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Good Practices and Remaining Challenges in Supporting Informal Carers

Lessons from Well-Developed Formal Long-Term Care Systems

Mirjam Pot
Selma Kadi
Niki Kalavrezou

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EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH

European Centre for Social Welfare Policy and Research
Berggasse 17, 1090 Vienna, Austria
www.euro.centre.org
ec@euro.centre.org
+43-1-319 4505-0

Table of Contents

Table of Figures

List of Tables

List of Abbreviations

EHIS	European Health Interview Survey
EQLS	European Quality of Life Survey
GDP	Gross domestic product
LFS	Labour Force Survey
LTC	Long-term care
PPP	Purchasing power
OECD	Organization for Economic Co-operation and Development

Summary

This report examines the policies implemented by countries with well-developed formal long-term care (LTC) systems to support informal carers, as well as the challenges these countries face in expanding and improving such support. Using an international benchmarking approach, Finland, Germany, Lithuania, and the Netherlands were selected as case studies. These countries were chosen because they combine relatively high LTC expenditure with favourable outcomes for informal carers, while representing different types of LTC systems.

To develop a comprehensive understanding of informal carer support in these four contexts, the study draws on 16 semi-structured interviews with experts from academia, carer organisations, and public administration, complemented by a review of both academic and grey literature.

The analysis focuses on four key dimensions of informal carer support: financial assistance, social security benefits, care leave arrangements, and measures aimed at promoting carers' well-being,

particularly respite care. While each country has introduced a range of initiatives, their approaches and policy priorities differ. The report also identifies examples of effective practices regarding inclusive policy processes and stakeholder engagement in shaping informal care policies.

Despite their progress, all four countries continue to face several common challenges: (1) the persistent underutilisation of available benefits and services; (2) the need to expand support measures by broadening eligibility, increase benefit levels, improve national coherence, and introduce new forms of support; and (3) the importance of acknowledging the diversity of informal carers and tailoring policies to their varied needs. These shared challenges demonstrate that even advanced LTC systems still have room for improvement in providing comprehensive and effective support to informal carers.

Drawing on the experiences of the case study countries, the report concludes with recommendations for how Sweden could strengthen its LTC system by enhancing its support for informal carers.

1 Introduction

This report addresses two central questions: What policies have countries with well-developed formal long-term care (LTC) systems introduced to support informal carers? And what challenges do these countries face in extending and improving such support?

Informal carers are family members or friends who provide unpaid care to individuals affected by illness, disability, or old-age-related frailty. Across Europe, LTC systems depend heavily on informal caregiving: an estimated 80% of all LTC[1] is provided informally (Hoffmann & Rodrigues, 2010). Informal carers are a heterogenous group, including young carers (i.e., children and youth providing care), people of working age, and retired people, who often care for their spouses. However, informal carers are more often women and people with lower levels of education and income (Brandt et al., 2023). While caregiving can be a meaningful role, it frequently places a heavy strain on carers, especially when care needs are intensive or continue over lengthy periods (Lindt et al., 2020). The consequences can include negative effects on caregivers' well-being, physical and mental health, labour market participation, and long-term financial security (Bauer & Souza-Poza, 2015; Brandt et al., 2023).

For a long time, informal carers received little policy attention. However, with rising demand for care due to demographic ageing and workforce shortages in the LTC sector, their role has become more visible, and they have entered EU and national policy agendas (European Commission, 2022). Governments in many Western countries have begun to develop targeted support measures for informal carers. These policy responses generally follow two approaches. First, by expanding access to formal services, the pressure on informal carers can be reduced, as the availability of such services is associated with fewer hours of informal care and a smaller well-being gap between carers and non-carers (Verbakel, 2014; 2018). Second, countries have introduced specific measures for carers themselves. These include financial transfers such as carer allowances, paid or unpaid care leave schemes, social health insurance coverage and pension credits for time spent on caregiving, respite services, and access to training and psychological support (Courtin et al., 2014; Eurofound, 2025; Rocard

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[1] The World Health Organization (2022) defines LTC as being provided over longer periods and including "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."

& Llena-Nozal, 2022). In this report, we focus primarily on direct support measures for informal carers.

The Swedish Ministry of Health and Social Affairs commissioned this study to better understand how other European countries with extensive formal LTC systems support informal carers. Countries with well-developed LTC systems typically consider LTC as a state responsibility. Informal care is typically more prevalent in contexts where formal services are weaker, but we assume that it is precisely in countries with strong LTC systems where most progress has been made in designing and implementing policies for informal carers. These cases are therefore particularly instructive.

Based on an international benchmarking exercise and a typology of LTC regimes (Kraus et al., 2010), we selected Finland, Germany, Lithuania, and the Netherlands as case studies. All of these countries combine comparatively high investments in LTC with relatively favourable outcomes for informal carers, and, at the same time, represent different LTC regime types. To gain a thorough understanding of informal carer support in the four countries, we conducted 16 semi-structured interviews with experts from research, carer organisations, and public administration, complemented by a review of academic and grey literature.[2]

The report is structured as follows. In Chapter 2, we conduct the benchmarking exercise, showing the criteria, data sources, and results that guided the selection of countries. The exercise was data-driven but constrained by the availability of indicators, as no measure directly captures how supportive a system is toward informal carers. We therefore focus on system maturity and resources, how informal care is shared across the population, and caregivers' ability to balance responsibilities with work and life. The results show that specific countries consistently stand out for their LTC system maturity and supportive informal caregiving. However, variation was applied as an additional layer, using an LTC system typology to ensure that the four selected countries represent different European models, rather than concentrating on a single region or welfare regime.

Chapter 3 introduces various support measures for informal carers and provides an overview of policies in Finland, Germany, Lithuania, and the Netherlands. We show that these countries vary considerably in their focus and approach. For example, Finland has a formalised support system centred on a carer allowance but limited leave options, while other countries, Germany in particular, offer more extensive leave arrangements. This chapter also highlights good practices in terms of policy processes

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[2] A description of the qualitative methods applied in this project is included in Annexe A.

and the involvement of diverse stakeholders to advance the agenda on informal care and shape tangible policy proposals.

Chapter 4 examines the main challenges the four countries are facing. Experts emphasised three overarching issues: (1) addressing the persistent non-take-up of existing benefits and services; (2) expanding measures through increasing eligibility, generosity, and national harmonisation, as well as the development of new measures; and (3) better recognising the diversity of informal carers and their varying needs in current and future policies. These challenges highlight that even in countries comparatively advanced in supporting informal carers, various issues still need to be addressed to provide more comprehensive and effective support.

Based on the experiences of Finland, Germany, Lithuania, and the Netherlands, the report concludes with recommendations on how Sweden may strengthen its LTC system by advancing support for informal carers (Chapter 5).

2 International Benchmarking

2.1 Introduction

This section identifies countries of interest that serve as leading examples, based on the maturity and structure of their long-term care (LTC) systems, as well as on informal caregiving trends and patterns. This is achieved through a data-driven, international benchmarking exercise that will guide the selection of four European countries that share positive characteristics (particularly high investment and positive caregiver outcomes), while also reflecting a degree of heterogeneity across LTC system types. These countries will then be the focus of a deep-dive analysis using qualitative research to explore, in greater detail, policy measures and challenges related to supporting informal caregivers, with the goal of generating insights that can inform policy priorities and development in Sweden.

To carry out the benchmarking exercise, we mainly draw on aggregate data from Eurostat, the OECD Health Database, and the latest European Quality of Life Survey (EQLS), as well as on analyses and charts presented in the European Centre comprehensive report *Facts and Figures on Healthy Ageing and Long-Term Care* (Kalavrezou et al., 2025), which were largely based on microdata analyses from sources such as the European Health Interview Survey (EHIS). To ensure a focused and meaningful comparison, the benchmarking assesses countries based on key LTC system and informal caregiving indicators, including:

- Public investment in LTC and the availability and accessibility of formal care services,
- Caregiving patterns, including the prevalence and intensity of informal caregiving, as well as key caregiver characteristics and outcomes (with an emphasis on labour market participation).

Specifically, the selection is guided by the following three (3) main criteria:

1. **Countries with Well-Developed LTC Systems and Services.** This criterion prioritises countries with relatively strong public investments in LTC and established service provision. Countries with robust and comprehensive LTC systems are assumed to be in a better position to support informal caregivers and care recipients alike.
2. **Countries with Manageable Caregiving Intensity.** Another criterion is to focus on caregiving patterns. The idea is that it makes sense to look into countries with a relatively low intensity of informal caregiving. The assumption

behind this criterion is that informal caregiving responsibilities remain manageable due to supportive systems and policies.

3. **Countries with High Incidence or Intensity of Caregiving but Good Caregiver Outcomes.** Some countries may experience high levels of informal caregiving, yet their caregivers report relatively positive outcomes. In this analysis, "good caregiver outcomes" are mainly considered in terms of labour market participation and freedom to choose the amount of care provided, rather than health or well-being measures. The assumption is that these outcomes may be linked to effective policies and support mechanisms that help caregivers balance their caregiving responsibilities with their work life.

We also examined high-intensity caregiving coupled with good health or life-satisfaction outcomes. However, no patterns emerged that could inform the benchmarking. For example, caregivers providing intensive care in some Mediterranean countries report consistently better physical and mental health than those in Nordic countries with comparable caregiving intensity. We consider that such differences cannot be straightforwardly attributed to LTC systems or support mechanisms and are likely influenced by factors beyond the scope of this report, such as epidemiological, genetic, or environmental health determinants at the population level. Consequently, for the purposes of the benchmarking exercise, we focus on caregiving intentions and labour market participation, which are more directly linked to the countries' LTC systems and support structures.

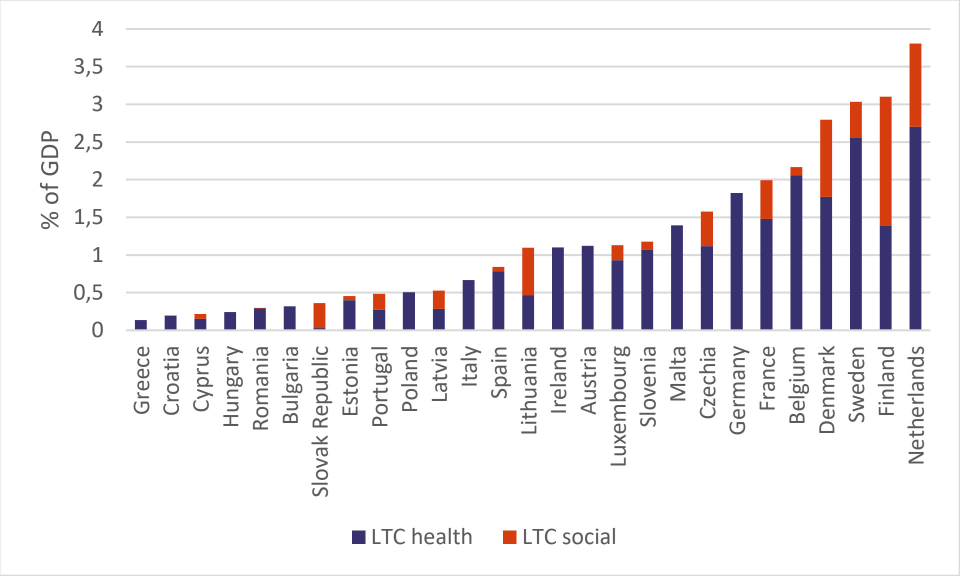
It is important to note that some countries may meet multiple criteria simultaneously. For instance, a country may have a well-developed LTC system while also exhibiting high informal caregiving rates with good caregiver outcomes. Overlaps were considered when finalising the selection of countries to ensure a balanced representation of different models and approaches.

Since there is no single indicator capturing direct support for informal carers, this analysis is not only data-driven but also data-constrained. Nevertheless, the three-layered criteria based on multiple indicators provide a triangulated basis for a robust benchmarking exercise.

2.2 Countries with Well-Developed LTC Systems and Services

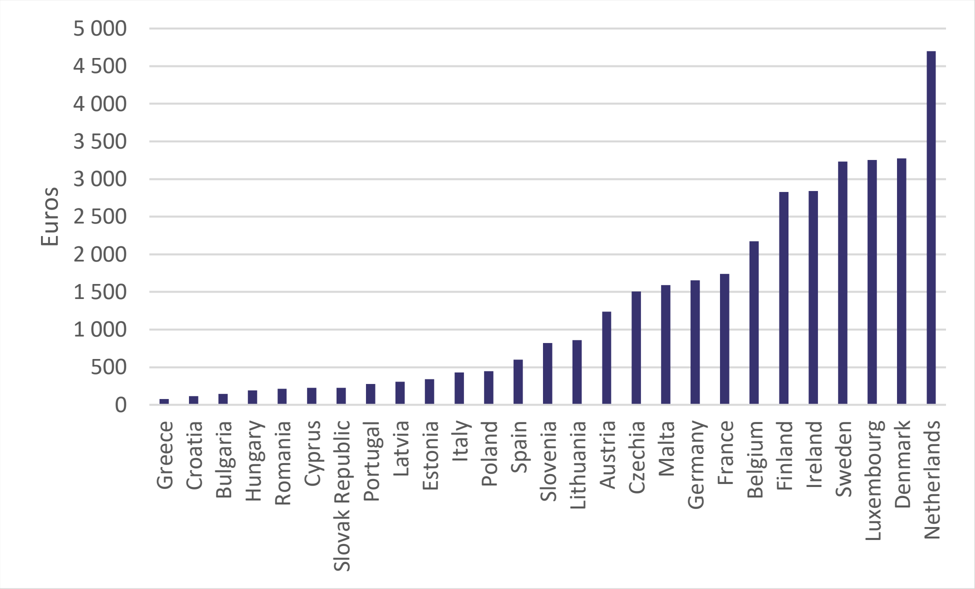
The first criterion for selecting high-performing countries is the maturity and strength of their long-term care systems and services. Selected countries should exhibit high levels of public investment, typically captured through long-term care expenditure statistics. Figure 1 presents public spending on LTC as a percentage of GDP, while Figure 2 and Figure 3 show public spending per capita (Euros, PPP, for inhabitants aged 65+). It is important to note that cross-country differences exist in how the "LTC social" component is reported; however, here we focus on the total level of public spending. The results indicate that the two metrics produce slightly different country rankings, yet Nordic countries and the Netherlands show clear patterns of prioritising public investment in LTC, whereas spending is particularly low in Southern European countries such as Greece, Croatia, and Bulgaria.

Figure 1. Public LTC expenditure by component (as a % of GDP), 2022



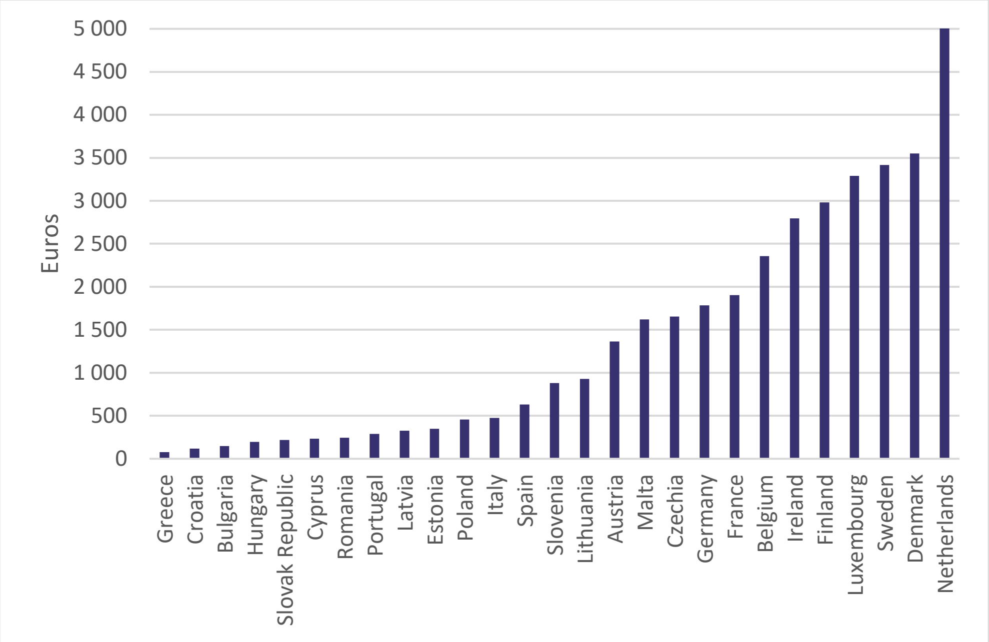
Source: OECD Health Database.

Figure 2. Public total (health plus social) LTC expenditure per person aged 65+ (Euros, PPP, in 2015 constant prices), 2021



Source: OECD Health Database, Eurostat Population Statistics and authors' calculations.

Figure 3. Public total (health plus social) LTC expenditure per person aged 65+ (Euros, PPP, in current prices), 2021



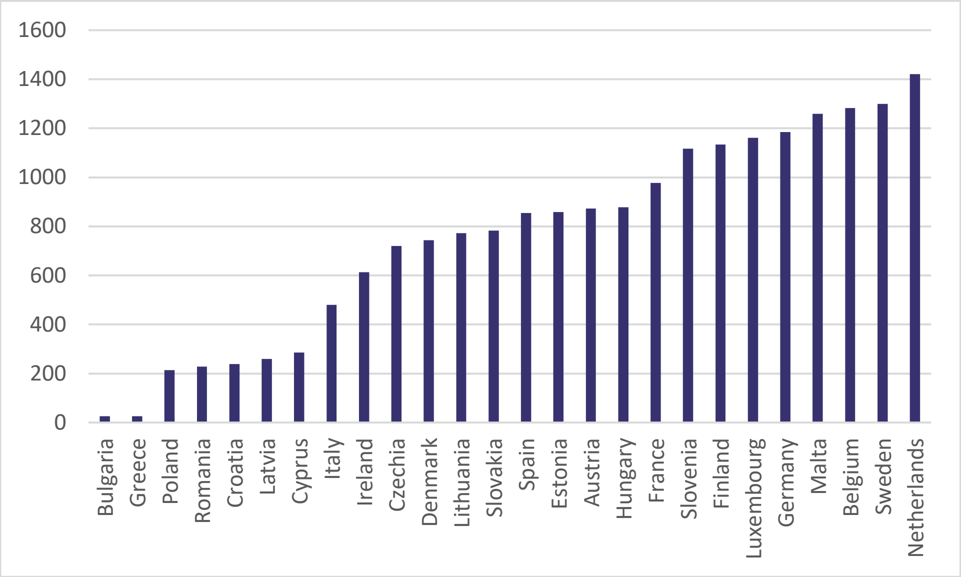
Source: OECD Health Database, Eurostat Population Statistics and authors' calculations.

The availability of formal services is proxied by the number of places in nursing and other residential LTC facilities per 100,000 inhabitants, which, when considered alongside public spending, provides a clearer picture of system capacity (Figure 4). Additional indicators include the share of respondents aged 55+ who require or need more help with at least one personal care activity, offering a measure of unmet care needs and, therefore, system capacity (Figure 6). Cost-related barriers to care are also considered, using EQLS survey data on how difficult it is for respondents to afford care services in their country (Figure 8).

To cross-validate these measures, scatterplots were used to demonstrate the relationships between public LTC spending and service availability (expected positive correlation) and between public LTC spending and unmet needs (expected negative correlation) in Figure 5 and Figure 7, respectively. Computed correlation coefficients confirm these relationships, indicating (a) a strong positive correlation between public LTC spending and system capacity, and (b) a moderate to strong negative correlation between unmet needs for personal care among the population aged 55+ and public LTC spending.

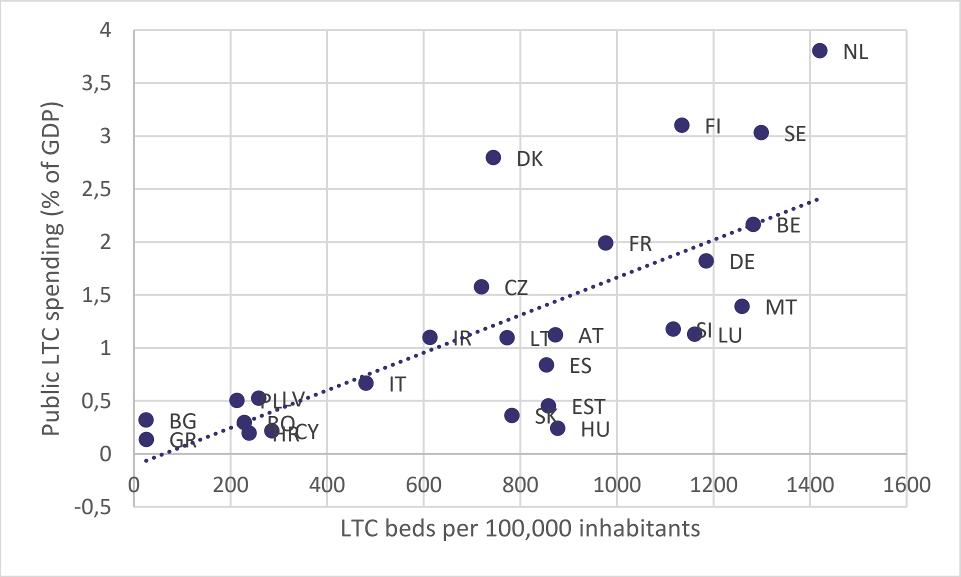
Based on these indicators, the countries identified as high achievers in terms of the maturity and strength of their LTC systems are the Netherlands, Finland, Belgium, Denmark, Germany, Luxembourg, Germany, Ireland and Lithuania.

Figure 4. Places in nursing and other residential long-term care facilities (per 100,000 inhabitants), 2022



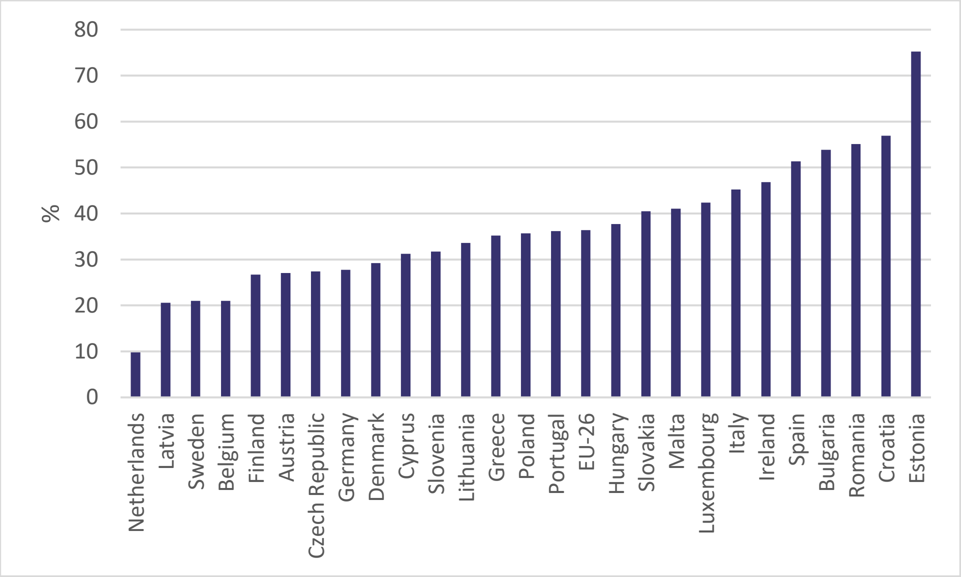
Source: Eurostat.

Figure 5. Places in nursing and other residential long-term care facilities (per 100,000 inhabitants) and public expenditure on LTC (total, % of GDP), 2022



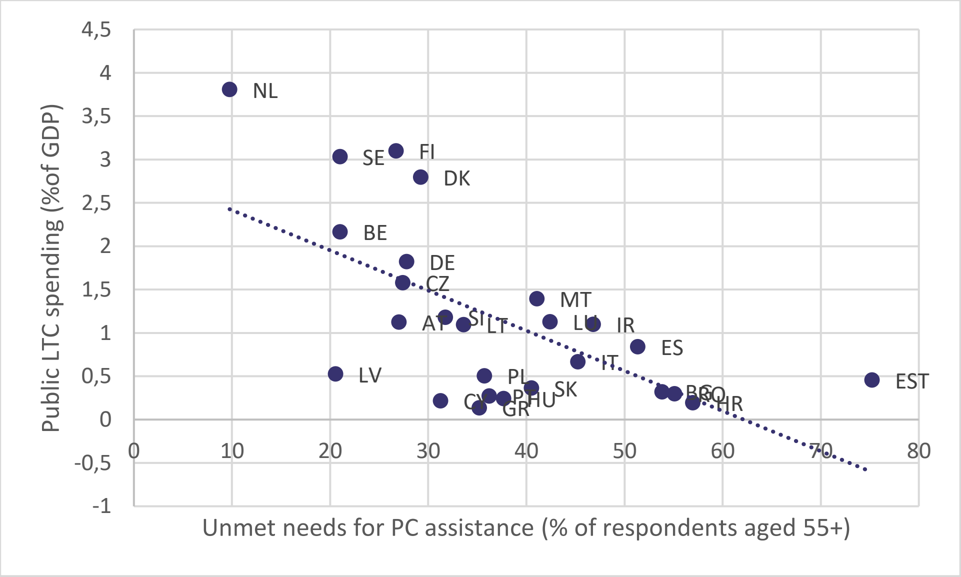
Source: OECD Health Database and Eurostat. Notes:1/ Correlation coefficient: 0.73 (strong positive correlation), 2/ anonymised microdata for France not available.

Figure 6. Share of respondents aged 55+ needing help/more help with at least one personal care activity, 2019



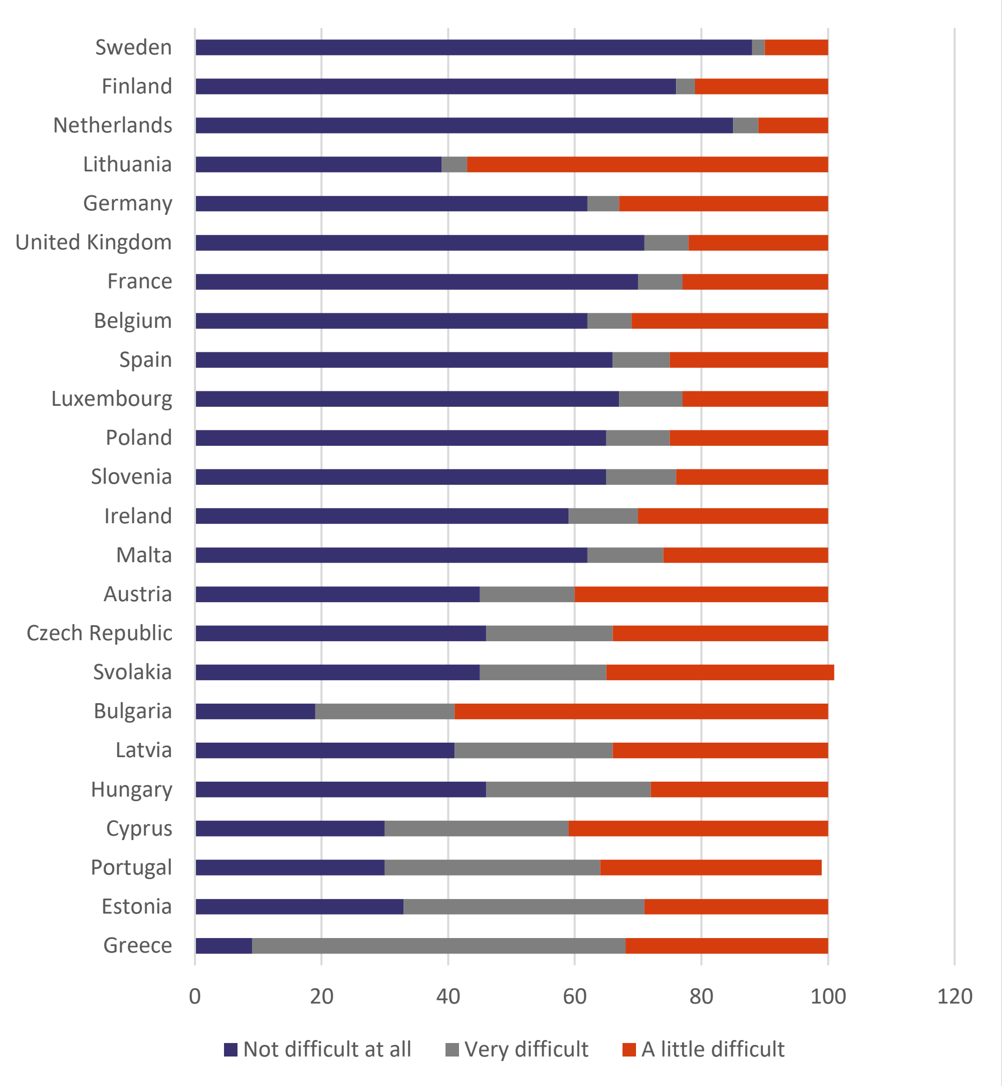
Source: Kalavrezou et al. (2025), Facts and Figures on Healthy Ageing and Long-Term Care; charts based on European Health Interview Survey (EHIS) microdata, wave 3 (2019). Notes: 1/ personal care activities include feeding oneself, getting in and out of a bed or chair, dressing and undressing, using toilets, bathing or showering, 2/ anonymised microdata for France not available.

Figure 7. Share of respondents aged 55+ needing help/more help with at least one personal care activity (2019) and total public LTC expenditure as % of GDP (2021)



Source: Kalavrezou et al. (2025), Facts and Figures on Healthy Ageing and Long-Term Care; charts based on European Health Interview Survey (EHIS) microdata, wave 3 (2019). Notes: 1/ correlation coefficient: -0.63 (moderate to strong negative correlation), 2/ personal care activities include feeding oneself, getting in and out of a bed or chair, dressing and undressing, using toilets, bathing or showering, 3/ anonymised microdata for France not available.

Figure 8. Cost difficulty in LTC: How difficult is it to afford LTC services in your country (% of respondents in each category), 2016



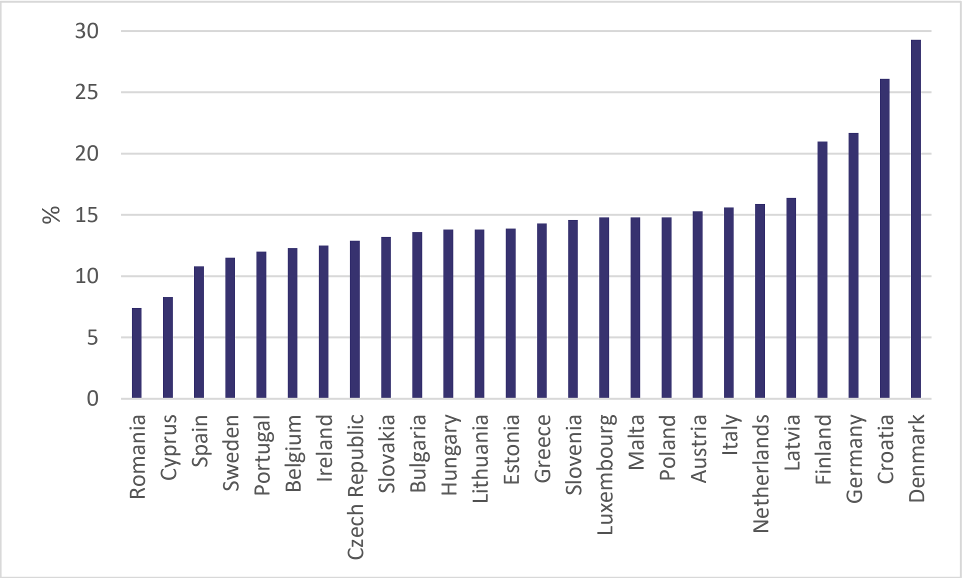
Source: EQULS, 2016 round (data retrieved from the EQLS interactive tool). Note: data not available for Denmark, Croatia, Italy and Romania.

2.3 Countries with Manageable Caregiving Intensity

The second criterion focuses on caregiving patterns, considering both the prevalence and intensity of informal caregiving. For benchmarking purposes, countries combining high prevalence with relatively low caregiving intensity are particularly informative. High prevalence indicates that informal care is widely shared across families and social networks, reflecting strong family ties and community cohesion, and ensuring that individuals in need are supported by their social environment. At the same time, low intensity suggests that caregiving responsibilities remain manageable and are less likely to impose excessive strain on individual caregivers who nevertheless remain actively engaged.

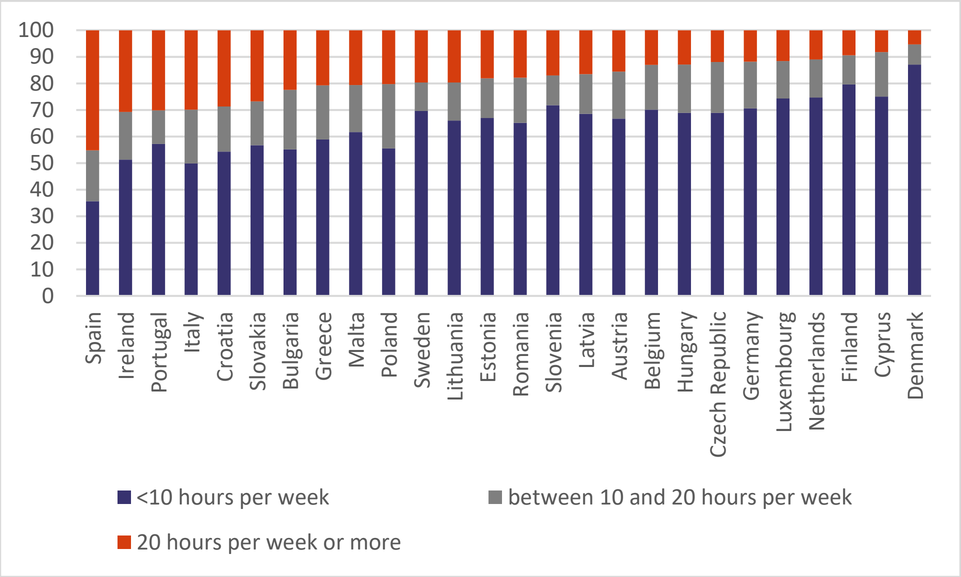
Figure 9 presents the share of the population who provide informal care at least once per week, reflecting overall citizen engagement in caregiving activities. Figure 10 illustrates caregiving intensity, capturing the proportion of caregivers providing low-, medium-, and high-intensity care (defined as 20 hours per week or more). Based on these indicators, Germany, Denmark, Finland, the Netherlands, and, to a lesser extent, Latvia and Lithuania stand out as countries where informal caregiving is both common and sustainably distributed. These patterns highlight contexts in which LTC systems and supportive policies may contribute to balanced and effective informal care arrangements.

Figure 9. Share of population providing care or assistance to one or more persons suffering from some age problem, chronic health condition or infirmity at least once per week (professional activities excluded), 2019



Source: Kalavrezou et al. (2025), Facts and Figures on Healthy Ageing and Long-Term Care; charts based on European Health Interview Survey (EHIS) microdata, wave 3 (2019). Note: anonymized micro-data for France not available.

Figure 10. Number of hours per week (% of total) the respondent provides care or assistance to the person(s) suffering from any chronic condition or infirmity due to old age, 2019



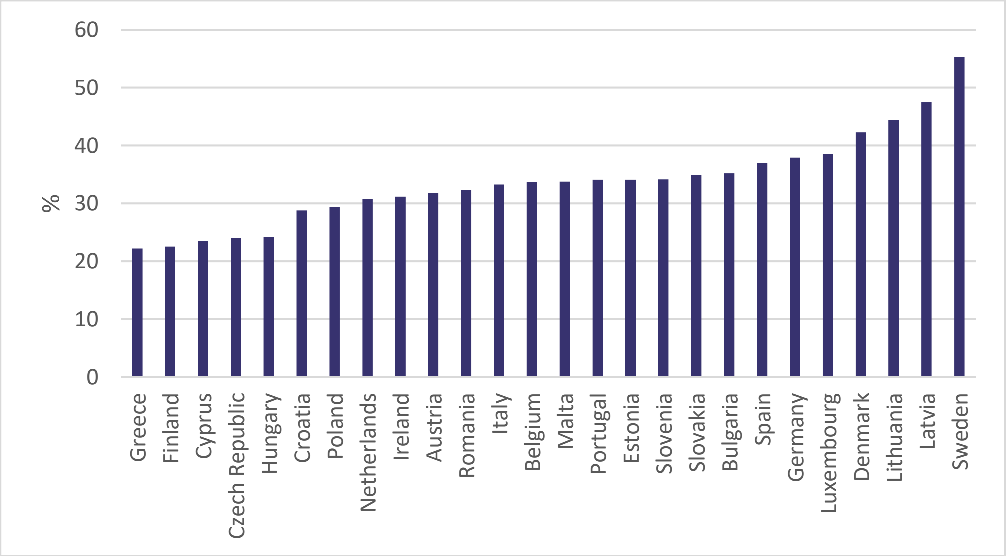
Source: Kalavrezou et al. (2025), Facts and Figures on Healthy Ageing and Long-Term Care; charts based on European Health Interview Survey (EHIS) microdata, wave 3 (2019). Note: anonymised micro-data for France not available.

2.4 Countries with Good Caregiver Outcomes

The third criterion focuses on caregiver outcomes, specifically in relation to labour market participation and the freedom to balance caregiving with other aspects of life. These outcomes are considered particularly relevant for benchmarking, as they reflect both the sustainability of informal caregiving and the adequacy of policies that support caregivers in managing their responsibilities.

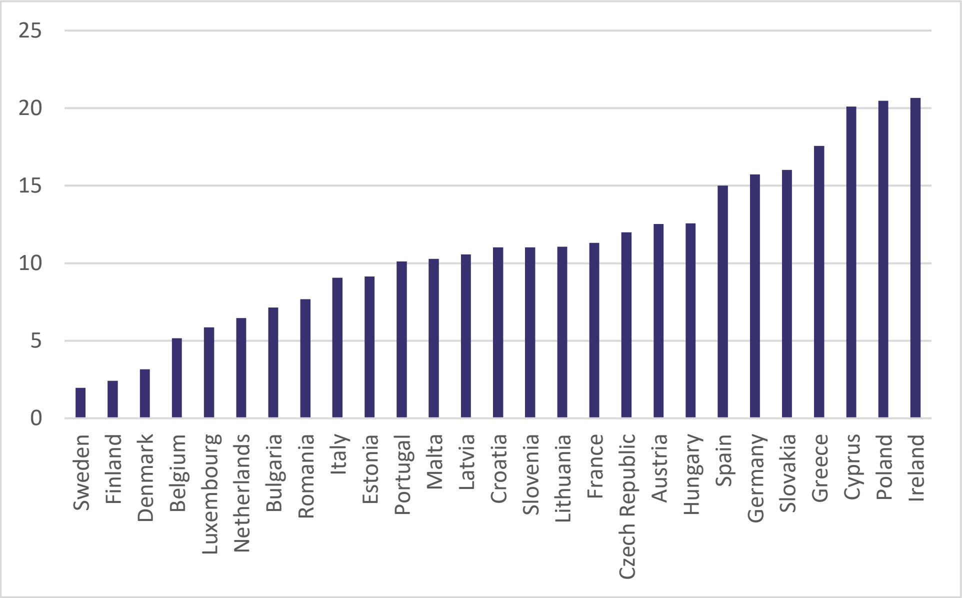
Figure 11 presents the employment rates of individuals providing intensive care (20 hours per week or more), illustrating the extent to which caregivers remain attached to the labour market despite their care commitments. Complementary to this, Figure 12 shows the share of individuals not working but who would like to work, citing care responsibilities as the main reason for not seeking employment. Together, these measures provide insights into the degree to which caregiving acts as a barrier to labour market participation.

Figure 11. Employment rates of persons providing care for at least 20 hours per week, 2019



Source: Kalavrezou et al. (2025), Facts and Figures on Healthy Ageing and Long-Term Care; charts based on European Health Interview Survey (EHIS) microdata, wave 3 (2019). Note: anonymised microdata for France not available.

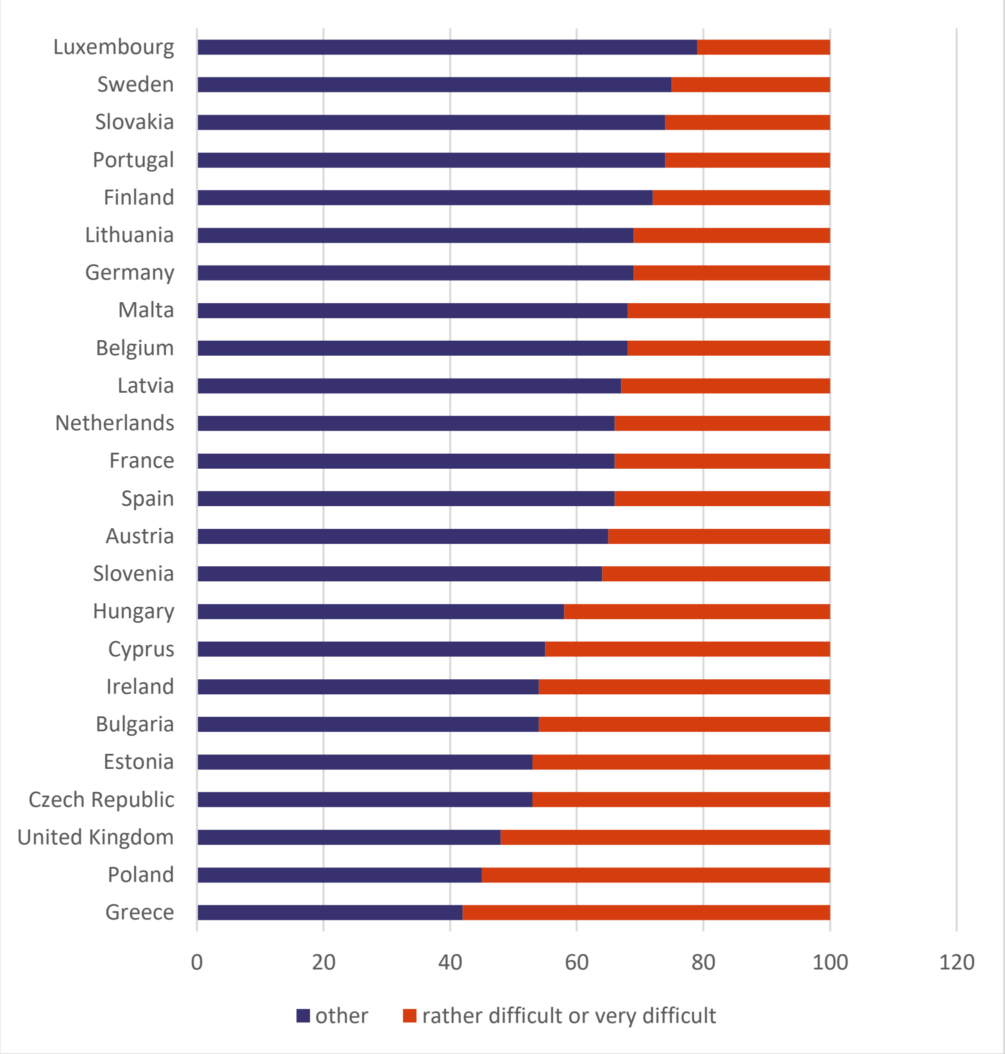
Figure 12. Share (%) of individuals not working but who would like to work, citing care responsibilities as the main reason for not seeking employment, 2022



Source: Kalavrezou et al. (2025), Facts and Figures on Healthy Ageing and Long-Term Care; charts based on Labour Force Survey (LFS) microdata calculations.

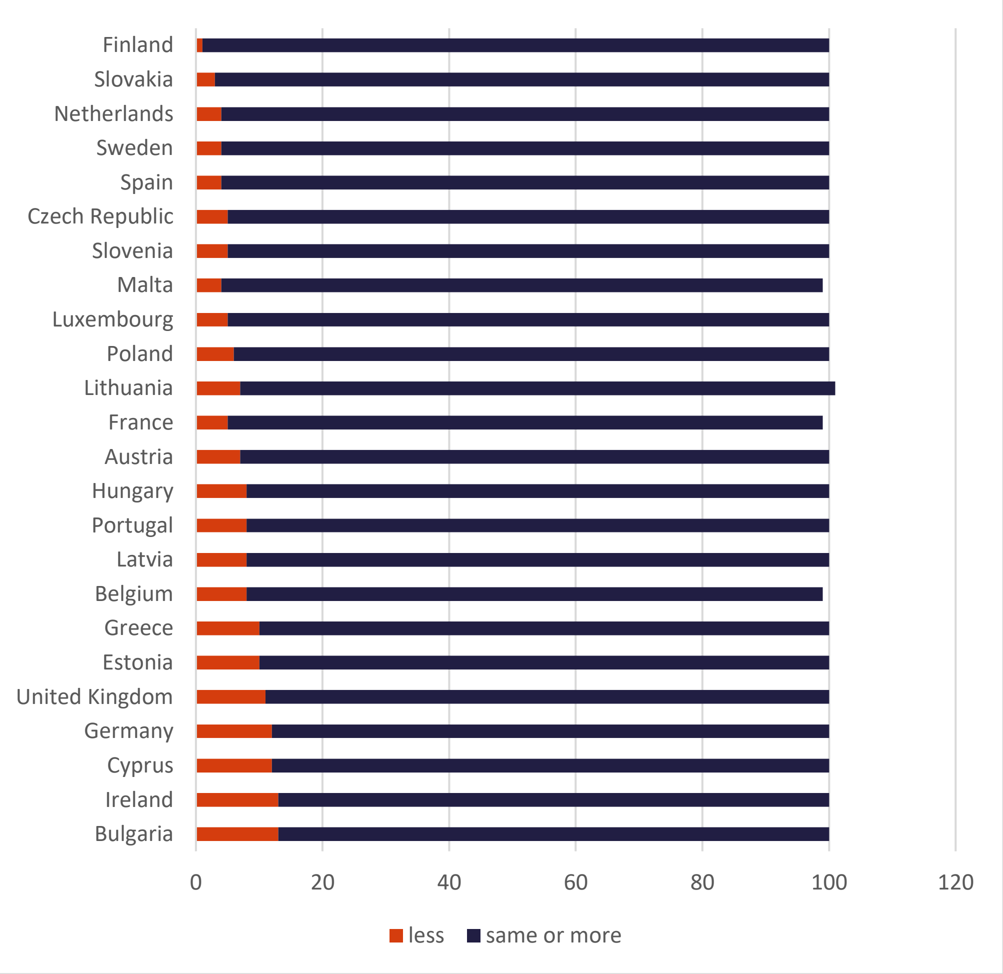
Beyond employment status, Figure 13 captures the share of respondents who perceive potential difficulty in combining work and care responsibilities if they were employed, highlighting broader challenges in reconciling caregiving with work. Finally, Figure 14 reflects caregiving intentions, showing the proportion of respondents who would like to spend the same, less, or more time caring for relatives, neighbours, or friends in need. This indicator sheds light on whether caregiving is perceived as a voluntary and manageable responsibility or as an involuntary activity.

Figure 13. Share (%) of respondents citing potential difficulty combining work and care responsibilities if they were employed, 2016



Source: EQULS, 2016 round (data retrieved from the EQLS interactive tool). Note: data not available for Denmark, Croatia, Italy and Romania.

Figure 14. Share (%) or respondents who would like to spend the same, less or more time caring for relatives, neighbours and friends in need, 2016



Source: EQULS, 2016 round (data retrieved from the EQLS interactive tool). Note: data not available for Denmark, Croatia, Italy and Romania.

Based on these comparative graphs, countries that perform well under the third criterion are those where caregivers can remain active in the labour market, where care responsibilities do not systematically exclude individuals from employment, and where a significant share of caregivers report satisfaction with the time they dedicate to providing care. Results highlight Finland, the Netherlands, Luxembourg, Denmark, Lithuania, and Slovakia as high achievers in helping caregivers manage their responsibilities without disproportionate costs to their labour-market participation or overall autonomy.

2.5 Benchmarking Exercise Results and Selection of Countries

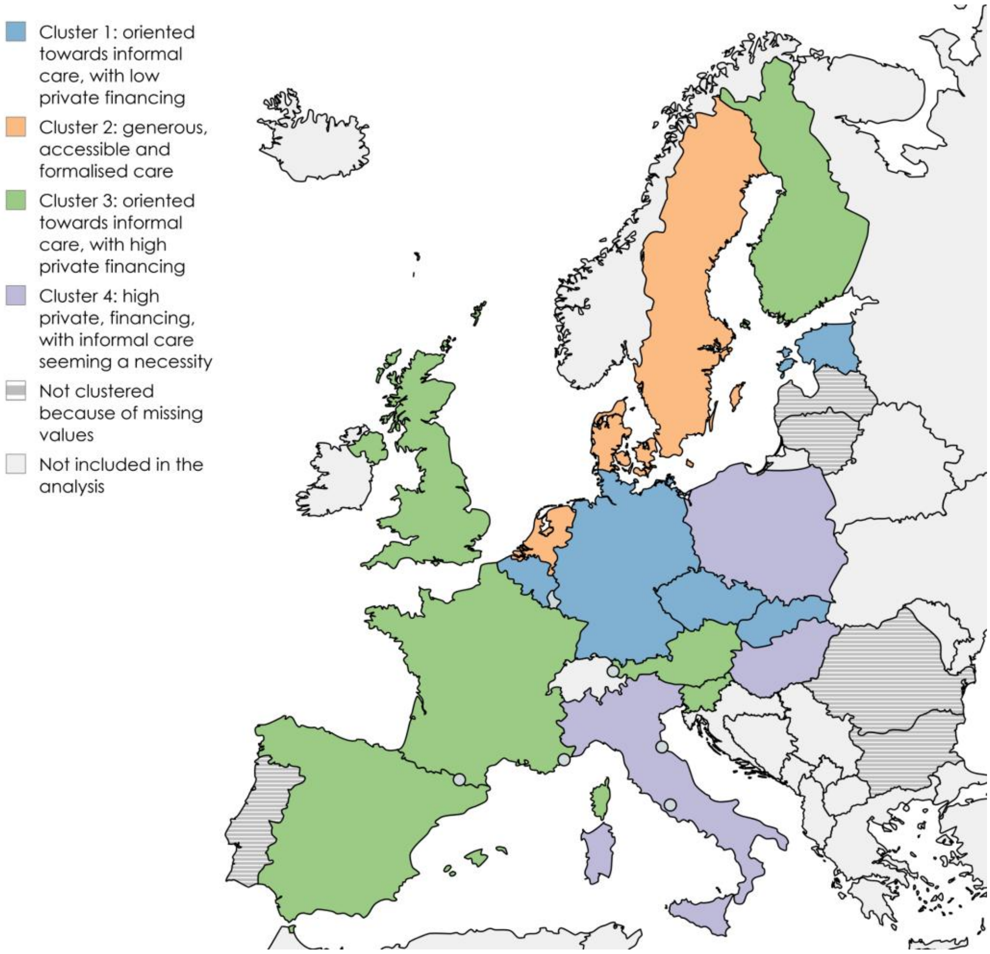
The benchmarking exercise applied three complementary criteria to identify countries with strong long-term care systems and favourable conditions for informal caregivers. Each criterion relied on a set of comparative indicators, and rankings were established by assigning scores to the top-performing countries (six points for the highest performer, down to one point for the sixth). For the second criterion, countries were selected based on the simultaneous presence of high prevalence and low intensity of informal caregiving.

Through the exercise, a group of European countries emerged that consistently perform well across various aspects of long-term care systems and informal caregiving. While individual criteria pointed to somewhat different configurations of high achievers, a core set of countries repeatedly emerged as strong performers. These included the Netherlands, Finland, Germany, Luxembourg, Denmark, Belgium, Latvia, Lithuania, Ireland, while Slovakia also appeared in some rankings.

To narrow down the list for further qualitative exploration, we complemented the benchmarking results with the typology of LTC systems proposed by Kraus et al. (2010). This framework was used to ensure that countries were not only comparable to Sweden in terms of overall system maturity but also sufficiently heterogeneous to represent different LTC models in Europe (Figure 15).

In applying this combined approach, greater weight was assigned to Criterion 1, which relies on “hard” system indicators such as public expenditure on LTC and the availability of formal services. These indicators are the most direct reflection of system maturity and are therefore central to the exercise. Additional weight was given to countries that performed strongly across multiple criteria. On this basis, four countries were identified as the most relevant cases for further analysis: **the Netherlands, Finland, Germany, and Lithuania.** The final selection balances high-performing, mature LTC systems in north-western Europe with a rapidly evolving system in central-eastern Europe and reflects the intention to capture both well-established models and emerging approaches.

Figure 15. Spatial map of clusters of European LTC systems



Source: Based on Kraus et al. (2010); author's own visualisation created with mapchart.net

3 Support Measures for Informal Carers in Four European Countries

In this chapter, we first introduce different types of support measures available for informal carers (Section 3.1). We then provide an overview of the policies implemented in Finland, Germany, Lithuania, and the Netherlands (Sections 3.2 to 3.5). This is followed by a comparative discussion of the main similarities and differences in how these countries approach support for informal carers (Section 3.6). The chapter concludes with good practice examples that illustrate how the countries studied have advanced the policy process and engaged a broad range of stakeholders in shaping informal carer policies (Section 3.7).

3.1 Different Types of Support Measures for Informal Carers

This section provides an overview of different types of public support measures for informal carers.[3] We differentiate between four types of support measures for informal carers: financial support, social security benefits, care leave and flexible working arrangements, and measures supporting carers' physical and mental well-being (see also Figure 16).[4] Not all of these policies are equally important to all informal carers. Rather, they (partly) reflect the fact that informal carers are a heterogeneous group with diverse support needs.

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[3] The focus on public measures implies that we exclude interventions implemented at the level of individual organisations (e.g. companies, hospitals), or by NGOs. However, in several countries, NGOs play an important role in implementing public support policies for informal carers, in particular, counselling and training (Rocard & Llena-Nozal, 2022).

[4] While these social policy measures can be accompanied by additional measures such as awareness raising campaigns (about informal care in general or support measures for informal carers more specifically) or strategies to improve the identification of informal carers (e.g. implementation of respective protocols in public service provision or healthcare settings), these accompanying measures are not discussed in this report.

Figure 16. Different types of support measures for informal carers

Financial support

- Direct cash benefits
- Indirect cash benefits
- Formal employment

Social security benefits

- Pension credits
- Accident insurance
- Unemployment insurance
- Health insurance

Care leave

- Paid care leave
- Unpaid care leave

Measures supporting carers' well-being

- Respite care
- Counseling and psychological support
- Training and educational interventions

3.1.1 Financial Support

An important financial support measure for informal carers is the provision of cash benefits. These benefits vary in type, with the key distinction being whether they are directed at the caregiver directly or at the person in need of care. The different types of cash benefits are typically needs-tested and/or means-tested.

Glendinning (2006) identifies four types of cash benefits. Two of them are specifically directed at informal carers. In the first model, informal carers receive financial compensation to offset income losses due to caregiving. Such benefits are often available alongside care leave policies and directed at people in employment (see Section 3.1.3). This approach aims to both recognise caregiving efforts and encourage continued participation in the labour market by enabling carers to perform caregiving duties for a certain period without having to quit work. In the second model, informal carers receive payments for the care they provide independently of their labour market situation and potential lost income.

Eligibility criteria often consider factors such as the relationship between the carer and the care recipient (e.g., limited to family members), co-residency, and the level of caregiving effort (Rocard & Llena-Nozal, 2022). In terms of impact, higher cash benefits can help reduce poverty by compensating for lost income. However, they may trap carers in low-income positions or discourage (full) labour market participation, which affects women particularly and may increase gender inequalities (Brimblecombe et al., 2018).

Two additional models of cash benefits are directed at the person in need of care, with informal carers only benefitting indirectly. In the first model, the person in need of care receives a cash benefit, which he/she can use to purchase formal care services or compensate informal carers. In the second model, the person in need of care also receives a cash benefit but is not required to justify its use. The funds may be spent on care services, informal caregiver compensation, or other expenses. While these models prioritise choice for care recipients, they also make carers financially dependent on them. Another concern is that these models can monetise family relationships, with individuals in need of care selecting from relatives who compete for the paid caregiving role (Wieczorek et al., 2022).[5]

A study of 33 OECD countries by Rocard and Llena-Nozal (2022) found that about two-thirds of these countries offer at least one type of cash benefit, either for informal carers directly (20 countries) or for individuals in need of care (13 countries). With five countries providing both types.

Beyond carer allowances, some countries offer formal employment arrangements for informal carers, although these have often been implemented as small-scale projects at the municipal or regional level (Bischofberger & Vetter, 2023; Radlherr & Österle, 2025). These arrangements differ in terms of who acts as the employer, such as the public sector, a quasi-public or non-profit organisation established for that purpose, a social service provider, or the person in need of care. While such arrangements have the potential to provide financial security for informal carers, tensions remain between formal employment and the application of general labour laws.

Another form of financial support for informal carers is tax relief. However, it is not widely regarded as a significant measure in many countries. Moreover, tax relief is typically not linked to the caregiver status but instead targets households with dependent family members (Rocard & Llena-Nozal, 2022).

3.1.2 Social Security Benefits

Another important type of support measure for informal carers is social security benefits, which include pension credits, accident insurance, unemployment insurance,

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[5] Although informal carers may benefit from cash benefits directed at the person in need of care, in the subsequent sections, we will only consider direct financial support for informal carers.

and health insurance.[6] They play a crucial role in ensuring that informal carers have a secure income upon retirement, access to treatment, rehabilitation and compensation in the event of accidents, as well as the ability to claim unemployment benefits if needed. There is considerable variation among countries in terms of whether these benefits are linked to carers' employment status or not. While many European countries have introduced social security benefits for informal carers, there is considerable variation among countries in terms of eligibility and whether benefits are linked to carers' employment status (Rocard & Llena-Nozal, 2022: 60; Zigante, 2018: 27-28).

The implementation of social security benefits varies across countries. In some cases, they are directly linked to cash benefits for informal carers. However, receiving cash benefits does not necessarily mean that social security benefits are included. Among the OECD countries examined by Rocard and Llena-Nozal (2022), one-third of those offering cash benefits did not provide any accompanying social security coverage. In other countries, social security coverage exists as an independent support measure, separate from cash benefits. Informal carers can also be eligible for pension credits if they reduce their working hours due to caregiving responsibilities. Typically, pension contributions and other social security benefits are funded by the government. However, in some countries, employers must continue to pay pension contributions for informal carers during periods of caregiving (Rocard & Llena-Nozal, 2022: 44).

3.1.3 Care Leave and Flexible Working Arrangements

Care leave is a support measure specifically designed for employed informal carers. High-intensity informal caregiving is linked to reduced labour market participation, negatively impacting income (accumulating over a lifetime), social security, and gender equality. Women, in particular, are more likely to provide intensive informal care, to reduce their working hours or exit the labour market altogether (e.g., Bauer & Sousa-Poza, 2015). Care leave aims to facilitate the combination of caregiving and gainful employment.

Rocard and Llena-Nozal (2022) identified a general trend in OECD countries towards better supporting employed informal carers, primarily through unpaid or paid care

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[6] Some countries have introduced health insurance for informal carers (Rocard & Llena-Nozal, 2022), in particular, where access remains linked to social security or employment-related arrangements. In many other European countries, healthcare coverage is universal or near-universal, and access is typically provided through general health system arrangements rather than through policies targeted specifically at informal carers. This is also the case for Germany, Finland, Lithuania, and the Netherlands, where no specific health insurance measures for informal carers exist.

leave. Their study of 33 OECD countries found that nearly two-thirds, mainly in Europe, provide some form of leave for caring for an older person, with half offering paid care leave. However, substantial differences exist regarding leave duration, eligibility criteria, and compensation levels. When compensation is not based on previous earnings, lower-income individuals—often women—are more likely to take leave. This may reinforce existing gender inequalities in caregiving patterns.

In general, paid care leave is often too short and mainly supports carers during critical transitions, such as a hospital discharge or end-of-life care. This reflects an understanding of informal caregiving as an exception rather than acknowledging that, for many, caregiving for persons in need of long-term care is an ongoing part of everyday life. Unpaid care leave tends to be longer, though there are also large country differences in these cases. Differences also exist within some countries between the public and private sectors, where unpaid leave in the private sector is shorter than in the public sector (Rocard & Llena-Nozal, 2022: 64-66).

Eligibility criteria for both paid and unpaid care leave vary. In many countries, the care recipient must be a family member or a member of the same household, and some countries limit leave schemes to carers of terminally ill relatives. Additionally, in some cases, employers can refuse leave requests, making access to care leave uncertain (Rocard & Llena-Nozal, 2022: 61-64). As an alternative to full-time leave, some countries offer part-time leave or allow workers to reduce their hours for caregiving. However, such options remain uncommon (Rocard & Llena-Nozal, 2022: 50).

Beyond care leave, additional support measures, such as the right to flexible working hours and telework, can help informal carers remain employed. However, caregiving is often unpredictable in duration and intensity, requiring flexibility beyond standard arrangements. Allowing carers to divide leave into multiple periods or request temporary part-time work may be as crucial as implementing flexible scheduling options, such as week-to-week adjustments based on caregiving demands (Wieczorek et al., 2022: 153). Currently, however, such measures are typically left to individual employers' discretion.

Overall, care leave is a vital tool for supporting employed informal carers, and evidence suggests that paid care leave can enhance carers’ ability to stay in the workforce, especially when combined with flexible work arrangements (Brimblecombe et al., 2018). However, care leave should be part of a broader policy framework that not only helps carers balance work and care but also reduces the overall burden of informal caregiving and recognizes carers’ rights to rest and personal time (Sardadvar & Mairhuber, 2018).

3.1.4 Measures to Improve Carers' Well-Being

A key category of support measures for informal carers in Europe focuses more directly on promoting carers' well-being. This includes training interventions, counselling services, health check-ups, psychological support, and respite care.[7] In recent years, most European countries have made progress in expanding these measures, although their availability, accessibility, and organisation continue to vary considerably across countries (Courtin et al., 2014; Rocard & Llena-Nozal, 2022).

Training interventions and counselling are particularly valuable for informal carers who may lack disease-related knowledge and care skills. Improved knowledge and care competencies can benefit not only the informal carers themselves by reducing stress and uncertainty but also enhance the quality of care received by those they support (e.g., Suhonen et al., 2015).

While the importance of supporting informal carers through training and counselling is widely acknowledged, the services provided across European countries tend to be highly diversified and fragmented. These services often span multiple levels of government and involve a broad array of stakeholders, including civil society organisations, public authorities, welfare associations, and self-help groups. One of the major challenges identified is the lack of centralised coordination and networking structures, which frequently results in fragmented service landscapes, making it difficult for carers to identify and access appropriate support. Some countries, however, have developed more comprehensive and integrated approaches, for example, where municipalities are legally required to provide counselling and support services for informal carers, ensuring a minimum level of provision at the local level (Merkle, 2018).

Despite the availability of diverse services, significant digital support services for carers remain scarce, as a 2018 study found (Merkle, 2018). However, more recently, some countries have made more efforts in this regard (Wieczorek et al., 2022: 154). While digital technologies hold potential for training and counselling, face-to-face group sessions often provide carers with additional opportunities to share experiences and build supportive peer networks, which can be equally important.

Respite care represents another crucial form of support for informal carers. Designed to offer caregivers temporary relief from their duties, respite care is widely regarded

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[7] Informal carers in most European countries are covered by general health insurance. Therefore, we limit the discussion of physical and mental health measures to those that are specifically designed for, and accessible only to, for informal carers.

as one of the most important services for alleviating caregiver burden. These services can take different forms, including home care, adult day services, or overnight care in institutional settings, and may be provided by nurses, professional caregivers, or family and friends. The duration and frequency of respite care differ across countries, as services may range from short daytime breaks to longer vacation periods. In most countries, public support for respite care is provided in kind. Only a few countries offer financial support for respite care (Rocard & Llena-Nozal, 2022: 33). Moreover, legal entitlement to respite care is not universal across Europe, and in many countries, public subsidies are limited to those on lower incomes (Wieczorek et al., 2022: 153-154).

In the following, we describe which policies—along the four categories discussed here—Finland, Germany, Lithuania, and the Netherlands have implemented to better support informal carers.

3.2 Support for Informal Carers in Finland[8]

In Finland, over one million people regularly provide some form of help to family members or friends with limited functional capacity or who are ill, and about 350,000 individuals are primarily responsible for the care of family members or friends (Ilmarinen, 2025).[9] Finland also has one of the best-organised carer organisations (Carers Finland) in Europe, due to government funding for its central and member associations. Carers Finland has almost 60 local associations across the country, with around 100 paid staff members, and 17 staff members in the central association.

In Finland, public support for informal carers in the most demanding care situations is regulated by the Act on Support for Informal Care, originally passed in 2006 and amended a few times, most recently in 2022. Before that, since 1993, informal carer support had been part of the Social Welfare Act. The current Act provides the legal framework for informal carer support and defines basic eligibility criteria.

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[8] The information presented on the specific support measures introduced in Finland, Germany, Lithuania, and the Netherlands (Sections 3.2 to 3.5) is based on expert interviews (see Annexe A), academic and grey literature, as well as government and informal carer organisations' websites. In particular, information on support for informal carers on government websites was often available only in the respective national languages. To access this information, we used the built-in translation tool of the Firefox web browser as well as the open access version of DeepL (deepl.com). As automated translation tools were used, minor inaccuracies or misinterpretations in the translated information cannot be entirely ruled out.

[9] In 2023, the total Finnish population was 5.6 million (Eurostat, 2024).

Informal carer support is organised at the regional level by 21 well-being service counties, plus the City of Helsinki. These counties are relatively new entities, established in 2023 as part of a major reform of health and social services (prior to the reform, responsibility lay with the municipalities). The counties are now responsible for organising and providing health and social services, including support for informal carers. However, support for informal carers in Finland is not a subjective right. This means that, although the well-being service counties are formally responsible for organising and providing support, financial constraints and political priorities sometimes prevent them from guaranteeing access for all recognised informal carers. In addition, while the Act on Support for Informal Care stipulates the basic services and eligibility criteria, the well-being service counties apply their own, more detailed criteria. Even though the state grants the funding for social and health care, the counties decide for themselves how they provide services in detail, including support for informal carers. As a result, specific services and eligibility criteria vary across counties.

Informal carers who provide care at or above a certain threshold of intensity can apply for an agreement with the county where the care recipient lives. This agreement formally recognises them as informal carers and specifies both their caregiving duties and the benefits and services they are entitled to as informal carers. Eligibility for these agreements is not restricted by the care recipient’s age or condition: care recipients can be disabled or chronically ill children or adults, or older persons with care needs. While the general capability to provide care is assessed, there is no age limit for the carers themselves. Even those above retirement age remain eligible. In fact, among Finland’s roughly 51,000 recognised informal carers in Finland, about 60% are above the age of 65 (Ilmarinen, 2025).

Support for informal carers is provided as a package of measures under the umbrella of the carer agreement (Sosiaali- ja terveysministeriö, n.d.). This agreement should grant access to financial support in the form of a carer allowance, regular respite care, pension credits and accident insurance. In addition, training and health and well-being check-ups should be organised when needed, as well as certain formal care services according to the needs of the care recipient. Support is usually provided at three to four different levels, depending on the care situation and the carer’s degree of involvement. The level is determined by factors such as how many times per day the carer provides assistance, whether they also provide care at night, and the overall intensity and demands of the care situation. Typically, to qualify for the lowest level of informal carer support, a carer must at least (a) provide care every day, (b) provide care multiple times a day, and (c) assist with several daily activities (e.g., personal assistance and household tasks) (Ilmarinen et al., 2024).

Although Finland has an established a comprehensive system of informal carer support, access to most measures is tied to being formally recognised as an informal carer through the agreement with a well-being service county. As a result, only a relatively small share of informal carers—about 51,000 of a total of about 350,000—have access to the public support system according to the Act on Support for Informal Care. However, for the current legislative period, the government has established a dedicated fund for projects supporting non-recognised informal carers, and they may still have access to additional benefits and support services such as care leave, training, and peer support. Additionally, the Social Welfare Act defines eligibility for respite care for informal carers in demanding care situations, but without an agreement.

Financial support

- **Carer allowance** (part of the informal carer agreement): The carer allowance is usually structured in three or four levels. While the exact amount varies somewhat between counties, the minimum allowance is nationally regulated and was €472 per month in 2025. About 70% of recognised informal carers receive the lowest level of the carers allowance (Ilmarinen, 2025). A government proposal to raise the minimum carer allowance is currently under discussion; if passed, it will take effect in 2026. The minimum allowance will then amount to €530 per month.

  The allowance is granted solely based on the intensity of care provided. Income, employment status, or other financial resources do not affect eligibility. While the allowance is officially intended only as compensation for caregiving, in practice, carers who qualify usually provide care at such an intensive level that (full-time) paid employment is often not possible. For many, therefore, the allowance is a form of income support. However, those facing financial hardship may also be eligible for additional financial benefits that are independent of their status as informal carers. According to Carers Finland, a tension within the current regulations is that the care allowances are counted as income when eligibility for most social benefits is assessed.

Social security benefits

- **Pension credits and accident insurance** (part of the informal carer agreement): Recognised informal carers are covered by accident insurance, covering accidents during caregiving activities, and—if they are of working age (up to 68 years)—accrue pension credits during their caregiving period. Accrual is based on the carer allowance, though the accrual rate is lower than for paid work, impacting overall pension contributions.

Care leave

In Finland, employees have various leave options to assist family members in need of care (Työ- ja elinkeinoministeriö, 2022).

- **Temporary childcare leave**: Parents whose children become suddenly ill may take one to four days of leave for each such illness. During this time, they continue to receive their wages.

- **Absence for compelling family reasons**: This leave applies if family members fall unexpectedly ill or suffer an accident. The duration of such absence is not specified, and it is usually unpaid.

- **Agreement-based absence to care for a loved one**: Based on an agreement with their employer, employees may take this unpaid leave if they need to care for a family member or a loved one requiring special care. There are no specifications regarding the duration of this leave.

- **Informal care leave**: Since 2022, all employed informal carers have the option to take up to five unpaid working days of care leave per year to support a person living in the same household. The prerequisite is that this person needs significant assistance or support because of a serious illness or serious injury that has significantly reduced their functional capacity and requires the immediate presence of a carer.

Support for carers' well-being

- **Respite care** (part of the informal carer agreement): Depending on the intensity of caregiving, informal carers are entitled to two to three days of respite care per month, during which someone else assumes the carer's responsibilities. Respite care can take different forms: the people in need of care may be temporarily placed in a care home or in a foster care home, or professional care or foster care may be provided at home. Counties may either deliver these services directly or issue vouchers that allow informal carers to purchase them, but the vouchers usually do not cover the full expenses of the respite care. Another option is for other family members or any other trusted person to step in temporarily; in such cases, they sign substitute agreements with the counties, formalising their role and responsibilities. There are about 10,000 substitute informal carers in Finland. The fee they receive, on average, ranges from €80 to €120 per day.

  While experts consider respite care one of the most important support measures for informal carers, only about 50% of the available respite days are actually used (Ilmarinen et al., 2024). One key reason is the limited flexibility in scheduling those days. Additionally, long distances to care homes prevent informal carers from using respite care (and the travelling expenses to respite care are usually covered by informal carers themselves).

- **Health and well-being check-ups** (part of the informal carer agreement): Since 2016, informal carers can access health and well-being check-ups. However, as the law only requires that these be provided "when needed", counties vary in how systematically they are offered.

- **Training, coaching, counselling, and peer support**: The law stipulates that for informal carers with a formal agreement, training is provided when needed. Furthermore, training, coaching, counselling, and peer support are often provided by NGOs or churches in collaboration with the counties. Carers Finland, the national organisation representing informal carers, plays a particularly active role in delivering such activities.

3.3 Support for Informal Carers in Germany

It is estimated that in Germany, 7.1 million individuals are informal carers (Zentrum für Qualität in der Pflege, 2025).[10] In 1995, a social care insurance was introduced: individuals covered by public health insurance were automatically included, while those with private health insurance were required to contribute to private long-term care insurance (Bundesministerium für Gesundheit, 2025a). The political debates that eventually led to this system started as early as 1974 (Naegele, 2014).

There are various carer organisations in Germany. wir pflegen! is a nationwide active association of informal carers cooperating in various committees with the German National Association of Older Citizens' Organisations. It is also represented on the German Independent Advisory Board on Work-Care Reconciliation (see Section 3.7.3). Moreover, wir pflegen! cofounded Eurocarers, the European network of informal carers associations. In addition, several other informal carers' associations exist (e.g. Pflegende Angehörige e.V.).

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[10] In 2023, the total population of Germany was about 83.1 million (Eurostat, 2024).

According to the German Social Code, care should primarily be provided by informal carers within the care receiver's home environment, with formal care considered secondary. Access to formal care services is usually subject to co-payments. Several types of support measures are available for informal carers (Bundesministerium für Gesundheit, 2025b). However, experts highlighted significant regional differences in the availability of support, particularly between rural and urban areas.

Financial support

Germany does not have a carer allowance, and direct financial support for informal carers is only available in connection with one type of care leave (see below). Also, in connection with some care leave options, informal carers are entitled to take out interest-free loans (see below). There is currently also no scheme that allows informal carers to be formally employed in their caregiving role. However, recent political debates have suggested introducing such a model at the regional level (Sozialdemokratische Partei Deutschlands Baden-Württemberg, 2025).

Social security benefits

Informal carers have access to different types of insurance based on their caregiving tasks.

- **Pension insurance:** The long-term care insurance pays contributions to an informal carer's pension insurance (*Rentenversicherung*) if the carer provides at least 10 hours of care on at least two days per week to one or more individuals and is not engaged in paid employment for more than 30 hours a week. If the carer already receives a partial pension, contributions from the care insurance can also continue. The amount paid depends on the level of care needed and ranges from €131.65 to €696.57 per month.

- **Accident insurance:** Informal carers are also insured against accidents without paying contributions. The insurance covers activities defined as care tasks under care insurance regulations, household management activities, and direct travel to and from the person in need of care if the care receiver and the informal carer do not live in the same household.

- **Unemployment insurance:** If an informal carer quits employment to provide care, their statutory unemployment insurance contributions are covered by the care insurance. This ensures that the informal carer is eligible for unemployment benefits if they are unable to return to work immediately after their caring role ends.

Care leave

Informal carers in Germany can use several types of care leave.

- **Short-term leave from work** (*kurzzeitige Arbeitsverhinderung*): All employees are entitled to take up to 10 days of short-term leave from work per year to care for close relatives (with care needs equivalent to at least care level 1[11]). During this time, informal carers receive 90% of their net income as a care support allowance (*Pflegeunterstützungsgeld*) if their employer does not continue to pay their salary (Bundesministerium für Gesundheit, 2025c). If several people take short-term leave from work for the same care recipient, they can collectively only claim a maximum of 10 days per year.

- **Care time** (*Pflegezeit*): Care time allows employees to take full or partial leave from work to care for a close relative (applies to all care levels) for up to six months, without financial compensation. This entitlement applies only in organisations with a minimum of 15 employees (In organisations with fewer than 15 employees, care time may be granted on a voluntary basis). If the person receiving care is a minor, this leave can also be claimed when care is provided in a residential facility. During this period, informal carers may apply for an interest-free loan to help cover costs.

- **Family caregiver leave** (*Familienpflegezeit*): Family caregiver leave allows employees to reduce their working hours for up to 24 months to provide care for a person with at least care level 1. It is available only in organisations with a minimum of 25 employees, and informal carers must work a minimum of 15 hours per week during this period. No financial compensation is offered, but informal carers may apply for an interest-free loan while claiming family caregiver time.

- **Support in the final phase of life** (*Begleitung in der letzten Lebensphase*): This unpaid leave allows employees to take up to three months off work to accompany a close relative during their final phase of life. It is available in organisations with a minimum of 15 employees.

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[11] Germany operates a system with five care levels, ranging from “minimal impairment of independence” (level 1) to “severe impairments of independence with special requirements for nursing care” (level 5). Based on this assessment, individuals in need of care gain access to services and financial support.

A medical certificate confirming that death is inevitable and expected within the coming months is required, but no formal care needs assessment is necessary. Informal carers are also eligible for an interest-free loan when they claim support in the final phase of life.

Support for carers' well-being

Several measures were introduced in Germany to support the well-being of informal carers. These include information services, counselling, training, and two types of respite care.

- **Care counselling** (*Pflegeberatung*): The care insurances offer care counselling to insured individuals who have applied for support, and these individuals have a legal right to it. Care counselling is not compulsory for informal carers. If informal carers prefer independent advice rather than advice provided by their care insurance, they can request a voucher to redeem at another organization. Care counselling can also be provided online on demand or at a community care point (see below). Care insurance providers are also obliged to inform about the respite measures available to informal carers.

- **Community care points** (*Pflegestützpunkte*): Community care points provide support to informal carers and persons in need of care. They can be established upon initiative by a federal county by health and care insurance funds. Community care points provide information and support in organizing care. However, according to a recent study, less than 50% of inhabitants are aware of the community care points (Kohl et al., 2022).

- **Care courses** (*Pflegekurse*): Care insurance funds also provide training in the form of care courses. These courses are available to informal carers and to individuals interested in volunteering in care. Participation in these courses is free of charge.

- **Substitute care** (*Verhinderungspflege*): Substitute care means that either someone from the care recipient's social network or a formal carer temporarily takes over when the informal carer is on vacation, ill, or unable to provide care. The long-term care insurance covers the costs of substitute care for up to six weeks per year. Eligibility requires a least care level 2, and the applicant must have provided at least six months of home care prior to applying.

- **Short-term respite care** (*Kurzzeitpflege*): Short-term respite care means that full residential care is provided while the informal carer is unavailable. The care insurance covers up to eight weeks of respite care per year, with costs up to €1,854. To qualify, the person requiring care must have at least care level 2. An individual with care needs can claim up to €3.539 annually for both types of care together.

3.4 Support for Informal Carers in Lithuania

There are no official numbers for the number of informal carers in Lithuania. However, the country's constitution stipulates that relatives are responsible for providing care to those in need. Nevertheless, over the past two decades, Lithuania has expanded its formal LTC system and made progress in integrating health and social care services (World Health Organization, 2024). These developments have also improved the situation of informal carers, as experts highlighted. In addition, Lithuania has introduced several policies to support informal carers directly (Lietuvos Respublikos Socialines Apsaugos Ir Darbo Ministerija, 2025). However, Lithuania's LTC system remains heavily dependent on informal carers (World Health Organization, 2024) and compared to the other countries included in this study, support measures for informal carers remain relatively limited. Lithuania also does not have a national carers organisation.

Financial support

Lithuania does not have a national carer allowance; however, informal carers may qualify for financial support if they are unable to work due to caregiving responsibilities.

- **Sickness benefits**: In Lithuania, informal carers in employment may receive a financial benefit when they care for a sick family member and are unable to work during that period. The benefit serves as an income replacement for the duration of caregiving. To access it, carers must obtain a certificate of incapacity to work from a doctor who has diagnosed the family member. Eligibility requires coverage under social health insurance (at least three months within the last 12 months or six months within the last 24 months; specific rules apply to self-employed persons). Exceptions apply for individuals under 26 in education or training, those who have performed military service, and those on parental leave without receiving parental benefits.

  The sickness benefit is administered and paid by the state social insurance fund. It amounts to 65.94% of the recipient's pre-tax income and may not be lower than 11.64% of Lithuania's average monthly salary. From this amount, income tax (15%) and social health insurance contributions (6%) are deducted.

The maximum benefit period depends on the care recipient and his/her condition:

  - Adults (e.g. spouse, parent) or children aged 14 and over: up to 14 calendar days (only working days).
  - Children under 14: up to 21 calendar days.
  - Children under 7 with a severe disability undergoing treatment: up to 120 days per calendar year.
  - Children under 18 with a serious illness: up to 180 days.
  - Children under 18 with an especially serious illness: up to 364 days.

- **Unemployment benefits:** Informal carers may qualify for unemployment benefits if they had at least 12 months of unemployment coverage during the last 30 months prior to registering with the Employment Service. Unemployment benefits are granted for nine months and consist of a fixed and a variable part: in 2025, the fixed part was €241.54, while the variable part is linked to the beneficiary's previous salary and insurance contributions. The total benefit is higher during the first months and gradually decreases over time. Informal carers are eligible as long as they remain available to take up employment again. This means that if the Employment Service offers them a suitable job or participation in an active labour market measure, they have to accept; otherwise, they lose their entitlement to unemployment benefits.

Social security benefits

- **Pension and unemployment insurance:** Informal carers of persons living at home may receive pension and unemployment insurance coverage. To qualify, the person in need of care must have been formally assessed as having "a special need for permanent nursing" or "a special need for permanent care". The carer must not have an insured income and must not have reached retirement age.

Care leave

The Lithuanian Labour Code (Article 184)[12] provides several forms of unpaid care leave. Among these, the following may apply to informal carers:

- Up to 30 calendar days of leave for employees caring for a disabled child under 18.
- Up to 30 calendar days of leave per year for employees who are the sole carer of a person with formally assessed continuous care needs (subject to agreement with the employer).
- Leave for the duration recommended by a healthcare institution when caring for a sick family member.

During this leave, informal carers may be eligible for sickness benefits (see above).

Support for carers' well-being

- **Temporary respite care:** Temporary respite care is available for carers of individuals assessed as having a "special need for permanent nursing or care". Respite care allows informal carers to take a temporary break from their responsibilities and can be provided either at home or in an institution. It is available for up to 720 hours per year per care recipient.

- **Social services:** Informal carers providing care at home may apply for social services in their municipality, including social services directed at themselves. These may include preventive social services, such as information about social assistance, counselling, self-help groups, or other general social services, such as transportation, food, clothing, and other daily support. When informal carers experience emotional distress, they may be offered psychosocial or crisis management assistance, which can be provided by social workers or psychologists.

3.5 Support for Informal Carers in the Netherlands

In the Netherlands, about 1.9 million individuals aged 16 and older provide an average of 13 hours of informal care per week (Centraal Bureau voor de Statistiek, 2025).[13] There are several informal carer organisations in the country. MantelzorgNL

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[12] https://e-seimas.lrs.lt/rs/legalact/TAD/TAIS.382280/?utm

[13] In 2023, the total population of the Netherlands was about 17.8 million (Eurostat, 2024).

is a nationwide association actively involved in government initiatives such as the informal carer agenda (see Section 3.7.1). Another informal carers' organisation is mantelzorgelijk.nl.

The Netherlands has a strong tradition of formal care. Since 2015, municipalities have been responsible for funding long-term care. Informal care has attracted attention as a policy issue due to budget cuts since the early 2000s. In 2017, the Central Court of Appeal ruled that there are limits to what can be expected of informal carers (Eurocarers, 2023).

Policy measures to support informal carers in the Netherlands are based on a broad definition of informal care, including assistance provided to relatives, friends, and neighbours. National-level measures include care leave, increased flexibility in working hours, as well as access to information, counselling, and training (Heeger-Hertter & Koopmans, 2023). Additional forms of support are offered at the municipal level, but these can vary considerably depending on the informal carer's place of residence.

Financial support

The Netherlands does not have a national carer allowance, although some individual municipalities may provide small amounts of financial support or vouchers to informal carers (*mantelzorgcompliment*). There is also no formal scheme for the employed persons in an informal carer role in the Netherlands. However, informal carers can receive payments through the personal budgets of care receivers. These payments do not cover social security or pension contributions, but they are considered taxable income and recognised in applications for unemployment benefit (Eurocarers, 2023).

Social security benefits

There are no social security benefits, such as pension contributions, for informal carers in the Netherlands.

Care leave

There are three options for care leave in the Netherlands:

- **Emergency care leave** (*calamiteitenverlof*): Emergency care leave is available to employees when an emergency situation arises. It can be taken for a couple of days, during which wages continue to be paid. This leave can be claimed for various reasons, including when caring for first- and second-degree relatives, household members, friends, or neighbours.

- **Short-term care leave** (*kortdurend zorgverlof*): Short-term care leave allows employees to take up to two weeks off from work per year. During this time, informal carers receive 70% of their pay. This leave can be used to provide care for a first- or second-degree relative, a household member, a friend, or a neighbour. Employers may deny leave for serious business reasons. Collective agreements in certain professions may offer more favourable conditions.

- **Long-term care leave** (*langdurend zorgverlof*): Long-term care leave allows employees to take up to six weeks off per year without pay. It can be used to care for a first- or second-degree relative, household member, friend, or neighbour who has care needs or a life-threatening illness. Employers may deny the leave for serious business reasons. Collective agreements in various professions may offer more favourable conditions. Approximately 2% of employees take long-term care leave.

In addition, two types of flexible working-time arrangements are available for informal carers in the Netherlands.

- **Flexible work from home** due to personal circumstances, including caregiving duties. This flexible working arrangement allows employees to work from home or outside their usual business hours, but may be declined by the employer due to a serious business reason.

- **Time arrangement** with focus on informal caregivers: The time arrangement allows employees to take leave for part of the workday on a weekly basis, or for a weekend each month to obtain respite care.

Support for carers’ well-being

Support for carers’ well-being includes, in particular, information, training, and legal advice (Dijk en waard, 2025).

- **Information and counselling**: There is a central support phone line for informal carers (*mantelzorglijn*), and informal carers’ support points (*mantelzorg steunpunten*) cooperate with MantelzorgNL and provide advice locally (MantelzorgNL, 2025).

- **Respite care:** Informal carers can apply for respite care through their municipality, which sometimes ask for minor contributions. In some cases, respite care is provided free of charge by volunteers, or the costs may be covered by health insurance funds. However, there are no national regulations specifying the extent of respite care to which informal carers are entitled.

3.6 Support Measures in Comparative Perspective

Finland, Germany, Lithuania, and the Netherlands have all implemented support measures for informal carers, although their focus differs across the four categories we analysed: financial support, social security benefits, care leave, and support for carers' well-being.

In terms of **financial support**, Finland is the only one of the four countries with a national carer allowance for informal carers. A distinctive feature of the Finnish carer allowance is that it comes with a package of other support measures directly tied to it, meaning that carers do not have to apply for each form of support separately. This is a recommended approach to reduce the bureaucratic burden caused by multiple applications. In contrast, some municipalities in the Netherlands provide small monetary tokens of appreciation, but these are neither consistent nor comparable to Finland's nationwide allowance. Germany, Lithuania, and the Netherlands do not have a dedicated carer allowance, though they offer financial support during certain types of care leave. Germany also provides interest-free loans for informal carers during unpaid care leave. While this option is reportedly not very popular, it illustrates the range of financial support mechanisms that have been implemented to support carers.

Social security benefits for informal carers exist in Finland, Germany, and Lithuania. Germany offers the most comprehensive package, including pension, accident, and unemployment insurance. Finland provides pension and accident insurance, while Lithuania offers pension and unemployment insurance. The Netherlands is the only country of the four without any such benefits for informal carers.

Regarding **care leave**, Finland has the least generous paid leave options, offering paid leave only for one to four days to parents whose children have suddenly fallen ill. In comparison, Germany allows 10 days, and Lithuania (for carers of adults) and the Netherlands allow up to two weeks. During these periods, carers in Finland receive their full salary, compared with 90% in Germany, 70% in the Netherlands, and 65% in Lithuania. Lithuania stands out for its extensive provisions for carers of minors with disabilities or serious illnesses. For example, those caring for children (under 18) with a serious illness are entitled to 180 days of paid leave, and even more generous leave applies for children with an especially serious illness. Furthermore, in Lithuania, informal carers may also be eligible for unemployment benefits during caregiving periods. Germany distinguishes itself in terms of unpaid leave options: full-time leave of up to six months and part-time leave (with a minimum of 15 working hours per week) for up to two years. However, access depends on employer size, as these entitlements only apply to workplaces above a certain threshold. In smaller companies, employers may grant such leave voluntarily.

All countries provide some form of **support for carers' well-being**. All four countries offer information and counselling for carers through websites, phone lines and/or community care points. Self-help groups and training courses are also available, although these are mostly provided by NGOs at the municipal or regional level and vary considerably. Finland is the only country with systematic health and well-being check-ups for informal carers. Lithuania also offers psychological support, but in a less structured way. In Germany and the Netherlands, no national programmes address carers' physical or mental health directly, although regional or NGO-based initiatives may exist.

Respite care is a key support measure. Finland, Germany, and Lithuania all have systematic provisions. In Finland, carers can access two to three days of respite care per month, while in Lithuania, they may claim up to 720 hours (i.e., 30 days) per care recipient per year. Germany offers more than €3,500 annually in compensation for respite care. In the Netherlands, respite care is arranged at the municipal level and sometimes included in supplementary health insurance. Certain recipients under the LTC or youth law are also entitled. However, compared with the other countries, Dutch provision is less systematic and lacks national regulations defining carers' entitlements.

The differences in caregiving support across these countries reflect variations in welfare state development, values, and policy priorities. For example, care leave does not play a significant role in Finland's support system, whereas Germany, Lithuania, and the Netherlands offer more options in this regard. This means that while Finland does not distinguish between different types of carers, the other countries emphasise support for working carers more strongly. The role of the state also differs: the Netherlands stands out for organising support mainly at the municipal level. In Finland, support is organised at the county level, but national legislation still defines basic types of support and eligibility, whereas in Germany, the state plays an even stronger role. These contrasts highlight that while all four countries acknowledge the importance of informal carers, they pursue support strategies shaped by different welfare traditions and policy goals.

It is important to underline, however, that the situation of informal carers is shaped not only by policies directly targeting them but also, more broadly, by overall levels of welfare state funding and, more specifically, by resources allocated to long-term care. Experts from both Finland and the Netherlands stressed that their countries have undergone severe budget cuts in welfare spending in recent years. These cuts have affected funding for health and social care, social security benefits and NGOs such as carer organisations. In long-term care, reduced budgets have resulted in fewer available formal services, particularly in institutional care. Access criteria have become stricter, meaning that only those with the most severe needs now qualify.

These austerity measures have placed greater pressure on informal carers. While this makes support for informal carers even more important, experts in Finland noted that funding dedicated specifically to such support has also been subject to reductions.

Beyond sufficient public funding, access to formal long-term care may also be limited by shortages of skilled staff or high co-payments for certain types of care, as German experts pointed out. With formal services harder to access and staffing shortages becoming more acute, collaboration between formal and informal care was also perceived as a challenge in some countries. For example, experts reported that working conditions that leave little time for interaction, combined with the increasing delegation of tasks away from formal carers, complicate collaboration. Against this backdrop, experts emphasised the need for stronger funding of long-term care and measures to reduce workforce shortages to improve conditions for informal carers.

While experts from Finland, Germany, and the Netherlands largely pointed to a trend of cutbacks and growing barriers to accessing formal services, Lithuania, in contrast, has expanded its long-term care provision over the last two decades and has made progress in integrating health and social care services. While experts underlined that there is still room for improvement, they highlighted that the increased funding and the expansion of both the quantity and variety of services have led to significant improvements for informal carers in the country.

Table 1. Overview of support measures in the four countries

	Finland	Germany	Lithuania	Netherlands
Financial support	• Allowance with 3-4 levels, minimum €472 (in 2025)	• Financial support during some types of care leave • Interest-free loans available together with all types of leave except short-term leave	• Financial support during some types of care leave • Unemployment benefit in case of contributions during previous 30 months	• Financial compensation during some types of care leave • Small amounts of monetary support in some municipalities
Social security benefits	• Pension insurance • Accident insurance	• Pension insurance • Accident insurance • Unemployment insurance	• Pension insurance • Unemployment insurance	Not available

Care leave	• Temporary childcare leave for suddenly ill children (1-4 days, 100% income)
	• Absence for compelling family reasons (period unspecified, unpaid)
	• Agreement-based absence to care for a loved one (period unspecified, unpaid)
	• Informal care leave (5 days per year, unpaid)
		• Short-term leave (10 days, 90% income)
		• Care time (6 months, no financial compensation)
		• Family caregiver time (24 months, no financial compensation)
		• Support in final phase of life (3 months, no financial compensation)
			• Sickness benefit in case of inability to work due to care (65% of income)
			  • Adult (14 days)
			  • Child (21 days)
			  • Child with disability younger than 7 (120 days)
			  • Child younger than 18 with serious illness (180 days)
			  • Child younger than 18 with especially serious illness (364 days)
				• Emergency leave (couple of days, 100% income)
				• Short-term (2 weeks, 70% income) care leave
				• Long-term care leave (6 weeks, unpaid)
				• Flexible working (from home, any time)
				All: care for first and second degree relatives, household members, friends or neighbours

Support for carers' well-being	• Information • Counselling • Training • Health and wellbeing check-ups *Respite care* • 2-3 days per month	• Information • Care counselling • Care courses • Community care points *Respite care* • Substitute care • Short-term respite care • Both together up to value of 3.539 € annually	• Information • Counselling • Daily support e.g. transportation, food, clothing • Psychosocial or crisis management assistance *Respite care* • Up to 720 hours annually per care recipient	Through MantelzorgNL and partner organisations • Information • Legal advice • Training • Phone line • Care points *Respite care* • Can be applied for at municipality • For some included in supplementary health insurance • If person receives care under LTC or youth act, paid through these → no regulations as to the amount of respite support that carers should be able to rely on

3.7 Good Practices of Advancing Informal Carer Policies

The countries studied have not only implemented a variety of measures to support informal carers but have also pursued different approaches to advancing informal carer policies and involving a broad range of stakeholders in these processes. The experts we interviewed highlighted four good practice examples. In the Netherlands, they referred to the implementation of an informal carer agenda (3.7.1) and the consideration of advice from the country's Social and Economic Council (3.7.2). In Germany, they highlighted the recommendations of the Independent Advisory Board on Work-Care Reconciliation (3.7.3). Experts from both Finland and Germany emphasised the importance of strong carer organisations and their active involvement in the policy process (3.7.4).

3.7.1 The Informal Carers' Agenda in the Netherlands

The Dutch Ministry of People's Health, Welfare and Sport managed to bring together a wide range of stakeholders to write the informal carer agenda *Mantelzorgagenda 2023-2026* (Ministerie van Volksgezondheit, Welzijn en Sport, 2023). Although not a political action plan, the agenda brings stakeholders together to jointly develop priorities and proposals. One motivation for this initiative was the lack of harmonisation among the different legal acts related to LTC (Social Support Act, Long-Time Care Act, Health Insurance Act), which were not always consistent. The informal carer agenda thus serves as a space to develop ideas for future reforms (e.g. to determine under which act unresolved issues should be addressed).

The organisations participating in the informal carers' agenda include associations representing informal carers, organisations supporting municipalities through knowledge transfer, volunteer organisations, municipalities, organisations for elderly people, care providers, as well as multiple ministries. Meetings are held bi-monthly.

The agenda is structured around three main priorities:

- **Recognising the position of informal carers**

  The agenda acknowledges that definitions and approaches to informal care vary across laws, regulations, organisations and municipalities, which contributes to fragmentation. It therefore seeks to strengthen the recognition of informal carers and improve their position, particularly when care responsibilities are combined with work or education. The overarching goal is to establish a clear and shared understanding of informal care, promote acceptance of its combination with other roles and tasks, and ensure that informal carers are treated positively and adequately supported. Specific actions are planned for informal carers in employment, young carers, carers receiving social benefits, and the facilitation of close housing arrangements between informal carers and care recipients.

- **Connection and collaboration with informal carers and their networks**

The agenda addresses the fact that informal carers often feel that care professionals focus mainly on the care recipient, leaving informal carers without an equal voice, even though they often know the situation best. Many also struggle to admit when the burden becomes too heavy, highlighting the need for stronger cooperation and coordination. Therefore, the aim is for professionals to act both as partners and supporters, recognising carers' contributions and signalling when they themselves need help.

The short-term actions planned under this heading include municipal "kitchen table discussions" to identify carers' needs, initiatives to explore how formal carers can be given more time to collaborate with informal carers, the development of care academies and virtual hospitals to transfer nursing tasks to informal carers, support for formal carers in using digital technology to advance collaboration, and specific training for district nurses. In the long-term, several stakeholders will work on integrating knowledge about informal care in different educational curricula.

- **Individual support for informal carers**

Under this heading, municipalities are encouraged to strengthen their support for informal carers. Information about effective tools to support informal carers will be made available to them. For young carers specifically, recommendations will be drawn from a young-carer-friendly school pilot. With regard to respite care, good practices will be shared with municipalities, which are encouraged to develop a range of respite care options. Different stakeholders will collaborate to pilot respite care for carers of persons with complex needs. Furthermore, research will be commissioned to investigate support for informal carers of individuals with lifelong care needs across different life domains. Finally, a knowledge exchange network will be established.

Interviewed experts thought that much had already been achieved without additional funds, but stressed that additional resources will also be necessary to implement the agenda goals. The agenda meetings also raised awareness among stakeholders about the relative invisibility of informal care within the Ministry of People's

Health, Welfare and Sport, which has traditionally focused primarily on medical care and public health.

3.7.2 Advice from the Social and Economic Council in the Netherlands

To improve the balance between work and care—for example, how to compensate for financial losses when working hours are reduced to provide informal care, or how to expand different types of care-related leave—and to achieve a more equitable distribution of informal care between women and men, the Social and Economic Council of the Netherlands was asked to provide advice. This is a measure included in the Informal Carer Agenda. Several experts highlighted it as an important upcoming action in reconciling employment and informal care in the Netherlands.

The Social and Economic Council of the Netherlands brings together employers, employees and independent experts (Sociaal-Economische Raad, 2022). It was established in 1950 through the Social and Economic Council Act and is financed through employer contributions. The Council provides advice to both the government and the parliament. It aims to promote sustainable economic growth by building consensus among different stakeholders, including employer associations and trade unions.

In connection with the Informal Carer Agenda, the Council's advice may include specific policy measures as well as recommendations to allocate funds differently. Such advice could also call on various ministries beyond the Ministry of Health, Welfare and Sport—for example, the ministries of labour, housing, or environment—to take action.

3.7.3 The Independent Advisory Board on Work-Care Reconciliation in Germany

The Independent Advisory Board on Work-Care Reconciliation was established by the Federal Ministry for Families in 2015. It consists of 21 members, including representatives of interest groups, employers, trade unions, welfare organisations, organisations for elderly people, care insurance funds, scientists, ministries, senators for youth and families, social affairs and employment, and municipalities (Bundesministerium für Bildung, Familie, Senioren, Frauen und Jugend, 2021). The board's advice is not binding, and it publishes a report every four years. The second report, which was published in 2023, includes the following recommendations (Unabhängiger Beirat für die Vereinbarkeit von Pflege und Beruf, 2023):

Reform of family caregiver leave

- For each person requiring long-term care, an informal carer should be entitled to take 36 months of family caregiver leave (*Familienpflegezeit*). Within this period, carers should be able to reduce their working hours fully for six months.
- The tax-funded family caregiver leave should be supplemented by an allowance, similar to the parental leave benefits. This allowance should be available for 36 months per person requiring long-term care. Informal carers (defined as family members or individuals with close personal ties) should be eligible.
- Short-term leave from work should be claimable several times per person requiring long-term care or end-of-life care. For each person, 10 days of care support allowance should be granted annually. Both employees and self-employed should be eligible.

Better adaptation of measures to the needs of vulnerable groups and their informal carers

- Specialised consultation and support measures according to needs for parents of children with disabilities should be provided.
- Support for children with long-term care needs in educational and support institutions, as well as in respite care and day care, should be improved.
- Reconciliation of informal care and employment in small and medium-sized companies should be addressed. The advisory board will also focus on this in the future.

Further measures

- The reconciliation of work and informal care should become a formal objective of the long-term care insurance funds.
- Formal care and support measures for informal carers should be expanded.
- Formal and informal care should be more closely interlinked.
- Outreach consultations should also address the impact of informal caregiving on health, employment and social protection.
- Legal certainty for live-in care arrangements should be ensured.
- Accessible formal care for younger people with care needs should be introduced.

Lessons learned from the COVID-19 pandemic

- Research on the experiences gained during COVID-19 should be examined and used to develop crisis management concepts.
- Crisis preparedness should become part of quality management in residential care.
- Further research on the reconciliation of employment and informal care under crisis conditions should be carried out.

3.7.4 The Relevance of Strong Carer Organisations

Experts from Germany and Finland highlighted the importance of strong informal carer organisations in improving the situation of individuals with care responsibilities. In Germany and Finland, these organisations, through their continuous engagement, have put informal care on the policy agenda and have contributed to the development of meaningful support measures. As one interviewee explained:

> *"I [think] that the situation of informal carers has been brought into the spotlight because our association,* wir pflegen!*, and other associations of informal carers have taken action […] We have succeeded in making the voice of informal carers much clearer and bringing it into politics. […] That's why I often compare us to a 21st-century trade union." (I01)*

Beyond political self-representation and the promotion of their collective interests, informal carer organisations also play a crucial role in organising and delivering low-threshold support measures for carers at the local level. This support system—in which informal carers support one another—is described as both "very cost-effective and also empowering" (I08). Nevertheless, adequate funding for regional and national informal carer organisations is essential if they are to establish such structures and continue providing support in this way.

4 Challenges and Ways Forward

After reviewing the support measures for informal carers available in Finland, Germany, Lithuania, and the Netherlands, in this chapter, we discuss the challenges these countries face in expanding and improving such support. Experts from all four countries noted that informal carers have become more politically visible in recent years and that meaningful measures to support them have been introduced. At the same time, they emphasised the need for greater awareness of carers' situation, more sustained political attention, and stronger political will to advance comprehensive policies in this domain.

Experts deemed it necessary to advance informal carer support for two reasons. On the one hand, they argued that many existing support measures are still largely "symbolic" (I16) and do not adequately reflect carers' real needs. Policymakers often continue to presume that informal carers will simply take care of their relatives without requiring substantial support. On the other hand, demand for support is expected to grow considerably in the coming years due to population ageing and a rising number of people in need of care. In several countries, such as Finland and the Netherlands, access to formal services has also become more restrictive, further shifting the burden onto families. As one Finnish expert explained:

> *"At the moment, it seems that we are going in that direction where it's more and more difficult to get public services, which means that [...] families and loved ones, they are a bit like forced to take more responsibility. And so, I think the informal care situations—the light ones and also the demanding ones—are getting more and more common, and I think that our system should react to that, should invest in those persons." (I13)*

Across countries, experts stressed that although informal carers are politically recognised as a group in need of support, there is still a lack of political will to move beyond incremental, piecemeal reforms. A key barrier to more comprehensive reforms is the limited recognition that informal care is a cross-cutting policy issue, spanning multiple domains and ministerial responsibilities. For example, a German expert highlighted that informal care is often treated solely as a matter of social or family policy, even though it also has major implications for the labour market and economic policy. Intensive caregiving responsibilities can push people out of employment, with knock-on effects for workforce participation and economic growth.

In the remainder of this chapter, we focus on three main areas that experts considered most relevant for improving informal carer policies: the non-take-up of existing support measures (Section 4.1), the expansion of existing measure and their complementation with additional forms of support (Section 4.2), and the recognition of differences among informal carers when further developing support measures (Section 4.3).

4.1 Addressing Non-Take-Up of Support Measures

One of the challenges identified across all four countries is that informal carers do not use the support measures they are entitled to. For example, experts from Germany highlighted that a recent survey based on a representative sample found that 96% of those eligible for different types of leave to reconcile work and care responsibilities had never used any of these measures. Experts discussed various reasons for the non-take-up of support measures. Among them were a lack of self-identification as informal carers and overburdening among the target group (Section 4.1.1), the absence of proactive outreach to inform carers about available support and bureaucratic application procedures (Section 4.1.2), as well as a mismatch between the design of support measures and carers' preferences (Section 4.1.3).

4.1.1 Lack of Self-Identification and Overburdening

Several experts pointed out that one reason for the non-take-up of support measures is that many people do not identify themselves as informal carers and therefore do not feel that the measures are meant for them. This can create a paradoxical situation: while support—either specific types of support or support in certain regions—may indeed be lacking, carers may also fail to make use of the measures that are available. In Lithuania, experts also noted that, particularly among older generations, there may be hesitation to openly discuss the challenges of caregiving and to ask for help.

> *"Informal caregivers do not think of themselves as persons who need support, help, and advice. It is also, on the one hand, there is a lack of this kind of services, but on the other hand, when there are these existing services, sometimes it's quite challenging to attract informal caregivers [...] It could be related to their ability to speak about their challenges. It could be related to—especially if it's an older person—cultural reasons because there was no culture to speak about your problems." (I16)*

This quote highlights the importance of raising awareness about informal caregiving and existing support, as well as addressing the stigma associated with not being able to manage caregiving duties alone. Another reason mentioned for low take-up is that those who provide intensive care in particular may be overburdened, lacking the time and energy to apply for support or participate in activities such as self-help groups and training. This suggests that for carers in demanding care situations, the first priority is relief from care tasks themselves, enabling them to access other forms of support.

4.1.2 Absence of Proactive Outreach and High Levels of Bureaucracy

Another set of reasons for non-take-up is linked to a lack of information and overly complex administrative procedures. Experts stressed that informal carers are not always aware of the measures available to them. While some countries provide overviews on government or organisational websites, this information is often insufficient to reach carers. German experts, for example, underlined the need for more proactive outreach (see also Section 4.2.4). They suggested that as soon as a person receives a diagnosis or an official care assessment, information about support for family members or other informal carers should be automatically provided.

Equally significant is addressing the bureaucratic hurdles associated with accessing support. Experts from Germany and the Netherlands highlighted that administrative procedures often deter carers from applying. In Germany, for instance, neighbours, friends, or family members can temporarily take on the carer role and receive compensation through the individual budget for respite care. However, in order to qualify, the substitute carer must present a criminal record certificate, an excessive requirement, according to experts, which discourages recourse to this support.

> *“People who should actually be entitled to support, and for whom this support should be easily and readily accessible, are overwhelmed with bureaucracy because they are not trusted. Yes, every person is viewed as a fraud and a swindler. […] It’s sheer madness. Yes, it is not designed to be used. […] And in this sense, some measures that look good on paper are simply not realistic.” (I01)*

To increase take-up of existing support measures and genuinely improve support, information and administrative barriers should be minimised as much as possible.

4.1.3 Mismatch Between Available Support and Carers’ Preferences

Experts also noted that the design of available measures does not always align with carers’ preferences, contributing to low take-up. In Finland, for instance, respite care regulations are not flexible enough. Recognised informal carers are entitled to three days of respite care per month, but practices differ per county. In some regions, carers must use these days each month; in others, they can save them up for a longer break (such as a two-week vacation) or transfer unused days to the following year. Experts explained that this lack of flexibility in some places contributes to the fact that carers use only about half of the respite days available to them.

Other issues discussed in connection with the limited uptake of respite care were that informal carers are not always satisfied with the quality of the services provided, that institutional respite care places are limited, and that access to home-based respite care is sometimes conditional on providing a separate room for the care worker—something that many carers with limited financial means cannot offer.

Support measures should also avoid clashing with other social benefits. In Finland, experts reported that some carers are reluctant to claim carer benefits, fearing that once they identify themselves as informal carers, their family members may lose access to formal services. Similar concerns were raised regarding financial benefits potentially “punishing” carers by moving them into higher tax brackets or excluding them from other social security benefits they may depend on.

Finally, some measures fail to meet carers’ real needs. German experts gave the example of the interest-free loan offered in connection with certain types of care leave. They pointed out, however, that fewer than a thousand carers used this option between 2015 and 2019. The experts argued that the measure is unpopular because carers are understandably reluctant to incur debt during periods of financial insecurity when they are already away from paid employment.

To increase take-up, support measures must be flexible enough to be practically useful, must not conflict with access to other services or benefits, and should be regularly monitored to assess effectiveness and identify barriers. Above all, support schemes should be co-designed with carers and carer organisations to ensure they genuinely address carers’ needs and align with their preferences.

4.2 Expanding Support Measures

To enhance support for informal carers, experts suggested broadening the eligibility criteria (Section 4.2.1) and increasing the generosity of current measures (Section 4.2.2). They also emphasised the need to address inequalities arising from local and regional variations by standardising support measures (Section 4.2.3) and introducing new forms of assistance (Sections 4.2.4).

4.2.1 Broadening Eligibility Criteria for Existing Measures

In Finland, experts highlighted that the current system only supports those providing care above a certain threshold of intensity (see also Section 3.2). As a result, around 50,000 formally registered informal carers are eligible for support, while an estimated additional 300,000 receive little to no assistance. While prioritising intensive caregiving is understandable, experts stressed that **those providing lower-intensity care may also require help**. Timely support for these carers could help prevent overburdening and more severe consequences later on. Instead, however, eligibility criteria in Finland have tightened in recent years, making it increasingly difficult to access the carer allowance and related services.

> *"The services are kind of more difficult to access. And then, at the same time, also the informal care allowance has become less available. So, what is left is informal care without support, at least that allowance support. […] So, it's a difficult situation in that sense." (I12)*

Experts warned that as informal care becomes more prevalent, driven by population ageing and cuts to formal services, in some countries, public support is paradoxically becoming harder to access, with benefits restricted to only the most severe cases. Ensuring broader eligibility, they argued, is a matter of both fairness—not abandoning those who shoulder caregiving responsibilities—and sustainability of the system; providing support to informal carers early diminishes the risks that they themselves will develop care needs early on and helps them to fulfil their caregiving role over longer periods of time.

Experts in other countries echoed the need to broaden eligibility. In Lithuania, one interviewee called for **expanding the criteria for respite care**. In Germany, an expert suggested **broadening the definition of who may apply for care leave**, expanding it beyond immediate family members. Several experts also noted more general debates about who should be counted as an informal carer and thus be entitled to public support. For example, in both Finland and Lithuania, discussions are ongoing about whether parents of neurodivergent children—such as those with ADHD—should be recognised as informal carers.

Broadening eligibility criteria for support measures not only ensures that lower-intensity carers, too, are supported but also gives families more flexibility in determining who should take on the caregiving role or share caregiver responsibilities. More broadly, changing disease profiles and demographic trends require a societal debate on the boundaries of informal care and what should be considered “normal” childcare or “normal” family support, and at what point such responsibilities become an informal caregiving situation requiring public recognition and support.

4.2.2 Increasing the Generosity of Existing Measures

Experts also underlined the need to increase the generosity of existing support measures for informal carers, particularly regarding financial assistance, care leave, and psychological support.

Where cash benefits for informal carers already exist, such as Finland’s carer allowance, experts emphasised the **importance of increasing financial benefits to achieve income security**, especially for carers of working age who often struggle to make ends meet. In Finland, a government proposal foresees an increase in the minimum carer allowance from 2026 onwards. However, experts stressed that for working-age carers, income security requires more than modest adjustments to the allowance.

> *“The monetary support is [...] too low for not getting into economic difficulties. This is a larger question; it’s not only related to the cash benefit for informal care. [...] If your whole economic situation is concerned, there should be other monetary support.” (I13)*

While Finland offers general social support schemes for individuals in financial difficulties, experts pointed out that these are often insufficient or not specific enough to compensate for the economic losses incurred by informal carers. One concrete proposal was to introduce financial compensation for carers who must take occasional days or lengthier periods off work because of their caregiving responsibilities.

Beyond financial support, experts also highlighted the **importance of generous paid leave arrangements** that allow carers to remain in the labour market. Germany, for instance, offers relatively generous unpaid care leave compared to the other countries studied (see Section 3.3). Yet experts noted that current entitlements remain inadequate for carers with long-term or lifelong responsibilities.

> *"24 months is definitely not enough for family carers. Not to mention that there are also family carers who look after their children who may have been born with a disability. That doesn't fit at all. These are people who are confronted with the care situation for the rest of their lives, and the work-life balance measures designed for 24 months are of very little help to them." (I02)*

Experts from Lithuania emphasised the **urgent need for stronger psychological support** for informal carers, given the emotional strain, stress, and risk of burnout associated with caregiving. They argued that carers should have easy and continuous access to psychosocial counselling throughout the caregiving period. While such support does exist in Lithuania and elsewhere, access is typically limited to only a few free sessions. Experts considered this insufficient, as care situations can last for extended periods or change rapidly, placing new emotional strain on carers.

Overall, existing measures provide important support, but they often fail to reflect the lived realities of caregivers. In particular, they do not fully account for income losses and increased expenditures, long-term or lifelong care responsibilities, or the ongoing psychological burden of caregiving. Expanding existing measures will not be relevant for every carer, but for those who rely on them, and such improvements could make a crucial difference.

4.2.3 Harmonising Measures and Overcoming Regional Inequalities

Experts from all countries highlighted regional differences in the availability of formal LTC services and in the additional support provided for informal carers. The availability of LTC services often depends on geographical location, with notable differences between urban and rural areas. Beyond these factors related to population density, some countries also experience variation in informal carer support because provision is decided at the municipal (e.g., the Netherlands) or county (e.g. Finland) level. As one Dutch expert explained:

> *"Every municipality chooses for itself. So, if you live in one city, then there are support groups [...] and then in another [city] they say, 'You know, what you do is so important, we make sure that you get financial aid and you get aid that helps you with running errands.' So, it really depends on which city you live in." (I04)*

Finland recently underwent a major reform, transferring responsibility for health and social care provision from 309 municipalities to 21 newly established welfare service counties (plus Helsinki). These countries are also responsible for supporting informal carers (see Section 3.2). While the reform led to some degree of harmonisation, experts noted that variations persist because counties retain discretion in how they allocate state funds and because the relevant legislation provides only general guidance. Importantly, support for informal carers is not a subjective right, and counties decide independently what forms of support to provide, how often health check-ups are offered, the extent of respite care, and the amount of the carer allowance (although a national minimum exists).

Experts stressed that this **variation in support measures and services for informal carers is a critical equity issue**. While they recognised the importance of granting regional authorities autonomy to tailor services to local needs, they emphasised that such autonomy also produces significant inequalities. One Finish expert illustrated this point:

> *"I think it varies because different areas have different attitudes towards informal care. In some areas, they have a strategy to increase the number of informal carers and want to invest in that, and in other areas they don't see it as important and therefore don't want to invest […]. The support for informal carers varies a lot between areas, and that's a problematic thing, if we think about the equity of caregivers." (I13)*

Against this backdrop, Finish experts emphasised the need for stronger national guidance and monitoring to ensure that counties dedicate sufficient resources to informal carer support. They also called for the development of national guidelines to standardise practices. Such guidelines are currently being prepared by the Ministry of Social Affairs and Health and the Finnish Institute for Health and Welfare, with publication expected in 2026. Their aim is to provide counties with practical guidance on how to organise support for informal carers.

Harmonising informal carer support is an important approach to broaden the coverage of effective support measures and make sure that informal carers are equally well supported throughout the country.

4.2.4 Adding New Forms of Support

Experts also stressed the need to introduce new forms of support for informal carers. However, views differed across countries, reflecting the specific measures already in place in each context.

In Germany, experts highlighted the absence of services and benefits that are targeted directly at informal carers rather than the person in need of care.

> *"Care policy and health policy cannot do without them [i.e. informal carers], but there are currently no specific benefits for informal carers in care or health policy. All these benefits in kind or cash benefits are received by the person in need of care and not by the informal carers." (I02)*

In particular, experts underlined the **importance of introducing a carer allowance**—a cash benefit for informal carers that serves as an income replacement for those who reduce working hours because of care obligations. While such a proposal has already been developed (see Section 3.7.3) and both the previous and current federal governments have expressed a general commitment to considering it, no more concrete steps have been taken to date.

German experts also emphasised the **need for independent and proactive advice**, consultations, and training for informal carers. At present, these services are mainly delivered by health insurance providers or administrative bodies, which may not always provide impartial advice, as they are also responsible for funding services and benefits. Equally important is the proactive delivery of advice. Informal carers, often overwhelmed by their responsibilities, may lack the time and energy to search for information or navigate administrative procedures to access support on their own.

> *"What we actually need is advice that goes into households, that kicks in automatically when someone is diagnosed. When it comes to discharge management in hospitals and diagnoses, things need to happen automatically at these important junctures and then be followed through. [...] The system tries, as far as possible, not to do anything that costs money, and that, of course, makes the task of caregiving relatives enormously difficult, because they have to gather everything together and often don't have the time to do so, precisely because they need so much time for care." (I01)*

In Finland, experts highlighted the **need to combat the loneliness and social isolation** often experienced by informal carers. Many carers feel solely responsible for the well-being of the person they support and are uncertain about where to turn in emergencies, such as if they themselves need hospitalisation.

> *"The public system should support informal carers in a way that [they feel] whatever happens, you are not alone. I think this is very important mentally. Small things [may suffice], in order to feel that you can get help if you need and you are not alone in this." (I13)*

Concrete measures mentioned included regular proactive outreach, such as checking in on carers' well-being, reminding them about peer support activities, or asking about their need for assistance. More structured peer support programmes were also seen as promising. For instance, one interviewee described a mentoring initiative in which former informal carers supported current carers. While not widely implemented, such programmes could benefit both sides: current carers gain guidance and emotional support, while former carers—especially those who had cared for long periods—can re-establish social connections.

Experts also called for stronger community-level initiatives to reduce isolation. Suggested examples include regular free lunches or coffee gatherings organised by municipalities, providing carers with low-barrier opportunities for social contact and mutual support.

4.3 Recognising Different Groups of Informal Carers

Across the countries we analysed, the experts we interviewed highlighted that informal carers are not a homogeneous group. Different subgroups of informal carers have specific support needs. These needs may stem from the particular condition of the person receiving care, or from characteristics of the carers themselves, such as their age or employment status. Experts emphasised that recognising these differences and addressing them is one of the main challenges in further developing effective support measures for informal carers. However, the subgroups requiring targeted support will vary from country to country, depending on what is already available in terms of informal carer support and wider welfare policies.

4.3.1 Differences Among Care Recipients

In political and public discussions, informal care is often linked to population ageing, the growing number of older people, and the resulting rise in long-term care needs. As a result, it is frequently assumed that informal carers mainly care for older adults. While this is true for many, **informal carers support people of all ages with a wide range of needs** connected to, among others, disabilities, chronic illnesses, mental illnesses, or substance use disorders. Experts across all countries underlined that research, public authorities, and even informal carer organisations themselves have long focused primarily on informal carers of older people. This has led to other forms of informal care being overlooked.

> *"I think that if we talk about informal care of children, like children with disabilities or children with long-term illnesses, then they are sort of less visible in society. And they also, those caregivers, they often are kind of unhappy that most of the research is not about them, but it's about long-term care [of older people]." (I12)*

More recently, experts noted that a broader understanding of informal care—covering people of all ages and conditions—is starting to gain recognition. However, they stressed the need to further promote this perspective. Simple measures include ensuring that government websites and other information materials about informal care present the topic in an inclusive way.

Because informal carers help people with a broad range of needs, their **support needs may differ depending on the care recipient's condition**. For example, informal carers of persons with mental illness or neurodegenerative diseases such as dementia and Alzheimer's, may be particularly prone to social isolation and loneliness. Experts explained that this can result from the stigma around mental illnesses or from difficulties communicating with the care recipient, such as in advanced dementia. For this group, psychological support may be especially important.

An expert representing a carers' organisation in the Netherlands underlined that parents of children with disabilities often require stronger financial support and assistance in navigating the care system:

> *"This group always says, 'Do not forget about us, we have special needs.' [...] The two things that they really need are that they say, 'I could use a certain type of aid that helps me with all the choices I have to make and all the dealings with all these different institutions and the other thing that they need more than other groups is financial compensation." (I04)*

The types of support required for particular subgroups of informal carers will vary across countries, but a key consideration is that informal carers are not a single, uniform group. Their needs differ according to their carer situation, and support measures should reflect this diversity.

4.3.2 Differences Among Informal Carers

Informal carers do not only differ because they face different care situations, but also because they have different characteristics and live in different circumstances themselves. Depending on these characteristics and circumstances, they may encounter particular challenges as informal carers and require specific forms of support. Experts particularly highlighted the needs of young and older informal carers, working informal carers, and migrant informal carers. Additionally, they emphasised that informal carer policies have to be sensitive to the gender dimension of informal care.

Young and Old Informal Carers

Young carers are children, adolescents or young adults with care responsibilities. The situation of young carers is unique because they may consider their age-inappropriate level of responsibility to be normal, they are often emotionally dependent on the person they care for, and they may lack the necessary information or skills to seek help on their own. Furthermore, caring responsibilities may affect their attendance and performance at school, training or work, with potential lifelong consequences. Therefore, young carers are a particularly vulnerable group requiring special support, as various experts highlighted.

> *"If you are of school age or you're supposed to study, then this is a kind of very specific stage of life, where you are supposed to build your future in a way. So, in that sense, even though it's not in numbers necessarily a large group, it may be worthy of attention in the sense of what happens if they spend their youth to some extent doing caregiving." (I12)*

While the situation of young carers across Europe has become an established research topic over the last few decades, and experts from all the selected countries highlighted the need for targeted support, interviewees from Finland and Germany noted that the topic was rather new or underexplored in their respective countries. One of the specific challenges in developing or advancing support measures for young carers is that they must include a broad spectrum of stakeholders, including formal care as well as education and training providers.

At the other end of the age spectrum, older informal carers also require special attention, albeit for other reasons. The difficulties that older adults face in providing care were mainly discussed in the Finnish context. In Finland, about 60% of recognised informal carers are 65 years or older (Ilmarinen, 2025). However, this subgroup of informal carers is currently not receiving sufficient attention. These older informal carers are most often spousal carers, looking after their wife or husband. However, due to their age, they often face health problems themselves or are at greater risk of developing health issues due to care-related overburdening. This group, as experts underlined, may also be particularly isolated. Older informal carers may need greater support in the form of formal services, more frequent health checks, and additional respite care so as not to risk their own health. Currently, as one expert highlighted, “Even those contract carers [i.e. recognised informal carers] may be in really bad shape. You often don’t know which one is the carer” (I09).

Working Informal Carers

A further group requiring targeted attention and support are working-age carers. Among working-age informal carers, many struggle to balance caring obligations with paid work. Experts also warned that this tension is likely to intensify in the future. With the retirement age rising in many countries, people will be expected to remain in the workforce longer while simultaneously taking on greater care responsibilities, driven by population ageing and, in some countries, reductions in formal care services.

The Finnish support system for informal carers currently does not differentiate between carers of working age and those of retirement age. Several experts criticised this situation, emphasising that informal carers of working age require different forms of support than informal carers who have already reached retirement age.

> *“I think we really should think differently of those carers who are working age and those who are already pensioners, because then it's, then you're not losing your careers or future pensions if you're already a pensioner. So, I think they should be treated differently” (I08)*

Some countries have attempted to mitigate the tension between work and care by introducing paid and unpaid care leave. Yet, there are country-specific differences. Germany, for example, has rather extensive care leave options compared to the other countries (see Section 3.3). However, care leave also only partially addresses the issue. It is typically time-limited, even though care situations can last much longer, and it usually only partially replaces lost income. Furthermore, taking care leave may have negative consequences for carers in the labour market later on or for their long-term financial security.

At the same time, experts from Germany and the Netherlands pointed out that it is often well-educated informal carers with sufficient financial security who can afford to reduce their working hours or temporarily leave the labour market to manage the tension between work and caregiving. People in lower-paid jobs or single individuals without a partner’s income often do not have this option and are therefore likely to face a greater burden. This inequality, if not addressed, may worsen in the future and warrants specific support for these groups.

Experts emphasised that addressing the care-employment tension requires a comprehensive approach, including:

1. Expanding formal LTC service to guarantee the right to remain in full-time employment;
2. Offering longer-term part-time or full-time care leave with income replacement equal to lost earnings;
3. Supporting the reintegration of carers into the labour market after long periods of absence.

Migrant Informal Carers

Furthermore, experts from Germany and the Netherlands highlighted that migrant informal carers are another subgroup who may need specific support. For example, due to language barriers in combination with limited knowledge about the health and care system, migrant informal carers may face difficulties in accessing support services and benefits.

> *"We also see that informal carers from other countries [...] they migrated to Holland, but there are language issues. They can't find their way to support. That's difficult. It's difficult to help them." (I06)*

Additionally, some migrant communities may have strong cultural norms that emphasise informal caregiving. This may result in situations where migrant informal carers provide high-intensity informal care but do not feel compelled to ask for help from formal care services or apply for benefits.

This implies that more active outreach strategies are needed to help migrant informal carers access existing support measures. At a basic level, this means providing information about support measures on government and other websites, as well as printed information materials in the languages of the largest migrant communities. Additionally, it may involve proactively sharing information with migrant communities and sensitising professionals who are in contact with migrant informal carers (e.g. care staff, healthcare professionals, employees at information points) about their specific challenges, including cultural norms concerning informal caregiving. A German expert further emphasised that this may be particularly important in rural areas, where awareness about migrant informal carers and their challenges may be lower.

Gender and Informal Care

Informal care is predominantly provided by women. This imbalance has significant consequences for gender equality, not only for their health and well-being but also for their income trajectories, career development, and long-term financial security, including pensions. Against this backdrop, experts underlined the importance of integrating a gender-sensitive perspective when designing direct support measures for informal carers.

On the one hand, such measures should avoid inadvertently reinforcing traditional gender roles by pushing more women out of the labour market. For example, increasing financial benefits for carers may disproportionately encourage women to reduce or abandon employment. However, if these benefits are structured as genuine income replacement, they might mitigate this effect by making caregiving a financially viable option for both women and men.

On the other hand, explicit efforts are needed to challenge cultural norms around care and encourage men to participate more in caregiving. Possible measures include awareness-raising campaigns that challenge stereotypes around masculinity and care, as well as targeted support programmes tailored to the needs of male carers. Moreover, allowing multiple household members to apply for support measures and benefits could distribute care responsibilities more evenly and increase the likelihood of men taking on a larger share of care work.

5 Recommendations

In the previous chapters, we described the social policy benefits and services available to informal carers in Finland, Germany, Lithuania, and the Netherlands, and discussed the remaining challenges that these countries face in providing adequate support for informal carers. We particularly highlighted the importance of addressing the non-take-up of support measures, expanding these measures in terms of eligibility, generosity, and national coverage, and acknowledging the diversity of informal carers in the further development of support policies. These issues were identified as relevant across all four countries and are equally important to consider in the development of support systems in other contexts, such as Sweden.

Building on these general recommendations, this chapter takes a closer look at the situation of informal carers' support in Sweden and, against the backdrop of the findings presented earlier, offers suggestions on how Sweden could further strengthen its support framework. In particular, we highlight the potential for the national harmonisation of informal carer support (Section 5.1), the expansion of care leave options (Section 5.2), and the recognition of informal carer support as a cross-sectoral policy issue that requires the involvement of multiple stakeholders and continuous monitoring (Section 5.3). However, beyond the specific recommendations discussed in this section, addressing issues such as the non-take-up of measures and better acknowledging the diversity of informal carers may be equally relevant for Sweden.

We acknowledge that the Swedish LTC system is characterised by a strong focus on formal services. This universal, service-oriented model has been highly successful in ensuring that care responsibilities do not fall disproportionately on families and in maintaining a clear distinction between professional and informal care. Furthermore, policy frameworks such as the Swedish National Informal Carer Strategy (Regeringskansliet, 2022) emphasise that all informal care should be provided voluntarily rather than out of obligation. This principle is both progressive and consistent with Sweden’s commitment to individual autonomy and gender equality. Consequently, some types of support measures for informal carers introduced in other countries, such as cash benefits or care leave, play a comparatively minor role in Sweden.

However, while formal services should remain the cornerstone of the Swedish LTC system, it is important to recognise that informal caregiving plays a vital role in many families. Some carers face substantial emotional, financial, and time-related burdens that cannot be fully mitigated by existing formal services. The future development of the system should therefore maintain its current emphasis on accessible and high-quality formal care, while also acknowledging the need for complementary support for those informal carers who require it, such as financial compensation, flexible care leave, or tailored respite opportunities. Providing these additional forms of support would not undermine the service-based model but would ensure that no carers are left without adequate help in situations where formal care is insufficient or temporarily unavailable, or informal caregiving becomes challenging for other reasons.

5.1 Harmonisation of Informal Carer Support

Since 2009, Swedish municipalities have been mandated to provide support to informal carers, and informal carers are legally entitled to an assessment of their care needs. However, because municipalities differ in size, resources, and budgets, they also vary in terms of the content, intensity, and quality of the support they provide (Eurocarers, 2024). For example, there is no national legislation on cash benefits for informal carers in Sweden, but municipalities may decide to offer such benefits at their own discretion. They also determine eligibility criteria and the level of payments.

In principle, there are two types of cash benefits available for informal carers (Nationellt kompetenscentrum anhöriga, 2021), as well as an additional allowance specifically for parents of disabled children (Försäkringskassan, 2025).

- **Attendance allowance** (*hemvårdsbidrag*): This benefit is paid on top of services provided to the care recipient. The allowance is formally received by the care recipient but is intended to compensate informal carers. Eligibility is usually tied to the level of dependency or the intensity of caregiving. For instance, the City of Stockholm offers an allowance ranging from 1,470 to 5,880 SEK (about €135 to €540) per month (Stockholms Stad, 2023).

- **Employment of informal carers by the municipality** (*anhöriganställning*): In this arrangement, carers receive a taxable salary and social security benefits similar to those of formal home-help workers. Employment is only possible for individuals below retirement age. This option is mainly relevant in remote areas where access to formal care is limited or language barriers hinder formal care provision.

- **Childcare allowance** (*omvårdnadsbidrag*): Parents who care for a severely sick or disabled child for at least six months, up to the child's 19th birthday, are eligible for this special allowance. It is taxable and accrues pension credits.

Because data collection on the attendance allowance and the employment of informal carers ceased in 2006, there are no up-to-date statistics on how many people receive these benefits. In 2006, 5,300 persons received an attendance allowance, and nearly 1,900 were employed by municipalities (Eurocarers, 2024). Although these numbers show that both measures play a minor role in supporting informal carers, their implementation depends on local decisions regarding eligibility and amount. As a result, these support measures are not equally accessible to informal carers across Sweden.

The same applies to measures aimed at supporting informal carers' well-being (Nationellt kompetenscentrum anhöriga, 2021). In principle, informal carers have access to respite care both at home and in care institutions, but the number of hours granted varies by municipality. Similarly, some municipalities provide respite care free of charge, while others require co-payments. Other measures to support carers' well-being include meeting centres, peer-support groups, educational programmes, training opportunities, individual counselling, digital technology support, and access to relaxation activities (e.g., yoga, spa sessions). However, the availability and quality of these services also depend on the respective municipality.

Informal carers should not only have the right to an assessment of their needs but also a guaranteed right to receive appropriate support when they need it. While regional needs and municipal capacities may naturally differ, carers throughout Sweden should be entitled to a minimum, nationally defined level of support that ensures equity across the country.

Recommendations

- **Establish a subjective right to support**: Ideally, informal carers should have a subjective right to receive specific forms of support if they meet nationally defined eligibility criteria. This would ensure that access to benefits does not depend on where a person lives but on their caregiving situation.

- **Define national minimum standards**: Sweden should introduce minimum standards for carer support that apply across all municipalities. These standards should include:
  - Clear eligibility criteria for support measures;
  - Nationally defined minimum benefit amounts; and
  - A guaranteed minimum amount of respite care to which carers are entitled.

  These standards should be embedded in national legislation to ensure legal enforceability and consistent implementation.

- **Promote harmonisation through national guidelines**: Sweden could follow the example of Finland, which is currently working to harmonise carers' support by developing national guidelines in cooperation with well-being service counties. Such an approach would promote coherence, transparency, and equality in how carers are supported throughout the country.

- **Address financial strain and recognise unpaid care work**: Although financial support plays a limited role in Sweden's LTC system, policymakers should explore ways to alleviate the financial pressure on informal carers and to recognise their unpaid contributions. Cash benefits intended as compensation for informal carers should be paid directly to the carer (rather than to the care recipient), and all such benefits should include pension credits (as is the case with the childcare allowance) to ensure that caregiving does not compromise future financial security.

- **Consider the introduction of linked benefits**: Also following the example of Finland, Sweden could introduce linked benefits. In Finland, when carers receive a carer allowance, they automatically become eligible for social security benefits, health check-ups, respite care, and other support services. This approach ensures comprehensive support and reduces the administrative burden associated with multiple applications.

5.2 Extend Care Leave Options to All Informal Carers

Currently, informal carers in Sweden have access to two main types of leave: a short-term leave for urgent family reasons and a longer leave, called compassionate care leave (Aldman et al., 2024).

- **Leave for urgent family reasons**: Employees are entitled to unpaid leave for urgent family reasons related to illness or accidents. The duration of the leave and the level of compensation are defined through collective agreements, which are more common in larger companies. As a result, entitlements vary significantly: the leave may last from a few hours to several days, and compensation can range from no pay to full reimbursement of lost income.

- **Compassionate care leave**: Employees caring for a relative with a life-threatening condition are entitled to compassionate care leave for up to 100 days per cared-for person (240 days if the person in need has HIV). The leave can be shared among family members. During this period, carers are eligible for a cash benefit (*närståendepenning*) amounting to approximately 80% of their income, depending on the extent of their absence from work.

In addition, there are specific leave entitlements for parents caring for severely ill or disabled children (Aldman et al., 2024):

- **Temporary parental benefits**: Parents of severely ill or disabled children up to the age of 21 are entitled to temporary parental benefits if they are unable to work due to care duties. The duration of the benefit varies from 10 to 120 days per child and per year, depending on the child's age, and income losses are fully compensated.

- **Contact days**: Parents of disabled children under 16 are entitled to up to 10 contact days per year and per child for parent education or training activities. During these days, they receive 80% of their lost income through social health insurance.

- **Reduced working hours**: Parents of disabled children up to the age of 19 also have the right to reduce their weekly working hours by up to 25%.

The current system reveals inequalities in access to leave for different groups of informal carers. Short-term leave for urgent family reasons is unevenly available, depending on the employer's sector and size. Compassionate care leave applies only to carers of relatives with a life-threatening condition, while more generous and flexible leave schemes exist only for carers of sick or disabled children. This fragmented approach leaves many informal carers—particularly those caring for older or chronically ill adults—without adequate support to balance work and caregiving responsibilities. To ensure fair and comprehensive support for all carers, leave entitlements should be harmonised and amended to reflect the diverse and long-term nature of caregiving.

Recommendations

- **Introduce national legislation guaranteeing equal access to care leave**: Leave entitlements should be regulated through national legislation rather than collective agreements to ensure equal access across all sectors, company sizes, and forms of employment. This would prevent disparities between employees from different sectors and between large and small employers, ensuring that all workers can take time off when urgent care needs arise.

- **Extend long-term leave options to all informal carers**: Long-term care leave should be available to any informal carer who struggles to reconcile work and caregiving responsibilities, not only to those caring for people with life-threatening conditions. Carers should have the flexibility to decide when and how to take leave—whether in continuous blocks or intermittently—to reflect the reality of caregiving, which often involves recurring or unpredictable periods of high intensity.

- **Base eligibility on care needs rather than age or relationship**: The more generous leave options currently limited to parents of disabled children should be extended to all informal carers, including those supporting adults and older people without family ties. Access to benefits should depend solely on the care recipient's level of dependency and the intensity of care provided, rather than on age or family status.

- **Ensure adequate income protection and social security coverage**: Ideally, all care leave should provide full compensation of lost income, alongside continued accrual of pension rights and social insurance benefits. This would prevent carers, especially women, from facing financial insecurity or long-term career disadvantages as a result of fulfilling essential caregiving duties.

- **Encourage flexibility and carer-friendly workplaces**: Policymakers should also promote workplace flexibility and awareness among employers. Encouraging remote work, flexible scheduling, and part-time arrangements can help carers remain in the labour market while meeting care responsibilities. These measures could be supported through statutory incentives or inclusion in national employment guidelines.

5.3 Cross-Sectoral Development and Evaluation of Informal Carer Support

In 2022, Sweden published its first National Informal Carer Strategy (Regeringskansliet, 2022), marking an important step forward in strengthening the recognition and support of informal carers. The Strategy sets out a comprehensive framework for addressing carers' needs primarily through three approaches: (1) improving welfare service provision for care recipients, thereby indirectly supporting carers; (2) integrating a carer's perspective into the planning and delivery of care services; and (3) offering direct support to carers in their caregiving role, including through information, education, respite care, and well-being services. This focus rightly builds on Sweden's strong service-oriented care model and reflects a growing awareness of the challenges faced by informal carers.

However, the Strategy explicitly excludes issues related to the labour market and social insurance, even though these areas are critical to working carers and their ability to combine paid work and caregiving responsibilities. While the publication of the Strategy represents an important policy milestone, future developments should take a broader and more integrated approach. Policymakers should recognise that informal care is a cross-cutting policy issue, intersecting with employment, gender equality, health, and social protection. Carers' access to flexible work arrangements, income security, and pension protection is a key condition for ensuring that caregiving remains a voluntary and sustainable activity rather than a source of economic disadvantage or social exclusion.

Recommendations

- **Adopt a cross-sectoral approach:** Future policy developments should explicitly incorporate labour market and social insurance dimensions, recognising that informal care affects employment participation, income stability, and long-term financial security. To ensure a truly cross-sectoral approach, a broad range of stakeholders should be involved in policymaking processes. Examples from other countries include consulting the Social and Economic Council in the Netherlands or the Advisory Board on Work and Care Reconciliation in Germany.

- **Involve carers and carer organisations in policymaking:** Carers and their representatives play a particularly important role in the further development of support measures. The design, implementation, and review of measures should be based on continuous dialogue with carers and their representative organisations, ensuring that policies respond to their actual needs and lived experiences.

- **Establish continuous monitoring of carer support measures:** It should be systematically tracked what types of support are available across municipalities and nationally, and how widely they are used to identify inequalities in access and gaps in provision. The effectiveness of support measures should be regularly evaluated with a particular emphasis on carers' feedback and outcomes, ensuring that evaluations capture both quantitative data (uptake, coverage) and qualitative insights (satisfaction, usefulness).

- **Ensure an adaptive and evidence-based policy process**: Based on evaluation findings, support measures should be updated, expanded, or discontinued to maintain relevance and efficiency. This approach will help ensure that resources are directed toward interventions that demonstrably improve carers' well-being.

To ensure that the Swedish long-term care system remains both equitable and sustainable, future reforms should strike a careful balance between maintaining the strong foundation of formal care and improving support for those who provide informal care. This means developing a more coherent national approach to carer support, one that guarantees minimum standards and access to assistance, regardless of where carers live or who they care for. Expanding and harmonising financial support measures and care leave options nationwide would not only strengthen the overall resilience of the care system but also promote fairness and recognition for all those contributing to care provision in Sweden.

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7 Annexes

7.1 Annexe A: Qualitative Methods and Materials

The findings presented in Chapters 3 and 4 of this report are, alongside desk-based research and an analysis of relevant academic and grey literature, primarily based on qualitative interviews conducted with experts from Finland, Germany, Lithuania, and the Netherlands. We identified three types of informal carer experts: 1) academic experts, 2) representatives of informal carer organisations, and) public officials responsible for informal carer policies within ministries.

Based on online searches and personal contacts, we compiled a list of potential study participants for each country and category. In addition, we employed a snowball sampling approach, asking interviewees to recommend further relevant contacts. In total, we contacted 34 experts across the four countries and arranged 16 interviews. These included three interviews with experts in Germany, six in Finland, three in Lithuania, and four in the Netherlands (see Table 1). When initially contacting potential participants, we provided an information sheet about the study (see Annexe B).

In Finland and the Netherlands, we conducted interviews with experts in all three categories. In Germany, however, we were unable to secure an interview with public officials. The same was true in Lithuania, where we were also unable to interview a representative from an informal carer organisation, as no such national organisation currently exists.

Table 2: Overview of study participants

Interviewee	Country	Expertise
I01	Germany	Informal carer representative
I02	Germany	Academic expert
I03	Germany	Academic expert
I04	The Netherlands	Informal carer representative
I05	The Netherlands	Academic expert
I06	The Netherlands	Public administration expert
I07	The Netherlands	Academic expert
I08	Finland	Informal carer representative
I09	Finland	Informal carer representative
I10	Finland	Public administration expert
I11	Finland	Academic expert
I12	Finland	Academic expert
I13	Finland	Academic expert
I14	Lithuania	Academic expert

I15	Lithuania	Academic expert
I16	Lithuania	Academic expert

All interviews were conducted between May and June 2025. Thirteen interviews were conducted online via video conferencing software (e.g. Microsoft Teams or Zoom), two were held in person, and one participant responded in writing. Prior to each interview, we obtained written informed consent from all participants (see Annexe C).

The interviews were guided by a semi-structured interview guide, covering topics such as the situation of informal carers, the evolution of informal carer support as a policy issue, and an assessment of existing support measures (see Annexe D). Interviews lasted between 45 and 65 minutes, resulting in over 13 hours of audio material. All interviews were recorded and transcribed verbatim. Initial transcriptions were produced using the transcription software aTrain, and all transcripts were subsequently reviewed and corrected by the respective interviewers.

For the analysis, we used the qualitative data software MAXQDA (version 2018.2) and followed a thematic analysis approach (Braun & Clarke, 2021), coding the interviews to identify and summarise the most prominent themes.

7.2 Annexe B: Information Sheet

Information Sheet

EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH

Good Practices in Supporting Informal Carers: Lessons from Well-Developed Formal Long-Term Care Systems

Dear Sir or Madam,

We would like to invite you to participate in the study *"Good Practices in Supporting Informal Carers: Lessons from Well-Developed Formal Long-Term Care Systems"* in the form of a one-hour online interview. We would be extremely grateful if you could support our study with your expertise!

What is the study about?
Informal or family caregivers play a crucial role in long-term care, even in countries with well-developed public long-term care systems. This study aims to understand which measures have been implemented in selected countries with strong long-term care systems to support informal carers. The goal is to identify developments, trends, and best practice examples.

Who is conducting and funding the study?
This study is being conducted by the European Centre of Social Welfare Policy and Research in Vienna, Austria. It has been commissioned and funded by the Swedish Ministry of Health and Social Affairs.

How will my participation take place?
Your participation consists of an online interview (e.g., via Zoom or Teams) that lasts approximately 60 minutes. The interview appointment will be arranged in coordination with you. The interview, designed as an informal conversation, will primarily focus on the situation of informal carers, available support measures, how these measures have evolved, as well as the strengths and potential weaknesses of existing offerings in your country. We are particularly interested in your expertise, experience, and assessment.

What happens to the interview and the results of the study?

We use the information from the interview to write a research report. In this report, we summarise the information from all interviews and analyse the public support measures available for informal caregivers in different countries, how these measures have evolved, as well as the strengths and potential weaknesses of existing approaches. The report will also include recommendations on measures the Swedish Ministry of Health and Social Affairs could take to better support informal carers in Sweden. The research report is expected to be published in early 2026.

Whom can I contact if I have further questions?

If you have any questions about this study or would like to inquire about your participation, you can contact Mirjam Pot via email (pot@euro.centre.org) or phone (+43 1 319 45 05-11) at the European Centre for Social Welfare Policy and Research, Berggasse 17, 1090 Vienna, Austria.

BERGGASSE 17 • 1090 VIENNA • AUSTRIA • TEL: +43-1-319 45 05 • FAX: +43-1-319 45 05-19
email: ec@euro.centre.org • www.euro.centre.org • ZVR-Zahl: 583470062

7.3 Annexe C: Informed Consent Form

EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH

Consent Form

Good Practices in Supporting Informal Carers: Lessons from Well-Developed Formal Long-Term Care Systems

- I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to ask questions, and all my questions have been answered satisfactorily.
- I understand that my participation in the study in the form of an interview is voluntary, that I am not required to answer individual questions, and that I am free to discontinue the interview at any time.
- I am also aware that I can withdraw my participation up to two weeks after the interview. In this case, the interview data will be deleted and not used for the study.
- I understand that my personal information will be treated confidentially. It will be securely stored, and the interview will be pseudonymised.
- I confirm that the interview may be used for the final report of the above study and for related academic publications. I acknowledge that pseudonymised quotes from the interview may be included in publications and presentations.
- I agree to the interview being recorded using an audio device. The recording will be deleted after transcription.

____

Date and place

____

First and last name

____

Signature

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7.4 Annexe D: Interview Guide

Introduction	• To start with, could you please briefly introduce yourself and explain in what capacity and in what form you are involved with the topic of informal carers?
Situation of informal carers	• Could you tell me a bit about the situation of informal carers in [*country*]? • As you know, we are particularly interested in understanding the situation of informal carers in countries with well-established LTC systems. Could you describe the relationship between informal caregiving and formal care in [*country*]? In [*country*], would you say that LTC is viewed primarily as a responsibility of society, or rather as something that individual families are expected to handle? • In your opinion, what are the most significant challenges that informal carers in [*country*] face? • Since informal carers form a diverse group, are there any specific subgroups whose situation or challenges are particularly noteworthy in [*country*]?
Politics of informal care	• Can you tell me when and how informal caregiving became a political concern in [*country*]? Which actors have brought informal caregiving onto the policy agenda? • Do you have any thoughts on why informal caregiving emerged as a political issue? • Since then, have there been any major changes in how informal caregiving is politically perceived or addressed? • What is the current status of informal carers as a policy issue in [*country*]? Is there a national strategy of informal carers in [*country*]? • How is informal caregiving typically discussed in [*country*]? Which issues dominate the discussion? Which policy areas consider informal caregiving as part of their remit or address it in their agenda (e.g. labour market policy, ageing policy, health policy)?

Is informal care also discussed in the context of disability or mainly in connection with long-term care for older people?

- In your opinion, are there any gaps in the political and public discourse on informal carers in [*country*] that should be more widely discussed?

Policies to support informal carers

- Can you give me an overview of the support measures available for informal carers in [*country*]? (If not mentioned ask for leave and measures to support return to the labour market, care allowances and other financial benefits, social security benefits, and support in caring role e.g. psychological support, counselling, training and education, respite care).
- What are your thoughts on the current state of support measures for informal carers in [*country*]? Are informal carers legally entitled to public support?
- In your experience, what are the most important support measures in [*country*], and could you explain why?
- Is there a particular measure that you find especially innovative or unique compared to other measures in [*country*] or internationally?
- Do you see any gaps in the public support available for informal carers in [*country*]?
- Is there a specific group of informal carers in [*country*] that you believe needs more or a different type of public support?
- In your opinion, what kind of support is particularly important for informal carers in countries with well-developed long-term care systems? This could be in [*country*] specifically or in similar countries more generally.
- What are your thoughts on the future development of support measures for informal carers?

Concluding questions

- If you were politically responsible for supporting informal carers and faced no restrictions or constraints, what would your policy agenda look like?

- Thank you for these interesting insights. I don’t have any further questions, but is there anything you would like to add on the topic?