those most in need.

Care appears in different parts of the Communication, with references to the Work-life balance Directive, to the collaboration with the European Agency for Safety and Health at Work (EU OSHA) on psychosocial risks at work for the care workforce, and to the European Care strategy. These references clearly reflect the growing recognition of the contribution of carers and of their support needs. As recognised in the analysis of Mental Health Europe, the Communication is an important first step in the right direction – towards the vision of a Europe where everybody's mental health can thrive. Some of the positive aspects of the Communication with high relevance to the WELL CARE project include, i) the adoption of a mental health in all policies approach; ii) recognition of the role played by socio-economic and environmental determinants in shaping our mental health and iii) the focus both on prevention and on the need for tailored support for people in vulnerable situations.

The Communication collects existing funding allocations and actions related to mental health, for a total of 20 flagship initiatives and EUR 1.23 billion to support their implementation. However, no new initiatives or funding were established. It is argued that the European Union continues to lack a long-term approach to address mental health (17). Hence, it is seen to be important to build on the commitment taken in the Communication and develop a European Mental Health Strategy. Such a strategy should have concrete targets, objectives, and budget as well as a clear timeline and indicators to monitor progress. This ask – which echoes that of European citizens participating in the Conference on the future of Europe- is supported by the European Parliament[6] and the European Economic and Social Committee[7] . Moreover, as highlighted by Eurocarers (18), where informal carers are concerned, future EU action on mental health could be strengthened and made more specific, for instance by acknowledging young informal carers among the groups of people in vulnerable situations, which deserve extra tailored support.

In relation to mental health at the workplace, the only current legislation at EU level is the EU Framework Directive on Occupational Safety and Health. According to this Directive, employers are obliged to protect workers' health and safety in all aspects of work. They must consider how to eliminate any risks at their source; in terms of psychosocial risks this would mean, for example, optimal work organisation. Despite the common obligations laid out in the EU Framework Directive, Member States do not tend to share common standards and principles regarding PSRs. On the contrary, legislation on PSRs differs widely between Member States, resulting in an unequal protection of workers. At the Member State level, there is considerable variation in how psychosocial risks have been addressed in national legislation and wider policies and initiatives[8]. Some Member States have no specific regulation on the issue at all, others have regulated parts of the problem, and others still have a fairly sophisticated and complete regulatory system on the issue[9]. For instance, the right to disconnect has been enshrined in law in some Member States (ES, PT, FR, BE, EL, IT); burnout has been included on formal lists of occupational diseases (IT, LV) or otherwise allowed to be recognised as an occupational illness (SE, NL, DK, EE, FR, HU, PT, SK, CY, MT). Interviews with trade union representatives show that where there is legislation, implementation is hampered by a lack of resources, such as in the form of labour inspectors, lack of political will and accountability and punitive measures to push reluctant employers to address PSR[10].

There is a clear need to develop more specific EU legislation, with a Directive on psychosocial risks, as new EU legislation in this area could create greater uniformity across Member States, setting minimum standards and ensuring that legislation covers new and emerging psychosocial risks. The call for a directive on psychosocial risks comes from the civil society, trade unions, as well as the European Parliament, which has been putting pressure on the Commission to introduce a new Directive on psychosocial risks and well-being at work, to be developed in consultation with social partners.[11]

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[6] The European Parliament Own Initiative Report on mental health calls for the European Commission and corresponding member states to develop comprehensive Mental Health Strategies with quantifiable objectives, a clear timeline, adequate budget, objectives, as well as measurable indicators to monitor progress, and a focus on the most vulnerable groups.

[7] Measures to improve mental health | EESC (europa.eu)

[8] Minimum health and safety requirements for the protection of mental health in the workplace, European Parliament

[9] Work-related psychosocial risks in the healthcare and long-term care sectors Sources, factors, and prevention measures

[10] Work-related psychosocial risks in the healthcare and long-term care sectors Sources, factors, and prevention measures

[11] European Parliament resolution of 10 March 2022 on a new EU strategic framework on health and safety at work post 2020 (including better protection of workers from exposure to harmful substances, stress at work and repetitive motion injuries) but also EP Report on mental health, 2023.

3. Section III: Country factsheets

This section consists of a country snapshot for each partner country within the WELL CARE project concerning their LTC frameworks, funding schemes, as well as policies and legislation – at national, regional or local level- that may impact on the mental health of informal carers and LTC workers. By assessing the country frameworks for Long-Term Care and funding mechanisms, it provides the reader with an overview of the country choices about how to share long-term care responsibilities and costs between society, users, and informal carers. It then endeavors to identify whether there are policies or legislation tackling gender stereotypes around care. In relation to LTC workers, it assesses the existence of legislation/policies to improve working conditions of LTC workers, to strengthen their skills, to protect their rights (including those of vulnerable groups, such as migrant carers). In relation to informal carers, the factsheets assess whether legislation or policies define informal carers and provide them with support (from combining paid work and care responsibilities, to financial support, respite care and training). The collection of information on policies, legislation and funding schemes has also brought to light many initiatives from civil society or other stakeholders (e.g. employers, trade unions), oftentimes taken to fill the gaps of the formal LTC system.

This section has limitations, as it is based on information gathered online or via consultation with stakeholders. Updated information will soon be available, as the national action plans in the framework of the European Care Strategy should shortly be published[12]. Moreover, the fact that support measures are envisaged in legislation or policies does not automatically mean that they are implemented in practice and that they translate in the expected outcomes of improved mental health. This is why the next steps of the WELL CARE project work activities –an in-depth examination of the implementation and assessing strengths and limitations of relevant national policies, legislation and funding schemes- will be crucial.

A detailed country snapshot is provided for each of the WELL CARE partner countries below, that is Germany, Italy, the Netherlands, Slovenia and Sweden. A brief, but not exhaustive, comparative overview is firstly provided concerning the national policies and initiatives across the five countries.

A main consideration is that the LTC systems of the partner countries vary widely and can be seen to reflect different welfare identities and traditions[13]. Hence, considerations related to who is responsible to provide care (families, State, market) vary considerably, at both societal and policy level across the project countries. For example, from Sweden, with a social democratic welfare state, where the State is given fundamental responsibility for all the citizens' needs (universalism), to Italy (Mediterranean model), where responsibility is put on traditional forms of social support (i.e. families or social networks). Despite the differences in the five country contexts, all countries are facing common challenges, related to the sustainability of their LTC systems, opportunity costs of informal care and costs of rising mental health problems.

Some actions have been taken in recent years to improve wages, working conditions and skills of LTC workers, in so doing improving their wellbeing and making the sector more attractive. For instance, Germany has introduced an obligation for LTC providers to pay their workers at least the collective-bargaining level. Since September 2022, the German statutory care insurance is only allowed to conclude supply contracts with LTC providers if they comply with this regulation. Actions have also been taken to

[12] The timeline included in the European Care Strategy envisaged a submission of national action plans by end of August. It is expected that the plans will be made publicly available by end of September 2024.

[13] For an overview of the main types of different European welfare models see Hajighasemi, A. (2019). Chapter 4- The five different types of European welfare model, *Social and Political Science 2019,* *https://doi.org/10.4337/9781789905564.00012*

strengthen the academic advancement of the care profession and empower care professionals, allowing for greater independence in care processes. Similarly, in Sweden the Eldercare Initiative was launched in 2020, with the aim to enhance competence in eldercare and contribute to the professional development of LTC workers (with the expected result of making the jobs more attractive and improving the working conditions of LTC workers). Another relevant, recent and concrete Swedish policy development consisted of making the title of "assistant nurse" a protected occupational title. The National Board of Health and Welfare Sweden must issue a certification for staff to use the title within health and social care. Certification is believed to have multiple benefits: it improves working conditions for staff by clarifying their role and areas of responsibility; it enhances the quality of care provided and it enhances the status and appeal of the profession.

In relation to informal carers and measures to support their wellbeing, some common challenges emerge from the country analysis. Firstly, in many cases (Sweden, Italy, the Netherlands), the national legislator does not specify whether and what types of support informal carers are entitled to. The decisions – on what support to provide, on eligibility criteria, level of payments- are left to authorities at regional or municipal level, with the result of different support depending on where people live within the specific country. Second, a major shortcoming of legislation to support informal carers is related to implementation: even when a support measure exists, take up may be low (as in the case of care leave in Germany or of the recent LTC reform in Slovenia, whose impact is difficult to assess, in the absence of implementing acts). This is a crucial element and will be the subject of further consideration within the WELL CARE project when interviews will be carried out with a range of experts to investigate how existing legislation is implemented.

Third, a further challenge related to support measures envisaged for informal carers in the five different countries consists in their coverage of only certain groups of informal carers and leaving others with no rights. This is the case, for instance, of care leave in Italy, which are valid only for private and public employees, excluding self-employed and those employed in domestic and household services. Similarly, in Slovenia the definitions under different legislations are quite narrow, with the result of rights and support being provided solely to a small portion of the informal carers population.

Finally, an important trend that appears from the country snapshots analysis is the role played by civil society to support the mental health of informal carers, to complement support provided by the legislator (or fill the gaps in case of lack of measures at legislative level). This role played by civil society is also particularly important in relation to challenging gender stereotypes related to care, with different examples of campaigns in the desired direction within several project partner countries.

There now follows the country snapshots for each of the WELL CARE project partner countries, namely, Germany, Italy, the Netherlands, Slovenia and Sweden.

Germany

LTC framework
Overview
Germany, as described by sociologist Gøsta Esping-Andersen is one of the classic examples of a conservative-corporatist welfare model. The German care regime is deeply embedded in the broader welfare state regime, particularly in its reliance on social insurance, subsidiarity, solidarity, and status maintenance. It is also characterized by a "publicly supported private care cluster," which also reflects its broader welfare state regime. This regime emphasizes a mix of state support and family involvement in care provision. (Theobald & Luppi, 2018). The German care regime rests on the subsidiarity principle[14] that explicitly encourages care at home, primarily by family members. Germany is 'a care regime reliant on unpaid care (though partly compensated for by the government)' (Anttonen & Sipilä, 1996). The German system – at least as enshrined in the law, if not at general public level- is still very much permeated by the consideration of care as an individual issue, not a societal responsibility, to be dealt at family level, with a strong presumption of family members (especially daughters) taking the care responsibility[15]. It has been noted that the primacy of informal care is currently hidden behind the positive-law requirement of 'homecare before residential care' (19). LTC in Germany is based on a long-term care insurance (LTCI) principle. Anyone living in Germany is obliged to take up LTCI (Pflegeversicherung), either in the statutory or private LTCI system. Approximately 90% of the population is covered by statutory insurance. The statutory LTCI is anchored in SGB XI (Sozialgesetzbuch XI), and is only a partially comprehensive insurance. Therefore, LTCI did not change the family's obligation to provide care – if anything, it reinforced it by adding a *legal* obligation to the moral obligation for families to provide care (11). The LTCI benefits are predominantly based on the principle of benefits in kind. People in need of care are entitled to a certain amount of care services being paid for by the care insurance. There is only an entitlement to cash benefits (care allowance) if part of the benefits in kind are waived and only to a lesser extent. The providers of care services are private or non-profit welfare organizations. There is no obligation on the municipalities to provide services. Therefore, if people in need of care cannot find a service, they do not receive any long-term care insurance benefits apart from the limited care allowance.
Funding
LTCI in Germany is based on the pay-as-you-go principle. is administered by 'long-term care funds' It is financed exclusively by contributions from the insured.

[14] The principle of subsidiarity states that a task (e.g. care for a relative) should be taken over by the smallest 'responsible' unit if possible (e.g. family). Higher-level units should only intervene if the lower units cannot. The principle of subsidiarity states that a task (e.g. care for a relative) should be taken over by the smallest 'responsible' unit if possible (e.g. family). Higher-level units should only intervene if the lower units cannot. On the other hand, the principle of subsidiarity also requires putting smaller units in a position to be able to fulfil these tasks - 'helping people to help themselves'. This second part of subsidiarity is not sufficiently recognised.

[15] The Independent Advisory Board for the Reconciliation of Caregiving and Employment – in its 2019 report to the German government- sets out principles going in the opposite direction, such as: LTC is considered a societal task; Every individual decision in favour or against caring should be respected; Carers should be supported to prevent them from giving up their jobs; There should be more measures encouraging a gender equal division of labour in caring.

In statutory LTCI, half of the contributions are paid by employees and half by employers. In 2024, the contribution rate will be 3.4% of wage income up to a certain annual income (Beitragsbemessungsgrenze) but will vary depending on the number of children.
In private LTCI, the contribution rate depends on age and the individual's state of health. Employees receive a contribution from their employer.

Policies to tackle gender roles in care

The LTC sector is highly feminised, with female participation amounting to 85 per cent.
The majority of informal carers are female. Estimates based on various studies put the figure up to 80%. On average, they are 57 years old and 2 out of 3 are married. Of all informal carers under the age of 65, 70% are employed in addition to providing care. Women provide the greatest amount of home care, averaging 21 hours per week. Compared to men, they are almost twice as likely to provide unpaid care in the family, which is clearly demonstrated by the current gender care cap of 44.3%. According to this figure, women do 1 hour and 19 minutes more unpaid work than men every day.
Informal carers do not receive any money for their work. The care allowance from the care insurance is intended for the person in need of care and not as payment for relatives. In comparison to parents, there is therefore no financial security if employment has to be reduced or given up to provide care. Parental allowance in Germany is financial support for parents after the birth of a child. There is no such benefit for informal carers.

LTC workers

Employment and working conditions

According to the 2021 care statistics, around 814,000 people were employed in nursing homes in inpatient care, 63% of whom worked part-time. 82% of all employees in inpatient care are female.
There has been a care crisis in Germany for years. Working conditions in the care sector and in hospitals have remained poor despite increased attention for the industry during the coronavirus crisis. The shortage of care professionals is acute and competition between facilities for staff is intensifying. Staff shortages and stress characterise everyday life. The main reason for this is the economisation of operations. Hospitals today are primarily profit-orientated companies. This is why there are so many private investors.
Compared to the responsibility, requirements and necessary qualifications, nursing professions are relatively low paid. One reason for the low wages in the sector is the low level of unionisation. Not all employees benefit from collective agreements, and effective representation of interests is particularly difficult in the many small private service providers.
All employees in the care professions earn the highest salaries in hospitals and the lowest in outpatient care. For example, skilled nursing staff in western Germany earn an average of 4,093 euros if they are employed in hospitals. However, if they work in outpatient care, they earn 559 euros less. These pronounced differences can be attributed to the different insurance systems (health insurance vs. nursing care insurance), but also to the size of the organisation and the ownership of the respective facilities (private, non-profit, public). The gradual increase in the minimum wage for nursing care and the introduction of compulsory collective bargaining in nursing care for the elderly has already led to wage increases in this area and can be seen as an improvement.
In 2019, Germany established a specialist agency for skilled labour in health and care occupations, DeFa (Deutsche Fachkräfteagentur für Gesundheits- und Pflegeberufe). It is the first point of contact for health and care providers intending to recruit international skilled staff and facilitates visa applications and the recognition of professional qualifications and work permits (the service costs

€350 per case). It also organises the selection of applicants and offers language courses (Federal Ministry of Health, 2019).

Alongside inpatient and outpatient care, live-in care also plays a role in German geriatric care system. It is estimated that there are between 300,000 and 500,000 live-in carers in Germany, mainly from Eastern Europe. In this sector, which is dominated by irregular employment, working conditions are characterised by excessive working hours and unpaid on-call duties.For live in carers, the working conditions are concerning, leading some stakeholders to talk about labour exploitation and to call for quality training, including linguistic skills, as well as industrial negotiation around issues such as stand-by time. Lack of language skills, unmanageable working hours, frequently changing work locations, as well as fear of authorities resulting from their insecure employment status are the reason why live-in carers may experience social isolation.

However, some placement agencies are establishing voluntary self-regulation measures. Furthermore, it should be noted that corporate self-regulation alone is insufficient to improve working conditions in the live-in care sector. State regulation and control instruments are therefore required, which do not yet exist.

Occupational health and safety

German legislation remains rather uncommitted as regards psychosocial risks in LTC sectors, while the range of prevention and mitigation measures is also relatively limited (20).

Issues such as violence in the workplace, long working hours, double shifts and poor management practices are often dealt with at company level and, in the best cases, through collective agreements[16].

In Germany, a law came into effect in 2019 to improve working conditions in the care sector (Pflegepersonal-Stärkungsgesetz). It promotes collectively agreed pay standards in care and seeks to improve work–life balance schemes and occupational health and safety measures. Germany has introduced an obligation for LTC providers to pay their workers at least the collective-bargaining level. Since September 2022, the German statutory care insurance is only allowed to conclude supply contracts with LTC providers if they comply with this regulation. Providers who do not pay wages according to this requirement are no longer allowed to perform care services that are funded by the German statutory care insurance.

Trainings and other support

As part of the reform of nursing training (Nursing Professions Reform Act - PflBRefG), a two-year joint generalist training programme has been in place since 2020. Afterwards, nursing students can specialise in paediatric or geriatric nursing or complete the generalist nursing degree. The training programme lasts a total of three years. With the generalist qualification, graduates can work in all areas. The reform is to be evaluated in 2026. Last year (2023), 33,600 nurses completed their training. Only one per cent of them completed a specialised degree. 99 per cent of students opted for a generalist qualification. In 2023, only 300 graduates obtained a degree specialising in healthcare and paediatric nursing and only 100 in elderly care.

Since 2020, the Nursing Professions Act has introduced a primary qualifying degree programme in nursing for the first time. However, less than 2% of all people in nursing training are currently studying. By way of comparison: in 2021, around 61,500 people in Germany began training to become nurses. This compares to 1,100 students with a career goal. Academic nursing training has not yet become established and is to be made more attractive by providing nursing students with a salary. According

[16] Data from Germany indicate that over half (52%) of home care workers report that their work has become more burdensome and one-third (34%) report that conflict situations with the care receiver have been more frequent since the COVID-19 crisis emerged (Horn and Schweppe, 2020).

to the "Nursing Studies Reinforcement Act (PflStudStG)", nursing students will in future receive appropriate remuneration for the entire duration of their studies. The financing of the practical part of university nursing training has been integrated into the existing financing system for vocational nursing training. Since then, it has been a dual study programme. However, the level of salary is not regulated by law. This is determined by the respective practical training company. It varies depending on the size of the company and the federal state. It is currently between €850-1,400 per month. The law came into force in 2024.

In order to relieve the generally poor staffing situation in the care sector, the law also makes it easier to recognise foreign qualifications. In particular, the scope and required form of the documents to be submitted are regulated by federal law. In addition, the possibility was created to waive a comprehensive equivalence test and instead complete a knowledge test or an adaptation course.

Since 2022 in Germany, nursing staff has been given more responsibility, and they will be able to prescribe nursing aids make more independent decisions in home care.

With the Nursing Staff Reinforcement Act (2019), the health insurance funds are now obliged to provide more than 70 million euros a year specifically for services to promote occupational health in hospitals and care facilities. This can also include the promotion of resilience of LTC-worker.

In this context a health insurance company in Germany (AOK Federal Association) started an initiative (Pflege.Kräfte.Stärken) for the nursing sector, outpatient services as well as care facilities and hospitals. With a wide range of offers, for example to strengthen resilience, stress management, healthy shift work or management culture, the AOK supports care facilities and hospitals that want to strengthen the resources of their employees and improve their work structures. In the second pandemic year of 2021 alone, the AOK community supported over 1,300 care facilities nationwide, occupying a leading position among the statutory health insurance companies.

Protecting their rights

Good working conditions in nursing are crucial for securing skilled professionals and ensuring the care of those in need. In recent years, the German government has supported the improvement of these conditions through various measures and projects, focusing on seven key areas:

1. Compatibility of family, care and work: Caring professionals need flexible work schedules, reliable shift planning, and childcare options. A funding program supports facilities financially in implementing these measures, and the “Care Support and Relief Act (PUEG)” enables the regular financing of contingency plans like float pools. The GAP project assists care facilities in improving working conditions for their staff.

2. Attractive pay: Fair pay is essential for the attractiveness of the care profession. Since September 2022, long-term care facilities are required by law to pay at least the tariff wage. From May 2024, minimum wages for registered nurses will rise to €19.50 and for care assistants to €15.50 per hour, with further increases planned for 2025.

3. Good staff adjustment: Staffing levels should reflect the actual care needs. Since July 2023, legally defined staffing ratios for nursing facilities have allowed for the hiring of additional care professionals. In hospitals, the Nursing Staff Regulation 2.0 (PPR 2.0) aims to improve staffing conditions. Additionally, the government supports the fair and ethical recruitment of care professionals from abroad.

4. Participative leadership models: Modern leadership styles that are collaborative and supportive play a key role in job satisfaction and retention in the care profession. It is already mandated by law that

care professionals in leadership roles must undergo relevant training, although requirements vary significantly across federal states.

5. Strengthening the care profession: The academic advancement of the care profession, along with continuing education and increased autonomy, enhances both the attractiveness and quality of nursing care. The government is committed to empowering care professionals, allowing for greater independence in care processes to make the profession more appealing.

6. Digital Work Environment: Care facilities can receive grants for digital and technical equipment as well as training. One-time grants of up to €12,000 are available through 2030. These initiatives are part of the digitalization strategy in healthcare and aim to overcome barriers and develop innovative solutions for practical care.

7. Active promotion of career entry and retention: Improved working conditions, adequate staffing, and fair pay are crucial for returning to the profession. Specific projects like "Modern Men Do Care" aim to make care more attractive to men. Additional funding programs support the balance of care, family, and work and provide strategies for retaining and attracting care professionals.

Informal carers

Valuing informal carers and promoting their rights

In Germany there is no formal definition of informal carers in general. Only in the law on social long-term care insurance (SGB XI) is there a definition of informal caregivers (Pflegeperson) who have certain entitlements to LTCI under this law: persons who provide non-professional care to a person in need of care within the meaning of that law in their home environment with at least ten hours per week. This definition is not limited to relatives but includes all informal carers. Informal carers who meet these criteria are entitled to social security benefits: these are benefits relating to pension, accident and unemployment insurance.

Combining work and care

Legislators recognise the particular burden placed on working family carers and have developed laws to improve the compatibility of care and work, which have now been in force for 10 years and have undergone a number of reforms. In March 2024, the 10th edition of the Caregiver Leave Act (PflegeZG) and Family Caregiver Leave Act (FPfZG) was published. The laws are briefly summarised below.

(1) Short-term absence from work and carer's grant

Short-term absence from work

Close relatives can stay away from work for up to ten working days in order to organise needs-based care in an acute care situation or to ensure the provision of long-term care in this time.

Wage compensation benefit

Informal carers who take a short-term absence from work are entitled to a care's grant. This can be applied for from the care insurance fund of the person in need of care.

(2) Caregiver leave

Complete or partial release from work for up to six months

Employees can still step out of work fully or partly for up to six months in order to care for a close relative in need of long-term care at home.

Interest-free loan

During this time informal carers are entitled to an interest-free loan to support their living expenses. The loan must be repaid in full at the end of the care period.

Up to three months to provide support in the last phase of life

It is also possible to take time off work partly or completely for up to three months to be with a close relative in the last phase of life.

(3) Family caregiver leave

Partial release from work for up to 24 months

If close relatives are in need of long-term care for longer, reconciling care and work can become a challenge for many families. Against this background, a legal claim to partial release from work for up to 24 months and an interest-free loan was introduced. No full release from work is granted here. The weekly working time in addition to care must be at least 15 hours.

Interest-free loan

Informal carers are entitled to an interest-free loan to support their living expenses. The loan must be repaid in full at the end of the care period.

All leave options under the Caregiver Leave Act and the Family Caregiver Leave Act can be combined. However, they must follow on seamlessly from one another. Their total duration is a maximum of 24 months.

By and large, the laws are failing to have an impact, as hardly anyone makes use of them (760 people from 2019 to 2020) and it is not poverty-proof, as there is no real wage replacement benefit.

In addition to legislation, there are workplace initiatives or HR policies, which are not mandated by law, yet envisaged, as many employers recognise the importance of supporting the mental health of working carers. These initiatives range from: flexible working arrangements, extra paid leave and time off, employee assistance programs, mental health support services; training for managers and colleagues on caring; work-life balance initiatives.

Financial support

There is no financial support for informal carers. The care recipients can receives a care allowance from care level 2 if they waive benefits in kind. The transfer of the care allowance to the informal carer is voluntary and is based exclusively on an intra-family agreement.

The amount of the care allowance (Pflegegeld) depends on the level of care needed by the care recipient and is determined by the care insurance assessment.

Carers who are not yet fully retired are entitled to free social insurance. The following conditions must be met:

(1) Health and long-term care insurance: There is no general health insurance for informal caregiver. Anyone who is not co-insured free of charge through another family member (e.g. spouse) must take out voluntary insurance. The standard contribution must be paid. This can be reimbursed on application to the care insurance fund of the person in need of care.

(2) Pension insurance: For informal carers, the care insurance of the person in need of care pays contributions to the pension insurance for the entire duration of the care activity if the carer has at least care level 2, the care is provided at home for at least 10 hours a week on two days (not for gainful employment) and the carer is employed for a maximum of 30 hours. The pension insurance contribution is reduced if the main carer uses professional help (e.g. from a care service).

(3) Unemployment insurance: For informal carers who leave their job to look after relatives in need of care, the carer's long-term care insurance pays the unemployment insurance contributions for the entire duration of the caring activity, if the carer has at least care level 2, the care is provided at home for at least 10 hours a week on two days (not for gainful employment) and the carer was subject to unemployment insurance immediately before starting the caring activity.

(4) Accident insurance: Informal carers are covered by statutory accident insurance free of charge for the duration of their care. This applies to all activities that are recognised as caring activities in the care insurance, as well as assistance with housekeeping. Accident insurance cover is also provided for the direct journey to and from the place of care if the person in need of care lives in a different home to the carer.

Other support

People in need of care are entitled to short-term, day and respite care.
Respite care is granted for up to 6 weeks per year if the registered informal main carer is unable to attend. The costs of replacement care by a professional service are then covered. Replacement care by other informal carers is not covered.
Short-term care is granted for up to 8 weeks per year if a person in need of care requires full inpatient care for a limited period of time. This is often the case after a stay in hospital or when home care must or should be suspended for a certain period of time. In reality this can hardly be honored because there are hardly any such places available.
People in need of care are also entitled to funding for day care depending on their level of care. However, the supply is so low that only around 3% of all people in need of care can take advantage of this. This means that most informal carers do not have access to this very important relief option for balancing work and care

Legal basis for care counselling

Since the Long-Term Care Development Act of 2009, the legal entitlement to free professional information, counselling and training has been laid down in the Eleventh Social Code (SGB XI). This means that all people in need of care who receive benefits in accordance with SGB XI and their carers have a right to:
- Care counselling in accordance with Section 7a SGB XI
- Care courses and care training in accordance with Section 45 SGB XI
- Counselling visits in accordance with section 37.3 SGB XI (mandatory from care level 2)

Care support centers are central points of contact for people with statutory care insurance and their relatives for questions, planning and assistance relating to care. The support centers are available in different regions, but unfortunately not in all federal states. The creation of local care support centers is regulated in Section 92c of the Eleventh Book of the German Social Code (SGB XI)

Section 45 of the Eleventh Book of the German Social Code stipulates that care insurance funds or other organisations must offer **free care courses and care training** to family carers. The aim is for carers to learn the basics of care. As part of these care **courses**, sometimes they also learn how to prevent **physical and mental stress** during care that could potentially impair care. Once family carers have completed the care courses, they should have the necessary knowledge to carry out the caring role either independently or partially.

The German Social Security Code (§45 SGB XI) stipulates that the care insurance funds are obliged to offer -and bear the costs- training courses to any interested carer. It also makes possible to support "self-help groups, organisations and contact points that have set themselves the goal of supporting people in need of long-term care, people with significant general care needs and their relatives". (SGB XI § 45d).

Beyond legislation and policies
The federal **Care Hotline** offers people in need of care and their relatives support in advising and organising care. People seeking advice receive all the essential information on care and help in old age. The care hotline also cooperates with the telephone counselling service, the Alzheimer's hotline and the federal working group of crisis hotlines. In addition, people in need of care and caring relatives can contact the counselling service directly in stressful and critical situations. Various initiatives at community level target carers' wellbeing. For instance, local communities often have support services in place to promote social inclusion among vulnerable groups, including informal carers. There are also caregiver support networks that provide carers with information, resources and peer support. Various organisations and healthcare institutions organise psychoeducational workshop and training sessions for informal carers, covering topics such as stress management, self-care strategies and understanding the emotional impact of caring. On International Day of Care (12 May), awareness campaigns are organised, in a collaborative way by government agencies, NGOs, healthcare providers.

Italy

LTC framework
Overview
In Italy the supply of long-term care (LTC) has traditionally been characterised by a highly selective public services system set against the considerable capacity of family (especially women) to internalise caring functions (Eurocarers). Italy is a 'familistic' country. The Italian LTC public system is organised around two institutional pillars. The most important one is the 'attendance allowance' (CA / *Indennità di accompagnamento*), a cash allowance programme for individuals with severe disability, which is run by the National Institute of Social Security (INPS) and financed through general taxation. The CA amounts to around €500 per month, with no variation in terms of the level of needs and no accountability as how it is used. The second institutional pillar is made of LTC in kind or in cash programs, provided by municipalities (for social care) and regions (for health/nursing care). Generosity and eligibility rules vary widely across regions (and municipalities), creating disparities and unequal coverage. Some analysis indicated the existence of different territorial welfare models in this country: the cash-for-care model in the Centre-South, and the residential care model in the North. The Italian LTC system for older people appears primarily cash-based, rather than focused on services. As the recipient of the attendance allowance is free to choose how to spend it (with no ex-post monitoring), the households tend to use the cash transfer to buy (oftentimes on the black labour market) the services of family assistants (in jargon called "badanti"), (often) migrant live-in carers. The system is strongly based on informal family support and migrant care workers, often with irregular contracts. A recent Enabling Law (Legge Delega n. 33/23rd March 2023) has the ambition to lead to a full restructuring of the LTC system, for instance by creating a national mechanism to coordinate services and benefits currently provided at regional and municipal level, by establishing one single entity to evaluate the access to services. The legislation has been considered an important first step in the right direction, even though it has been noted that some issues are not adequately addressed, mainly the funding of the programs, the professionalisation of "badanti" and the creation of incentive mechanisms for families to use formal care.
Funding
The Italian LTC expenditure is mostly financed with public funds (70% funded by government, while the remaining is paid out of pocket by the user). However, because most of the homecare is provided by informal carers, a proper accounting of the total cost of LTC in the economy should include the opportunity cost of informal care (in terms of forgone working opportunities).
Gender roles in care
Informal long-term care is largely borne by daughters and by daughters-in-law, typically with a low educational level. This informal care provision is complemented by a large irregular market for care workers, mainly immigrant women (family assistants, also called 'badanti'). More than 85% of the formal home care workers are women, while women providing informal care amount to 61.8% of the total number of caregivers. The whole system and the resources allocated to non-self-sufficiency encourage a model that sees "women who replace other women in an activity that confirms itself as a female-only destiny", as Sgritta writes (2009).

LTC workers
Employment and working conditions
The care services sector, including residential and home-based care, is not very developed, resulting in a relatively small, estimated number of people working in this field. However, the estimated number of care workers is close to 400,000, with the majority being women. The main profile of professional care worker in Italy who can work in both nursing homes and home-care settings with VET qualifications is the Medical-assistance Operator (Operatore Socio Sanitario, OSS), which has health-related training and preparation. In addition to formally employed care workers, there are also family assistants, so called "badanti" (around 1.000.000). Almost half of them are without a regular employment contract - or with a contract that underestimates the actual working hours' commitment (Barbera et al., 2017). Unions have provided domestic workers with a collective agreement framing their working conditions. The minimum wage levels indicated in the collective labour agreement are on average lower than the minimum levels in other sectors.
Occupational health and safety
Working conditions in the formal long term care sector are often problematic, leading to high turnover rates, staff shortages, and risks to physical and psychological health, such as burnout. In relation to family assistants ('badanti'), it has been noted that the 'emotional dissonance' between emotions and feelings and possibility to externalise them can foster burnout phenomena (Brotheridge & Grandey, 2002; Scottese, 2009; Facchini, 2018). Research has also pointed out to the loneliness of family assistants, who find themselves living in a country with a different language, different habits. Moreover, these women have left their own families in their country of origin to help other people's families. This can create distress.
Trainings and other support
Training courses are among the first initiatives in favour of family assistants. They are organized by municipalities with the help of commercial or non-profit organizations. Their contents range from rather basic subjects such as Italian language and Italian cooking to medical knowledge and social know-how such as how to interact with general practitioners, public offices etc. Courses differ in general organization, in the amount of total lesson hours and in the degree to which they give the opportunity to obtain training credits for other professions. They are always free of charge. Each region sets the basic parameters of these courses because there are no shared standards or common definitions at the national level of what training for personal assistants should consist of. It is crucial to raise the level of professionalism of the family assistants currently employed in the family environment. The recent Enabling Law (Legge Delega n. 33/23rd March 2023) seeks to go in this direction, as it sets out to introduce training standards for family carers to enhance their professional skills. However, these won't be set as entry requirements for the profession.
Protecting their rights (including of vulnerable groups)
Italy was the 4th ILO member State and the first EU member State to ratify the ILO Convention on domestic workers which seeks to improve the working and living conditions of tens of millions of domestic workers worldwide. Yet, in the collective agreement for personal assistants, the sick, injury and maternity leaves are shorter than in other sectors agreements.

Informal carers
Valuing informal carers and promoting their rights
At national level, the recognition of informal carers is recent. The 2018 Budget Law (Article 1, paragraph 255 of Law 205/2017) established the Family Caregiver Fund [17] and formally identifies and acknowledges the family caregiver as the "individual who helps and looks after certain people". Several proposals of law - such as Draft Law no. 1461 "Rules for recognising and supporting family caregivers" - have been submitted to the Italian Parliament, but they are still under review. Informal carers are recognised and defined also in the regional laws of 13 out of 20 Regions and 2 Autonomous Provinces so far. Emilia-Romagna was the first Italian Region to recognise informal carers, with a regional law introduced in 2014. Informal carers are defined 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".
Combining work and care
The Italian care leave system is relatively substantial and developed. It offers a combination of both short-term and longer leave provisions (Law 104/92): short term leave (3 working days of paid leave per month); longer leave (up to 2 years of paid leave) in order to care for a seriously disabled child or relative. To access to this type of long leave, the informal carer has to live under the same roof as the person cared for. Only public and private employees are entitled to these types of care leave. The self-employed and those employed in domestic and household services are excluded. Law No 183/2010 introduced the principle of "sole carer", which means that in a household, only one worker can attend the needs of a severely disabled person. Law 104/92 enable carers working in organisations having multiple branches, to choose their workplace to be closer to the person they are assisting. Informal carers can activate the 'Ape Sociale', an early retirement option, in some cases[18]. During the Covid-19 emergency period, workers with care responsibilities were entitled to work remotely. Currently, the granting of remote working is no longer mandatory, but can be granted as a priority by the employer for employees with care responsibilities. Through Article 18, of Law 81/2017, it is decreed that both public and private employers, once the opportunity for remote work has been established, must give priority (among others) to requests for agile work from male and female workers who are caregivers of family members with an established severe disability or who have children with disabilities.
Financial support
Carers' allowances (bonus caregiver) are foreseen by the vast majority of Italian regions, although amounts, criteria and regulations varies. At national level, there is a financial support for people who have caring needs (the already mentioned 'companion allowance') which is often used also to contribute to the costs of caring but in this case the actual beneficiary is not the carer but the care-recipient who can then decide how to use the funding they receive.
Other support

[17] This fund offers financial aid to Regions for laws that aim to acknowledge the social and economic worth of care given by family caregivers. Moreover, the 2021 Budget Law established a "Fund to Boost Non-Professional Caregiver Activity". The Ministry of Labour and Social Policies manages this, with an annual budget of €30 million for 2021-2023.

[18] If they have been assisting a spouse or first- or second-degree relative for at least six months; or if the person with the illness or disability has parents or a spouse who are at least 70 years old and have a disabling disease.

Respite care is part of the minimum standard offer of social services that must be provided at national level (comma 163 law n. 234/2021). The intensity and availability of the services, as well as the ways in which it is provided, vary at the local level.

The government introduced provisions to support companies offering to their employees' welfare-related benefits which might also include psychological support, peer support groups and similar activities. In this context, some companies are now using these schemes to offer targeted support services for their employees who are also carers.

A recently approved policy aiming to broaden access to professional psychological counselling free of charge (so called "psychologist bonus") might have among its beneficiaries informal carers as well.

Moving to the regional level, different form of support are envisaged. The Emilia Romagna Regional law (n. 2, 28th March 2014) includes training for informal carers, recognition of competences acquired as a result of caring (in view of looking for opportunities on the job market), psychological support, agreement with employers for flexibility at work, as well as campaigning activities and agreements with insurance companies to cover accidents of responsibility during the exercise of caregiving functions.

Beyond legislation and policies

There are several initiatives promoted by NGOs, however they are not consistently offered at national (or even regional) level, depending very much on the availability of funding, human resources and projects at local level. In Emilia Romagna region, every year, in the period between April and May a series of events and initiatives are organised as part of Caregiver Day, to highlight the daily commitment of all family caregivers in the community and to create a space to raise awareness of this important figure and to promote all the services that public health services, local authorities, NGOs and voluntary associations in the area are able to offer for people who act as informal caregivers. Friuli Venezia Giulia Region has been doing the same in the past 2 years but in October (on occasion of European Carers Day).

Some universities are starting to introduce projects and arrangements to support students with caring responsibilities, for example by considering them the same as working students.

The Netherlands

LTC framework
Overview
The Dutch health care system has many characteristics of a conservative-corporatist welfare model, mainly based on public, obligatory health care and long-term care insurance systems. Within the health care system so called controlled market-mechanisms are in place with competition between health care insurers and providers. The long-term care system operates by-and-large according to a geographically distributed responsibilities of public heath care insurers. Social care, is a decentralized social democratic and tax based system under the responsibility of 342 municipalities. Amongst others, support for informal carers and volunteers mainly falls under this regime. All three systems have in common that solidarity and access for all is a basis principle. Further, the very large majority of providers operate on a private not-for-profit basis. The Netherlands has a long tradition of public long-term care provision. The Dutch system provides universal access to a wide range of long-term care services, which not only include good quality nursing home care, but also extensive home care and social assistance for citizens who require care due to illness, disability, or old age. The Dutch LTC system is divided into three acts: the *Social Support Act* (WMO), the *Health Insurance Act* (ZVW) and the *Long-Term Care Act* (WLZ). The WMO decentralized LTC (mainly social care) to municipalities, aiming to strengthen the roles of social networks in the provision of care, and supporting citizens to continue participating and living in society. Entitlements include home help, transport facilities and house adjustments. Only when their social networks are insufficient or incapable of providing care is an individual eligible to receive formal care, thereby allowing publicly funded support to become available. The ZVW offers home nursing and personal care for citizens who require care for less than 24 hours per day. The WLZ provides care to the most vulnerable people of Dutch society. With strict eligibility requirements, only someone who requires 24-hour supervision or care in the vicinity can receive WLZ benefits. All LTC providers are private. Most are not-for-profit organizations, and their work is publicly regulated and (mostly) publicly funded.
Funding
Care is financed by three public schemes: long-term care insurance (WLZ), health insurance (ZVW), and the Social Support Act (WMO). WLZ covers residential care (not just nursing homes, also for people with intellectual disabilities), but also (increasingly) care at home for people who require 24-hour supervision. ZVW pays for nursing and personal care provided at home, and the Social Support Act makes municipalities responsible for organizing and financing assistance and social support for people living in their community. Each of these public schemes covers the entire population, and enrolment in the social insurance schemes is mandatory. Eligibility for care is based on needs and strong regulation ensures equal access for all. The two social insurance schemes are primarily funded through earmarked insurance premiums, and the Social Support Act is fully financed through general taxation. Cost sharing is relatively low. Private LTC is virtually absent. This universal and comprehensive coverage of long-term care expenditures comes at a cost: in 2022, total long-term care expenditure in the Netherlands stood at 3.8% of GDP, the highest value in the EU

by a wide margin. Costs are expected to increase substantially[19]. The 2024 country specific recommendation – in the framework of the European Semester- suggests that there is scope for improving the fiscal sustainability of long-term care by reducing inefficiencies in the system without compromising its high quality and coverage[20]. It is also suggested to address sector-specific labour and skills shortages, including by tapping into underutilised labour potential, such as people with a migrant background or those working in part-time employment. Furthermore, government policy aims to increase collaboration between formal and informal care (including volunteer support) with a focus on participation and sharing care.

Gender roles in care

No legislation or policy specifically describes targeted measures to overcome traditional gender roles and to actively promote the equal sharing of caring responsibilities. There are campaigns or studies with those ambitions, such as 'Mannen en mantelzorg, niet te missen!' ('Men and informal care, not to be missed!") by Movisie: a publication consisting of literature review combined with interviews with men and experts, with the aim of breaking stereotyping and traditional perceptions and role patterns, also within the labor and care domain. Women are more likely to provide informal care than men and are also more likely to be heavily burdened. The strain they experience has also increased. In 2012, for example, 15 thousand women aged 55 to 60 with parents aged 80 and over were heavily burdened by informal care, versus 27 thousand in 2022. In this period, the total number of women burdened by informal care rose from 53 thousand to 78 thousand[21].

LTC workers

Employment and working conditions

Collective bargaining is common at sectoral and company level. Close to 100% of the LTC workforce is covered through collective agreements. Most LTC workers are covered by a 'nursing homes and home care' agreement (others by agreements in 'disability care', 'mental healthcare', 'youth care', 'social work, welfare and social services'). The collective agreement for residential and home care stipulates that time spent travelling between clients should be counted as working time.

Since the outbreak of the COVID-19 pandemic, wages for nurses and some groups of personal care workers were increased by 1.5% in addition to an increase of 2.5% of all wages in the care sector, as a measure to boost social recognition of LTC workers.

On a national level, nursing home personnel were included in the initiative to provide a bonus for healthcare workers to acknowledge the additional efforts they made to provide care as best as possible in very difficult circumstances (Rijksoverheid 2021). However, the practical implementation of the bonus, where many care workers were excluded or never received the bonus at all, probably caused the opposite of what was intended (van Essen 2021).

[19] The 2024 Ageing Report projects that this figure will increase by 1.0 pps by 2040 and 1.9 pps by 2070.

[20] An example of such inefficiencies is that municipalities, which are the providers of home care in the Netherlands, have incentives to shift responsibility for patients to the residential care sector instead of continuing to provide home- and community-based care to them as long as possible. In addition, inefficiencies in the long-term care system could be addressed, for example by using more digital and innovative solutions or investing in prevention to delay the onset of long-term care needs and the dependence on support for daily living activities.

[21] https://www.cbs.nl/nl-nl/longread/statistische-trends/2024/vader-en-moeder-op-leeftijd/6-conclusie

Occupational health and safety
According to the survey conducted by the Dutch Association of Nursing Staff, 74% of nursing staff indicated they experienced higher levels of pressure on their mental health due to the pandemic (Kruse et al. 2020a). Many nursing homes established "helplines" for nursing staff to address any problems healthcare workers were facing and to share ways to take care of themselves and others (Gerritsen and Voshaar 2020). Some nursing homes asked their psychologists and social workers to provide mental health support to care personnel. From the experiences during and challenges from the first wave, the Dutch Ministry of Public Health, Welfare and Sports and the LTC sector drew some important lessons (AWO-ZL 2020; VWS 2020). One of the most important lessons learned was the importance of focusing more on supporting the mental health and well-being of nursing home staff in times of emergencies. The provision of mental health support offers nursing home personnel the opportunity to seek help and openly speak about the stress they are facing (VWS 2020).
Trainings and other support
There are only formal training requirements for medical and paramedical staff for which registration is mandatory, i.e. doctors, registered nurses and pharmacists, psychotherapists, physiotherapists, medical psychologists. Various other job titles are registered and legally protected and go along with educational requirements, such as auxiliary nurses in LTC. Providers need to ensure that their workers are sufficiently qualified for the tasks that they have been assigned and this is checked by the Healthcare Inspectorate.
Protecting their rights
Freedom from discrimination, adverse social behaviours, sexual or other forms of harassment are envisaged in legislation valid for the whole population, not just for LTC.
Informal carers
Valuing informal carers and promoting their rights
The long-term care act (WLZ) defines an informal carer ("mantelzorger") as: "a person who provides care that results directly from an existing social relationship between people and which takes place outside a professional or commercial framework". The Social support act (WMO) defines informal care ("mantelzorg") as: "Assistance for self-reliance, participation, sheltered housing, social shelters, youth assistance, the upbringing and growing of young people and care and other services as referred to in the Health Insurance Act, which arises directly from a social relationship between persons and which is not provided in the context of a helping profession." The Social Support Act (WMO) makes municipalities responsible for providing support to informal caregivers. Municipalities offer different forms of informal care support: information meetings, courses, training or informal care support centers. The Social Support Act (WMO) explicitly aims to promote the provision of informal care, Only when their social networks are insufficient or incapable of providing care is an individual eligible to receive formal care[22], thereby allowing publicly funded support to become available (Alders and Schut 2019; Kroneman et al. 2016).

[22] The Act states how a person is eligible for individual support 'when [someone's] own strength, usual help, informal care or help of others does not allow him to be sufficiently self-reliant or participate as a result of impairment, or chronic psychiatric or psychosocial problems'.

It is important to stress that, even though municipalities and care offices will always take into account the possibilities of informal care in a given case, this does not make informal care compulsory.

Combining work and care

The Employment and Care Act (Wet arbeid en zorg, Wazo) gives employees the right to take leave to care for a sick partner, child or parent, siblings, grandparents, grandchildren, housemates or acquaintances. The Wazo Act provides short-term care leave, calamity leave and long-term care leave.

- Short-term care leave gives an annual right to 10 days of care leave if the employee works full time (40 hours/week). It can be taken over several spells during the year, so long as it does not exceed the maximum 10 days. During this leave, 70% of the wage is maintained and paid by the employer. The percentage may be higher if this is arranged in a collective agreement or other employer regulations.
- Calamity leave: in the event of unforeseen circumstances, such as a family emergency or illness of a loved one requiring urgent care. This leave can last from a few hours to a few days, depending on the situation. The employer continues to pay salary during the leave.
- Long-term care leave gives people the right to care on a more substantial basis when needed by the care recipient. The maximum duration of long-term care leave is six times the weekly working hours of the employee concerned (so, in the case of a full-time contract for 40 hours/week, the maximum is 240 hours or 30 days). Long-term care leave is unpaid, unless there is a collective agreement or other regulation in which employers have made their own decisions about payment. The long-term care leave has to be taken in one go.

People who are self-employed do not have access to short-term or long-term care leave.

The Flexible Working Act (Wet Flexibel Werken) is not specific for carers, but can provide flexibility for balancing work and caregiving responsibilities. The employee can ask the employer to adjust their working hours, workplace, or schedule for both fixed and varying periods, provided they've been employed for at least 26 weeks prior to the requested change, except in unforeseen circumstances.

Financial support

While there may not be a specific "carers' allowance", various forms of financial assistance and support are available to help alleviate the financial burden on informal carers. These forms of financial support may vary depending on the municipality and individual circumstances.

Some municipalities offer allowances or subsidies specifically targeted at informal carers to help cover the costs of caregiving-related expenses, such as transportation, home modifications, or assistive devices.

Informal carers may be eligible to receive a personal budget (persoonsgebonden budget or pgb) to hire professional caregivers or purchase services that support their caregiving responsibilities. Sometimes this personal care budget is also used to 'hire' informal caregivers. The pgb allows carers to have more control and flexibility in arranging care according to their needs and preferences. Personal budget payments differ from wages; in that they do not cover social or pension contributions. However, PGB payment is taxable income. Also, this payment can be included in the sum to calculate the amount and duration of unemployment benefits.

Informal carers may be eligible for various tax deductions or benefits to help offset caregiving-related expenses. For example, they may be able to deduct certain healthcare expenses or claim tax credits for specific caregiving-related costs incurred during the tax year. Besides, informal carers may qualify for double child benefit if they care for a child with intensive care needs. This benefit is provided by the Sociale Verzekeringsbank (SVB).

Informal carers who are unable to work due to their caregiving responsibilities may be eligible for social security benefits, such as sickness benefits (ziektewet) or disability benefits (WIA), depending on their circumstances and the extent of their caregiving duties.

Other support

Policies and legislation related to respite care include the Health Insurance Act (Zvw), Long-term care act (Wlz), Social support act (Wmo), and Youth Act (Jeugdwet).

Most health insurers have included a certain number of days for respite support in the supplementary insurance packages (not the basic health insurance). In other cases, respite support is paid for out of the Wlz, if the person being cared for receives care under the LTC Act (Wlz), or out of the Wmo/Jeugdwet, if s/he receives care under these laws. There are no regulations as to the amount of respite support that carers should be able to rely on. With these acts, the national government wants to support municipalities in paying attention to the well-being of informal carers. Respite care can take many forms such as light respite care, day services, in home or institutional care.

Another measure of support consists of an exemption from Job Interviews when Receiving unemployment benefits. Carers who are receiving unemployment benefits may be exempt from the requirement to attend job interviews or actively seek employment, provided they meet certain criteria. This exemption recognises the additional responsibilities and commitments of carers and acknowledges that their caregiving duties may limit their availability for work. It ensures that carers are not unfairly penalized for prioritizing their caregiving responsibilities while receiving financial support through unemployment benefits.

Beyond legislation and policies

MantelzorgNL is a national organization that provides information, support, and resources for informal carers. They offer various services, including a helpline, online forums, and training courses for informal carers. MantelzorgNL also initiated the yearly 'Dag van de Mantelzorg' ('day of informal care') to raise awareness and thank informal carers.

There are awareness raising campaigns in relation to informal carers, as well as specific, vulnerable groups of carers, such as young carers (National Young informal caregiver's Week and Campaign 'Meer dan je denkt' - 'More than you think').

Many municipalities in The Netherlands have local support centers or caregiver support organisations that offer a range of services for informal carers. These services may include support groups, counselling, and practical assistance with navigating the healthcare system.

Slovenia

LTC framework
Overview
Slovenia, a former socialist country, transitioned to a hybrid welfare model after gaining independence. This model combines conservative-corporatist and social-democratic elements from Esping-Andersen's typology (1990). The State remains the primary provider of welfare services, with compulsory social insurance schemes playing a crucial role. However, care policy is characterized by dualisation: childcare is highly defamilialised, while older people care can be categorized as familialism by default, in which the welfare state's support is minimal, and families are the main providers of care. Additionally, there has been significant private, for-profit development in the older people care over the last 20 years (Hlebec and Rakar, 2017; Filipovič Hrast and Rakar, 2021; Rakar et al., 2024). On 21 July 2023, the National Assembly of the Republic of Slovenia adopted the Long-Term Care Act (ZDOsk-1). The aim of the Act is to regulate the field of long-term care, placing the individual in need of care at the centre of its consideration, aiming to preserve their independence and provide personalised care. The law describes, among other things, the right to home care, residential care, option of an employed family member or a cash benefit, e-care services and services to maintain and enhance independence, which act as a preventive measure and enable the individual to remain in the home environment for as long as possible. Implementation of the ZDOsk-1 started in 2024. Prior to the adoption of the LTC Act, different LTC areas were regulated by different acts: the Social Assistance Act, the Healthcare and Health Insurance Act and the Pension and Disability Insurance Act. The LTC Act now unites various services under one act. It defines non-monetary and monetary rights. The non-monetary rights are residential care, community care and an employed family carer. The Health Insurance Institute of Slovenia will deal with monetary rights. The Association of Social Institutions of Slovenia emphasizes that in its current form, the LTC Act does not fully ensure better and more accessible services for users. Before the implementation of the right to long-term care, it is necessary to adopt some key regulations to ensure that users actually receive all the services they need at the moment they need them. As not all regulations have been adopted yet, it is still impossible to reliably predict whether users will actually receive the promised services and whether they will pay less. This is supported by the analysis provided in the 2024 Country Specific Recommendation, in the framework of the European Semester. The recommendation stresses that the implementing acts - still pending- need to be adopted swiftly to ensure a coherent regulatory framework and provide sufficient time for stakeholders, as the implementation of the new LTC law is already facing headwinds, in particular pervasive labour shortages[23].
Funding
The LTC Act establishes a budgetary source of funding, and it also introduces a compulsory LTC insurance. All specifications of the insurance will be set out in another act in the next years. Currently

[23] The country specific recommendation stresses that Slovenia encounters obstacles in securing an adequate number of staff in order to apply the new long-term care (LTC) law effectively. At entry points to LTC, which are critical for evaluating individuals' eligibility for care, there is a specific shortcoming of staff, in particular, understaffing and a lack of expertise. The efficient and effective functioning of the newly established LTC system will require further investments, beyond the Recovery and Resilience Plan, in both infrastructure and human resources for all types of care offered (institutional, community, day care).

the long-term services in residential care homes are covered by Health Insurance Institute of Slovenia (for health services) and out of users' pockets. The right to long-term care in an institution will come into force in December 2025 and financing should be clearly defined by that time.
According to the data from December 2022 (Association of Social Institutions of Slovenia), institutional care for older people is in majority paid by residents themselves (or their families, other liable obliges, and municipalities) – 53 %, 37 % is paid through health insurance, 10 % through other sources. Funding of LTC services according to the LTC Act will come into force in the following years and it is still not clearly set.

Gender roles in care

The topic is an emerging area and it has started to appear in parts of the legislation.
On the basis of Article 15 of the Law on Equal Opportunities for Women and Men, the National Assembly adopted the Resolution on the National Programme for Equal Opportunities for Women and Men 2023-2030 on 22 September 2023. Among the key challenges and orientations, the Resolution describes the reconciliation of private and professional life as an important part of family policy and at the same time a key element for the promotion of equal opportunities for women and men in society.
Women in Slovenia still do significantly more unpaid work than men. Although they are present on the labour market in almost the same proportion as men and work mostly full-time, they do most of the caring work (caring for the household, children, the elderly, the sick). The Resolution therefore identifies among the key challenges a greater role for men in childcare and other necessary care, as well as employers' support for family-friendly policies. The Resolution on the National Programme for Equal Opportunities for Women and Men 2023-2030 identified GOAL 4: A more equal sharing of care work between both parents or partners. To achieve this, it identifies an action targeted primarily at informal carers (ACTION 4: Developing and strengthening activities and projects to improve the quality of life of older people that contribute to relieving the burden of caring work in the family or to facilitating the reconciliation of work and private life of family members and other informal carers of older people).

LTC workers

Employment and working conditions

Concerns have been raised by the Association of Social Institutions of Slovenia in that without a workforce capable of delivering services, the rights established in the LTC Act will remain mere words on paper—applying both to care in nursing homes and home assistance. Immediate comprehensive action is needed to address the acute personnel crisis in social care. This is recognised in the 2024 country specific recommendation, which states that labour and skills shortages in healthcare and LTC sectors hinder the smooth provision of services.
Slovenia is among the 9 OECD countries that have improved the remuneration of LTC workers (either permanently or via bonuses or temporary wage increases in relation to COVID-19), as a way to improve the social recognition of LTC workers.
Collective bargaining is common at sectoral and company level.

Occupational health and safety

The rights and duties of employers and workers in relation to safe and healthy work and measures to ensure occupational safety and health are set out in the Occupational Safety and Health Act. Article 7 (planning and occupational safety and health) provides, inter alia, that (2) In planning work, the employer shall take into account the mental and physical capacities of workers and shall reduce the risks arising from the workload which may affect the safety and health of workers at work. To maintain and improve the physical and mental health of workers, employers must carry out systematic, targeted

activities and measures within the framework of Health Promotion at the Workplace (Article 6., Health promotion at the workplace). Slovenia has a strong national mental health programme (MIRA) that works on several programmes on mental health promotion at different stages of life, psychological first aid, training, workplace mental health prevention and advice network on where to go for help.

Trainings and other support

The Health Care and Health Insurance Act and the Social Assistance Act both include provisions related to the education and training of healthcare and social care professionals. This law includes requirements for ongoing professional development and continuing education for workers. In some cases, certification and licensure requirements for health care workers may include mandates for ongoing education and training to maintain professional credentials. Overall, continuous education and training for LTC workers are considered essential for maintaining high standards of care and meeting the evolving needs of care recipients.

Protecting their rights (including of vulnerable groups)

Employed formal carers (formal carers in home care, care facilities, etc.) are protected by the same legislation as all employees in Slovenia - e.g. in the areas of discrimination, harassment in the workplace (under the Employment Relationships Act), violations of fundamental rights of workers, and workplace bullying (under the Penal Code), among others. There are also protocols (e.g. the Resolution against Violence against Doctors) available to health and care employees, and various protocols (e.g. the Protocol - Support for Health Care Employees, the Protocol for Addressing Acts of Violence in Health and Midwifery Care, the Protocol for the Management of Violence in Health and Midwifery Care, the Protocol for the Management of Violence against Doctors).

Informal carers

Valuing informal carers and promoting their rights

Different legislations in Slovenia refer to people who fall into the broader definition of informal carers. Yet, the definitions under the different legislations are quite narrow, subjects to very specific conditions under which person can receive certain rights and thus cover just certain subgroups of informal carers. The Long-term care Act introduces the institute of "employed family member", who is – among other requirements- a member of the family of the beneficiary who has reached legal age and has a registered residence at the same address as the beneficiary and resides there. The employed family member shall leave the labour market (or enter a part time employment relationship if the user has two family carers). Another condition for being an employed family member is the completion of a basic long term care training of 30 hours (ZDOsk-1 and 30). Refresher LTC training of 20 hours must be attended at least every three years.

The beneficiary, in cooperation with the employed family member, shall conclude a personal plan with the selected LTC coordinator, who is employed by the home-based LTC provider. The LTC coordinator employed by the home care provider shall inform the health insurance institution and the entry point of the conclusion of the personal plan. Based on the concluded personal plan, the entry point shall enter the employed family member in the register of employed family members and register him/her in the compulsory social insurance. Before the ZDOsk-1 law came into force, the institution of an employed family member already existed in a similar form under other legislation (the Social Welfare Act). The Social Welfare Act referred to the institution of family assistant, but this did not constitute an employment relationship as regulated by labour law, and therefore the family assistant was not entitled to any rights under the employment relationship (regress, annual leave, paid sick leave, severance pay on retirement, etc.). The institution of family assistant was re-classified to employed family member

with the entry into force of the ZDOsk-1 law. Under certain conditions, an individual in need of care can also exercise the right to personal assistance (under the Personal Assistance Act), but this is exclusive of the rights mentioned in long-term care (ZDOsk-1).
The Family Law define spousal support obligations (Family Law, Article 62: spousal support during the marriage) and parental financial support obligations. Article 185 of the Family Law defines "obligation to support parents": (1) "A child of the age of majority shall be obliged to maintain his parents to the best of his ability if they do not have sufficient means to live on and are unable to acquire such means, but for no longer than the period for which the parents have actually maintained him. (2) A child of full age shall not be obliged to maintain a parent who, for unjustifiable reasons, has failed to fulfil his maintenance obligations towards him".

Combining work and care

Thanks to the national transposition and implementation of the EU Work-life balance Directive for parents and carer, since 2023, under the Employment relationships act, employees are entitled to 5 days of unpaid care leave and the right to request flexible working arrangements.
Reconciliation of paid work and family care is frequently also a part of collective agreements. For instance, the Collective Agreement for Non-Economic Activities in the Republic of Slovenia – for public servants- specifies that an employee may be absent – up to 7 days and with the right to salary compensation - to take care of a close family member.
A legal measure that directly supports family carers in reconciling work and care exists in the form of statutory short-term or urgent absence to respond to the urgent care needs of a family member. This paid leave to care for sick family members was regulated in the 1992 Health Care and Sickness Insurance Act, which was subsequently amended several times. This leave is meant to be used to care for a sick family member who lives directly with the person (spouse and children). The leave does not apply to elderly parents and other relatives as they are not defined as 'close family members'. In terms of benefits, the leave is compensated by the employer at 80 of the person's average gross earnings for all employment in the previous calendar year. However, the compensation may not be less than the guaranteed salary. The duration of sick pay depends on the illness and is estimated individually based on a medical certificate. In general, 10 days of leave can be taken for each episode of illness per dependent family member (or 20 days for children under the age of 7 and those with special needs). In exceptional cases, the period can be extended to up to 40 days (for children under 7 and those with special needs) or up to 20 days for other close family members and, in extreme cases, up to 6 months. There are no rules limiting the duration of the annual entitlement, but only for each individual episode of leave. In the event of a child's serious illness, leave can be extended until the child's 18th birthday at the request of the paediatric council. Job security is assured in that the law requires that leave can be taken without risk of job loss; this applies to all workers in regular employment.

Financial support

Employed family carers are entitled to an allowance in the amount of 1,2 of minimal salary when providing care to one care receiver or 1,8x of minimal salary when providing care to 2 care receivers, however in order to be eligible for the allowance they must leave the labour market, provide care to individual with high care needs (4th or 5th category according to needs assessment scale of 1-5) and reside in the same household with the care receiver.
Financial support for care recipients (indirect support to informal carers) is also mentioned under the Long-Term Care Act, whereby the user can receive a fixed amount of money each month, depending on the long-term care eligibility category into which they are classified. The amount of money is intended to cover the costs of the care that the user normally receives within his/her informal network.

Other support
The Long-Term Care Act (ZDOsk-1) describes in the Article 22 (rights of the employed family member) the rights of the employed family member to: - partial payment for loss of income; - inclusion in compulsory social insurance schemes; - planned absence; and - training and professional advice. In relation to training, the current legislation in the area (ZDOsk-1) only addresses the training of a small group of informal carers who will act as employed family member. Organisations such as the Anton Trstenjak Institute and the Slovenian Association of Informal Carers are working to ensure that the training of the whole group of informal carers finds its place in the legislation. In relation to respite care, the Long-term Care Act mentions substitute care within the insured person's right to an employed family carer, for the duration of the planned absence of the family carer. The duration of the absence is set to maximum 21 days/year and needs to be coordinated in advance with the LTC coordinator. During the absence of the family carer, the user is entitled to substitute care in an institution, to long-term care at home or to a temporary cash benefit in a pro rata amount. Some retirement homes in Slovenia also offer short-term (temporary) accommodation. This is a form of all-day institutional care for individuals: who have care provided outside institutional care and need temporary institutional care because care outside institutional care is temporarily not provided (e.g. due to absence/leave of relatives, waiting for approval for medical treatment, etc.), or individuals who need a service because of an acute deterioration in health and could, with appropriate support, achieve at least partial independence and therefore would not require a long-term, full-day form of institutional care in the future. Short-term placement usually lasts up to three months. The admission procedure is set out in the Rules on Procedures for Exercising the Right to Institutional Care. This form of institutional care also supports the family in terms of relieving the burden on the family. Most of the support and help for informal carers comes indirectly (through rights and services for the people they care for). For instance, the Social Welfare Act regulates services for dependent people provided at home (e.g. measures to ensure social inclusion) which indirectly support informal carers, by relieving them of their caring role. A particularly important figure is that of a community nurse, acting as a bridge between doctors, users and relatives and implementing an advisory role for care recipient and informal carers.
Beyond legislation and policies
Informal carers are still under recognised and under supported at legislation and policy level. Many initiatives to support them takes place at civil society level. For instance, the Anton Trstenjak Institute runs the Slovenian Association of Informal Carers, which brings together carers, raising awareness of caring topics and raising the visibility of the needs of informal carers. The Association organizes various activities for carers (training for informal carers, support line, family support groups, practical you tube videos for carers, etc.), which are aimed at supporting carers in a variety of ways. Support associations and programmes for patients and their relatives are also very active in that area, as well as humanitarian organizations working in the local community.

Sweden

LTC framework
Overview
The Swedish **LTC system is decentralised** and traditionally is based on a social democratic welfare state model where the State provides for its citizens "from the cradle to the grave". This generous model however has been subject to increasing challenges in terms of fiscal constraints operating within municipalities and health care regions, together with ageing demographic trends and major challenges to recruit and retain sufficient LTC workers. At the national level, parliament and the government set out policy aims and directives by means of legislation and guidelines. The primary national legislations governing LTC are the Social Services Act (SoL) and the Health and Medical Services Act (HSL). The legislation aims to ensure that municipalities provide the necessary care services to eligible groups. The 21 regions are responsible for most of the healthcare provision, including healthcare provided in the care recipients' home and residential care facilities. Municipalities are responsible for organising and providing LTC services in care recipients' own home and residential care. Both regions and municipalities have significant autonomy to tailor services to the local population's needs. Alongside the public sector, private providers have taken up an increasing share of welfare services in Sweden. New Public Management (NPM) – the adoption of market-oriented principles and practices within public services- has transformed the traditional Swedish welfare model since the 1990s by introducing competition, efficiency measures, and a focus on outcomes. This shift has led to the **marketisation** (i.e. private for-profit provision of publicly funded care) **and privatisation of welfare services** in Sweden, putting an end to the monopoly of municipalities and regions on care services provision. In 2023, the share of private providers in social care was 21% and 20% in healthcare. Nevertheless, there are large regional differences with higher figures in Stockholm and much lower in Norrbotten, a region in the northernmost part of Sweden (Statistics Sweden, 2023). All citizens are, if needed, eligible for health and social care services (**service universalism**). Access to social care is based on a needs-assessment, as opposed to being means-tested. However, there are no national regulations on eligibility. Eligibility criteria, service levels, and the range of services provided (for both home help and institutional care) are decided locally. Cash benefits are also decided locally. Since 2000, the significant reduction in residential care availability (as result of the deinstitutionalisation process) has led to a notable increase in care provided by family and friends (**re-familisation trend**), as homecare services alone are insufficient (i.e. the cutbacks in institutional care have not been compensated for by an increase in home-help services)[24]. A **dualisation of care** challenges universalism: family care remains more common among less-formally educated individuals, while privately purchased services are still more prevalent among those families with more formal education. Specific groups in Sweden receive services under the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) and the Assistance Benefit Act (LASS). The introduction of the Personal Assistance (PA) scheme under LSS marked a milestone, empowering both people with disabilities and their families, reducing mutual dependency and enhancing social inclusion. However,

[24] The proportion of older people who received care from both home-help services and family members in order to manage their activities of daily living increased substantially during the early 2000s (Ulmanen & Szebehely, 2015). Moreover, the number of hours that relatives spend on caregiving has increased.

recently approval rates for new PA applicants have declined, and there are indications of stricter admission criteria, raising concerns about the accessibility of the PA system. Even existing PA recipients face increased scrutiny during re-assessments, heightening the risk of losing their support. The implications of such a shift would be significant both at the individual and societal levels. Individuals may be forced to rely on municipal services that may not adequately meet their needs. As a result, a large group of people with disabilities and their relatives will be exposed to **increased familial dependency and reduced agency** (Olin, Dunér & Rauch 2018).

Funding

The funding of LTC services in Sweden is a combination of public social security, private insurance, and out-of-pocket contributions. Services are largely funded through taxes, making them affordable for most residents. Users pay a user fee to the local authority. The fee is usually related to income and reflects the care required. This ensures that LTC services are available to all residents, regardless of their income level.

Gender roles in care

The goal of gender equality policy in Sweden is for women and men to have the same power to shape society and their own lives. Despite more extensive general gender equality policies in Sweden, especially with regards to parental leave (most generous in the world) and childcare- there are currently no equivalent targeted measures to actively promote the equal sharing of LTC responsibilities.

LTC workers

Employment and working conditions

In Sweden, collective bargaining and social dialogue play a significant role in improving the wages and working conditions of LTC workers. Organisations such as Kommunal (the Swedish Municipal Workers' Union) and Vårdförbundet (The Swedish Association of Health Professionals) negotiate on behalf of LTC workers. These agreements ensure that wages and working conditions are standardised and improved through regular negotiations.

However, research on care work shows that efforts are still needed to improve working conditions. Almost always experiencing physical and mental fatigue and having back pain after a shift also significantly relates to staff considerations of leaving their employment. It is important to acknowledge the extensive strain that care workers are under and the consequences it has both for the profession's status and for individual wellbeing (Szebehely, Stranz & Strandell 2017).

Occupational health and safety

Sweden has comprehensive standards for occupational health and safety, including for LTC workers. The Swedish Work Environment Authority oversees these standards, which include provisions for both physical and psychological wellbeing. Stress and other psychosocial issues at work, which can lead to various health-related problems, must be addressed as part of a systematic work environment management.

In Sweden, there are specific HR policies and initiatives aimed at improving the mental health of LTC workers. The decentralised Swedish healthcare system allows for regional and municipal authorities to tailor these policies to local needs. Efforts to enhance working conditions for LTC workers include mental health support, reflecting a commitment to worker wellbeing and quality care. Concerns have been voiced regarding whether HR policies targeting the mental health of LTC workers are sufficient. There is a call for more community-centered approaches that emphasise communication, collaboration, and support within the workplace. **The focus on individual mental health actions, rather than systemic workplace improvements, is seen as inadequate**. (Arbetsmiljöverket 2022).

Trainings and other support

The Swedish government and the Swedish Association of Local Authorities and Regions (SKR) agree on the importance of developing the best possible care and ensuring that all residents receive good, equal, and knowledge-based care regardless of where they live in the country. A particular example is the Eldercare Initiative, launched in 2020, which aimed at enhancing competence in eldercare. The Government invested 3.3 billion SEK (2.9 billion EUR) in educational support for eldercare in 2021. This investment made it possible for staff to take - during paid working hours- various competence-enhancing courses in areas such as Swedish or leadership and allows employees in eldercare to further their education to become care assistants, assistant nurses, or specialist assistant nurses. This Initiative aims to contribute to the professional development of LTC workers. In so doing, it make jobs more attractive and it improves working conditions of LTC workers. The Initiative was met with enthusiasm from both trade unions and employers, and it will be continued in 2024. Yet, according to the National Board of Health and Welfare's 2022 report, municipalities struggled to fully utilise the initiative, mainly because of staff shortages, i.e. the difficulty to release employees for training due to a lack of additional staff and substitutes.

Another relevant recent policy development consists in making the title of assistant nurse a protected occupational title. The National Board of Health and Welfare must issue a certification for staff to use the title within health and social care. Certification is believed to have many benefits: it improves working conditions for staff by clarifying the role and area of responsibility; it enhances the quality of care provided; it enhances the status and appeal of the profession.

Protecting their rights (including of vulnerable groups)

Sweden has implemented extensive legislation and policies to counteract discrimination and promote equal rights and opportunities regardless of gender, transgender identity or expression, ethnic origin, religion or belief, disability, sexual orientation, or age (1 ch. 1 §, the Discrimination Act).

Informal carers

Valuing informal carers and promoting their rights

Almost all Swedish welfare state programmes are based upon individual independence, springing from the high value attached to individual independence and the idea that family bonds should be voluntary rather than obligatory. Consequently, there is no legislation giving families the responsibility for caregiving. Sweden has a comprehensive public LTC system.

The Social Services Act states that municipalities are obliged to offer support, but it does not stipulate the type of extent of support to be offered to carers. As Sweden has a devolved government this means that the type and extent of carer support services offered in the 290 municipalities varies considerably, something that was clearly highlighted in the first National Carers Strategy in 2022.

The national Carers Strategy (2022) stated that informal care is voluntary. The person providing care, support or treatment is referred to as an informal carer (Anhörig). The definition can include both a family member and someone outside the family circle, such as a friend or neighbour.

Combining paid work and care

Compassionate care leave is provided within the framework of the National Social Insurance Act. Those who forgo gainful employment (persons under 67 years of age) to take care of a severely ill, closely related person (family, but also friends or neighbours) at home or at a care facility can receive this benefit. Severely ill refers to a life-threatening condition (it does not include care of a person with

a chronic, long-lasting condition/disability). The benefit (up to almost 80% of the sickness benefit) requires a doctor's certificate, is taxable, and is paid for up to 100 days for each cared-for person (this can be shared between more people). The allowance is flexible in that the claimant may apply for leave for part of a day, days of the week or month or postpone it for several months (if the significant other's condition stabilises) and then resume it again should their significant other become worse again. The uptake of this form of leave is nevertheless low.

Short term leave is also provided. According to the law on the right to leave for urgent family reasons (1998:209), an employee is entitled to unpaid leave from employment for urgent family reasons that are related to illness or an accident that make the employee's immediate presence absolutely necessary. The maximum length of the leave and possible compensations are mostly decided in collective agreements. Thus, leave provisions vary across the country and range from part of a working day to several days. Collective agreements may affect the definition of close relatives. Compensation for loss of earnings during the short-term leave is also mostly decided in collective agreements between national unions and employers and ranges from no payment to 100% of the normal pay. (Aldman, Sennemark, Hanson, In press).

For eligible parents with a child with profound and multiple disabilities who receives LSS (Law on Special Support and Service) they are able to apply to become a personal assistant for their child for some agreed hours following an application either to the municipality or to the Swedish Social Insurance Agency and they are paid approximately equivalent of an assistant nurse salary with other benefits. This is generally a high level of allowance than the general carers allowance or home care allowance (for more details see Aldman, Sennemark, Hanson, In press).

Financial support

There are two types of municipal cash benefits available for informal carers in Sweden. These are, however, not provided everywhere; each municipality may decide whether to provide this programme or not, and what the eligibility criteria, level of payment, etc. should be.

One allowance is the **home care allowance**, which is given on top of services provided to the care recipient (within the Social Services Act). This is a net cash payment given to the care recipient, to be used to pay for help from a family member. Each municipality has the right do decide whether to provide this programme or not, eligibility criteria, level of payment, etc.

The other benefit is **carer employment** (within the LSS legislation targeting people with disabilities). In some instances, if the care receiver is part of one of the target groups of the LSS, carers (up to 67 years) can be employed by the municipality and those paid to provide care to their loved ones. This allowance is higher than the one under the Social Services Act (carers who become personal assistants for their loved ones are paid approximately equivalent of an assistant nurse salary with other benefits). This programme is also a matter for the local municipality to decide on, i.e. no national/federal regulation exists.

Other support

The Social Services Act states that municipalities are obliged to offer support to carers. However, it does not stipulate the types of support to be provided. It follows that most of Sweden's 290 municipalities have some kind of policy/guidelines regarding informal carers. Most municipalities offer some form of carer support groups, often in collaboration with local carers associations and also individual supportive conversations- offered by dedicated carer advocates employed by the municipality. Approximately just under half of all municipalities also offer keep well/feeling well activities, e.g. group pole walking, water gymnastics, massage. Some municipalities offer approximately 10 hours of at home respite care per individual (care recipient) that are cost free. Most

municipalities offer day centres for the care recipient (older people, people with dementia) that act as a form or indirect support for carers and a number of municipalities offer short term institutional respite care and also some form of "shared care" where the care recipient stays 1 week per month in a short stay setting or residential care and the other remaining weeks at home. For people living with multiple and profound disabilities, there is a strong rights-based law in place "Law on Special Support and Service" (1993). As a result, nearly all municipalities offer respite services in accordance with LSS- generally service provision for people receiving LSS (and also their informal carer) is more generous than for people 65+ (and their informal carers).

The national Carers Strategy (2022) states the importance of providing access to information for informal carers as well as support.

Several NGOs such as Red Cross, patient organizations and Carers Sweden, among others, offer support for carers with telephone counselling, support groups and information and education. Some of the support groups and information and education sessions are carried out in collaboration with dedicated carer advocates working in the municipalities.

Upcoming policies

- The Public Health Agency of Sweden has mapped involuntary loneliness and will propose a national strategy to reduce involuntary loneliness and its consequences. The assignment must be completed no later than 1 February 2025. The project partner Swedish Family Care Competence Centre (NKA) will lobby to help ensure that informal carers are specifically addressed as a group worthy of attention within this proposed strategy.
- A major new mental health and suicide prevention strategy is underway and NKA will lobby for specific provisions for informal carers. The 2024 Country specific recommendation – in the framework of the European Semester- refers to this Strategy, when pointing out that a specific cause for concern is Sweden's comparatively high death rate due to suicide[25].

[25] According to the country specific recommendation, suicide rates have decreased in Sweden since 2005, but remain above the EU average for women. About 1 in 6 people had a mental health issue in 2019, which was close to the EU average. The most common mental health issues in Sweden are anxiety and depression, with higher prevalence among women and people on lower incomes. In a recent Eurobarometer survey, most respondents from Sweden reported that either they or a family member had encountered issues accessing mental health services due to long waiting lists and delays before diagnosis or treatment. A significant proportion of respondents said that they did not know of any good specialist.

Next steps

This Report is the first step in the work with policy analysis, evaluation and recommendations in the WELL CARE project.

The country factsheets will be further developed via a number of interviews with key informants in all 5 countries to provide more in-depth analysis as to how the named policies and legislation actually work in practice (Task 4.2, to be finalised in June 2025). Crucially, for the next steps of the project, the National Action Plans in the framework of the European Care Strategy -which had to be submitted to the European Commission by end of August but have not been made public yet- will be available. They will hopefully include references to concrete measures that Member States plan to carry out to improve the wellbeing of informal carers and LTC workers.

The country factsheets and the interviews with experts will both help inform the Country Profiles, which will include country specific policy recommendations (Task 4.3, to be published in June 2026). Recommendations at EU and international level will be the focus of a future task (4.4, to be completed by December 2026).

In this sense, the WELL CARE project will offer concrete tools for policymakers to take action, which must be driven by a strong political will. Based on the previous sections, it is already possible to identify priorities that need to be urgently addressed in all the 5 countries and at EU level. The next Section aims to put forward recommendations and concrete courses of action to ensure that care is revalued, redistributed and rewarded and that good mental health of informal carers and LTC workers is promoted and protected.

Conclusions

Our vision: valuing care and caring together to achieve thriving societies

Our vision as WELL CARE project partners is that of a Europe where care and mental health are considered as a value and a right in themselves and where different actors at community level are involved in the care process, on an equal footing, based on the recognition of each actor's respective knowledge and expertise. We call for human centred care systems, where the human rights of all actors involved are promoted and everyone can thrive. We believe that good quality care is strictly dependent on the wellbeing of those who provide it.

Human rights considerations are the main rationale for our asks, as the right to health – which includes the right to mental health – and the right to receive care are key values underpinning the European project. Beyond the human rights argument, promoting mental health of informal carers and LTC workers is also instrumental to achieving other key objectives, such as the sustainability of long-term care systems, increased participation of women in the labour market (hence, gender equality) and prevention of opportunity costs related to lack of support to informal carers and to mental health problems. Therefore, it is in the interests of Member States to step up their efforts in promoting mental health of both informal carers and LTC workers. The recommendations below and the concrete actions to implement them will enable us to move closer to a vision of a Europe that cares for carers and where everybody can thrive.

Recommendations to Member States

In relation to LTC workers:

- ✓ Adopt a **comprehensive strategy to address psychosocial risks at source**. This will require improving working conditions, increasing wages and ensuring safe staffing levels. Better wages will prevent in-work poverty with consequent negative impacts on the mental health of care workers. Better wages, improved working conditions – coupled with actions to challenge gender stereotypes around care- will also make the care profession more attractive. Another crucial action consists in ensuring that all care workers have access to social protection and mental health services, which should not be considered a luxury.
- ✓ Actively **promote social dialogue in long-term care services** and improve coverage of collective bargaining. Strengthen civil dialogue between civil society organizations and public authorities to develop effective social care policies tailored to local needs. In countries where civil dialogue is currently weak, intensify efforts to build capacity and foster collaboration to improve care solutions.
- ✓ Ensure that the **human is at the centre of long-term care services** and that the rights of all actors involved are respected. This will require investing public resources in the sector and closely monitoring quality in care services, both public and private. Quality enhancement goes hand in hand with the well-being of those who provide care.
- ✓ Better recognise the **interplay between restrictive migration policies and the poor working conditions in the domestic work sector**, for instance by establishing firewalls between labour inspections and immigration services.

In relation to informal carers:

- ✓ **Support the mental health of informal carers**, by addressing the risk factors and enhancing protective factors, according to a mental health in all policies approach. The first action is to

ensure that informal caring is a viable choice, by promoting robust (good quality, affordable and accessible) LTC services across the EU. Other actions will consist in policies that prevent poverty and social exclusion among informal carers, including financial compensation, respite care options, and mechanisms to balance paid work and caregiving responsibilities. Access to mental health services or other forms of support for psychological wellbeing and resilience also need to be put in place.

- ✓ **Recognise the societal and economic value of informal carers' role** and ensure that they are considered as **equal partners in care**, at policy and practice level. This will require creating the conditions for dialogue, exchanges and developing of care plans where all actors – care recipients, informal carers and care workers – are meaningfully engaged on an equal footing, each with their respective, yet complementary knowledge and expertise.

General recommendation:

- ✓ Develop a **concrete action plan** explaining how Member States intend to meet the above recommendations. This can take place in the framework of the European Care Strategy Action Plans, to be submitted to the European Commission by end of August 2024 and made publicly available. Such plans need to be **timely, adequately funded and based on targets and indicators**, so that progress can be monitored.

Recommendations to the EU:

- ✓ **Mainstream mental health in all EU policies**, by developing and enforcing comprehensive policies that integrate mental health into broader health, social, and economic frameworks.
- ✓ **Enhance data collection and research on the interplay between care and mental health:** Ensure the annual collection of EU-wide data on informal (unpaid) care, work–life balance and access to LTC services, at local, national, and international levels, disaggregated by gender, with a focus on working conditions and wellbeing.
- ✓ Establish **common targets and indicators** to enable effective monitoring of the European Care Strategy similarly to the Barcelona targets on Early Childhood Education and Care. Proper implementation and financing are crucial to ensure the ambitions of the European Care Strategy are fully realised and avoid the risk of a minimal impact. It will be crucial to align other monitoring processes – such as the European Semester – to the priorities of ensuring quality of care and wellbeing of all actors involved, by encouraging Member States to implement reforms in this direction, rather than asking them to cut investments.
- ✓ **Facilitate Knowledge Sharing Across Member States**: Promote the exchange of best practices and successful strategies on the promotion of mental health for informal carers and LTC workers among EU Member States, to enhance mutual learning and the scale up of innovative practices.
- ✓ **Allocate funds** to support Member States' efforts towards person centred, integrated care systems, enhancing the rights and wellbeing of all actors involved: those in need of care, informal carers and LTC workers.

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Annex 1

WELL CARE project Questionnaire: Legislation and policies supporting the mental health of long-term care workers

Introduction

In the framework of the WELL CARE project, an analysis of legislation, policies, care frameworks and funding schemes that best support the mental health and wellbeing of informal carers and Long-Term Care (LTC) workers will be carried out. We are interested in collecting answers related to the following five countries: **Germany, Sweden, Italy, Slovenia and The Netherlands**.

This questionnaire is related to legislation and policies targeting LTC workers (see definitions hereafter).

When answering, please add as many details as possible, including links to relevant resources. If relevant for your country, please also consider the **regional level**, in addition to the **national level**.

Please complete this questionnaire by 30 April 2024. Your input will feed into an analysis, which will be published at the end of September 2024.

Definitions

Informal carers are persons who provide – usually – unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework (Eurocarers 2023).

Long-term care (LTC) is defined as a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care. (EC and SPC, LTC report 2021)

Long term care (LTC) workers including primarily (EC 2021, OECD 2021) qualified nurses (ISCO-08, codes 2221 and 3221) and personal care workers (ISCO-08, codes 5321 and 5332), either employed by a LTC provider (in home or residential settings) or directly by the care recipient/family (i.e. live-in carers, mainly in home settings). The latter also includes migrant care workers.

Name

Organisation

Country

Email

General questions

1) What is the **framework for Long Term Care** (LTC) in your country? For instance, is LTC regulated at national or regional level? Is it dealt with in the health care sector, the social care sector or both?
2) In your country. are there policies and/or legislation ensuring **accessible, affordable, and good quality formal LTC services**?
3) In your country, are there policies and/ or legislation ensuring a **collaboration between informal carers and LTC workers**?
4) Concerning the funding of LTC services, what is the balance between public social security (e.g., health services), private insurance mechanisms, and out-of-pocket and in-kind contribution by users and their families?

Questions regarding Long Term Care (LTC) workers

5) In your country, is there **collective bargaining and social dialogue** with a view to **improving wages and working conditions** of LTC workers?
6) What are the **standards of occupational health and safety** for LTC workers? What do the provisions on **psychological wellbeing** include?
7) In your country, are there human resources (HR) policies targeting the mental health of LTC workers?
8) In your country, are there **measures to tackle gender stereotypes** around care and, for example, to attract more men to the care sector?
9) Are there legislation, policies and/or care frameworks concering **continuous education and training for LTC workers**?
10) Are there legislation, policies and/or care frameworks **protecting the rights of LTC workers** (e.g. freedom from discrimination, adverse social behaviours, sexual or other forms of harassment)
11) Are there legislation, policies or care frameworks **protecting vulnerable groups of LTC workers** (e.g. migrant care workers)?
12) In your country, are there **initiatives other than policies or legislation** addressing any of the above items? If so, please elaborate on them.
13) In your country, are there any policies and/or legislation that are conducive to good mental health of LTC workers that we didn't think of? If so, please elaborate on them.

Thank you for filling in the questionnaire!

WELL CARE project Questionnaire: Legislation and policies supporting the mental health of informal carers

Valuing informal carers and promoting their rights

1) In your country, are there policies and/or legislation **defining informal carers**? If so, please elaborate.
2) In your country, are there policies and/or legislation **protecting the rights of carers** (choice, non-discrimination, no abuse)
3) In your country, are there targeted measures to overcome traditional gender roles and to actively promote the equal sharing of caring responsibilities?
4) In your country, are there policies and/or legislation concerning **access to information, advice and training** for informal carers?
5) In your country, are there policies and/or legislation concerning **targeted supports for carers**, such as support groups, counselling, keeping/feeling well activities?
6) In your country, are there policies and/or legislation concerning **respite care**?
7) In your country, are there policies and/or legislation **protecting vulnerable groups of informal carers**? (e.g. from migrant communities)
8) In your country, are there policies and/or legislation **combatting social isolation**, with specific dispositions for informal carers?
9) In your country, are there **initiatives other than policies or legislation** addressing any of the above items? (For instance, awareness raising initiatives to ensure social recognition of the role of informal carers or initiatives to tackle social exclusion of carers, innovative forms of support for and with carers etc.)

Financial support, access to education and employment

10) In your country, are there policies and/or legislation enabling informal carers to **combine education/employment with caring responsibilities**? (e.g. flexible working arrangements, carers leave)
11) In your country, are there human resources (HR) policies targeting the mental health of working carers (that is, informal carers who combine paid work with caring activities?
12) In your country, are there policies and/ or legislation concerning **financial support to informal carers**? (e.g. carers' allowance)

Other

13) In your country, are there any policies and/or legislation that are conducive to good mental health of informal carers that we didn't think of? If so, please elaborate on these.

Project partners

Linnæus University

Nka

VU Vrije Universiteit Amsterdam

Nederland Zorgt Voor Elkaar

IRCCS INRCA

ANS Anziani e non solo società cooperativa sociale

Hochschule Zittau/Görlitz University of Applied Sciences

wir pflegen! Interessenvertretung und Selbsthilfe pflegender Angehöriger e.V.

University of Ljubljana

The University of North Carolina at Chapel Hill

Mental Health Europe

EURO CARERS European Association Working for Carers

European Ageing Network www.ean.care

EASPD