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Care in a Changing World





Care in a Changing World

Edited by
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Social Justice Ireland

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INTRODUCTION

Care, in all its forms, is the quiet foundation upon which societies are built. It is the work that sustains families, communities, and the social and economic fabric. In Ireland, the meaning and delivery of care have evolved dramatically over the past century, shaped by shifting demographics, economic transformation, migration, and changing social expectations. From the traditional image of multi-generational households and community networks to today's complex system of professionalised services and digital supports, care has undergone a profound transformation that mirrors the broader story of Ireland's social change.

Care embodies a fundamental pillar of the common good. It is a concept and an action, transcending mere assistance, central to right relationship between people, institutions and the environment. The provision of care encompasses a wide spectrum of activities, ranging from care of self, the nurturing of familial and community relationships through to housing and food systems as well as healthcare and democratic systems. However, despite its intrinsic importance, the notion of care has often been undervalued and inadequately addressed within policy frameworks. As we navigate through an era marked by profound demographic shifts, economic transformations, and evolving social dynamics, the need to prioritise care within our societies becomes increasingly evident.

How we understand and deliver care in Ireland today and into the future raises significant questions: what is it exactly? who needs it? who deserves it? who provides it and how should they be supported? For much of the twentieth century, care in Ireland was largely unpaid, unseen, and gendered. Women, particularly mothers and daughters, were the primary caregivers for children, older relatives, and those living with illness or disability. The State's role was limited. As Ireland urbanised and entered a new economic era, this model began to strain under the pressures of mobility, employment, and changing family structures. As more women entered the workforce and families became geographically dispersed, the demand for formal care services grew. Nursing homes expanded, childcare became a professionalised industry, and migrant workers became essential to sustaining Ireland's care economy. At the same time, the State began to recognise care as a policy priority rather than a private responsibility. Initiatives such as the Carer's Allowance, home support services, and national strategies for older people reflect a growing awareness that care is both a public good and a matter of rights.

The story is not one of simple progress. The austerity years following the 2008 financial crisis exposed deep vulnerabilities in Ireland's care infrastructure. Cuts to social spending, staff shortages, and fragmented provision revealed the fragility of a system dependent on underpaid workers and overstretched families. More recently, the impact of Covid-19 also revealed much about the vulnerabilities in our system. Today, as Ireland faces numerous challenges, the question of how to deliver sustainable, dignified, and equitable care has never been more urgent. With demographic change in the years ahead, the demands on our system of care will change. Public policy is required to address questions posed by demographic change and the need for sustainable and equitable provision of care.

We must re-imagine care as a central tenet of public policy, acknowledging the multifaceted nature of care, encompassing not only healthcare but also support for systems, families, communities, and individuals across their lifespan. By adopting an inclusive approach to care, we can address the diverse needs of individuals and communities while promoting principles of equity, solidarity, and sustainability. We need to move away from a “world in which carelessness reigns”¹ and return to a “care-centric narrative”.²

These papers were originally presented at a conference organised by *Social Justice Ireland* on the theme: Care in a Changing World.

Social Justice Ireland expresses its deep gratitude to the authors of the following chapters who made this publication possible. They brought a great deal of experience, research, knowledge and wisdom to their task and contributed their time and obvious talent to preparing these chapters.

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Social Justice Ireland advances the lives of people and communities through providing independent social analysis and evidence-based policy development to create a sustainable future for every member of society and for society as a whole. We work to build a just society through developing and delivering

¹ The Care Collective, *The Care Manifesto: The Politics of Interdependence* (2020) <https://www.versobooks.com/products/2625-the-care-manifesto>

² Kathleen Lynch, *Care and Capitalism* (2021) <https://www.wiley.com/en-ie/Care+and+Capitalism-p-9781509543854>

credible analysis and policy to improve society and the lives of people. We identify sustainable options for the future and outline viable pathways forward. In all of this, we focus on human rights and the common good. This publication is a contribution to this process.

In presenting these chapters we do not attempt to cover all question that arise around this topic. This volume is offered as a contribution to the ongoing public debate around these and related issues. We trust that those engaged in shaping Ireland's future for the coming decades will find it of value.

Susanne Rogers



Care in a Changing World



Social Justice Ireland

1. Population and Labour Force Projections 2023-2057 and other Demographic Trends.

Conor J Crowley

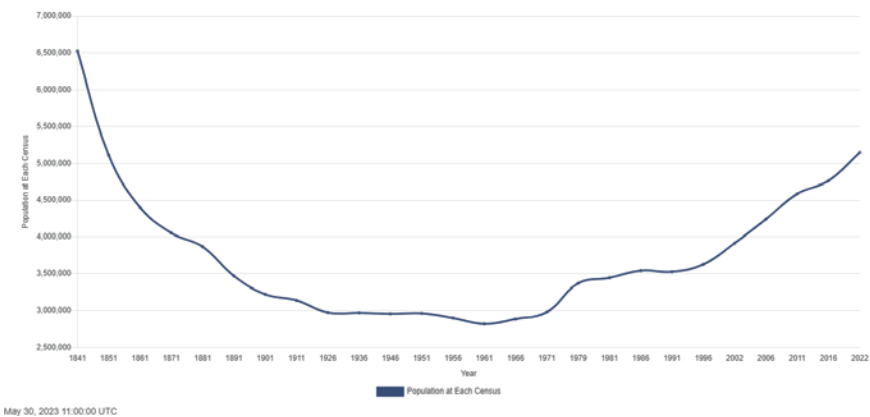
1. Ireland's Historical Population

Ireland is one of the few countries on Earth with a lower population now than it had 200 years ago. What is now the Republic of Ireland had a population of 6.5 million in 1841, and this number has fallen to 5.46 million [1] in 2025. This shows the effect that the Famine had on even the current day demographic picture of the State. On the other hand, the population of Ireland has almost doubled in the last 60 years, from a low of 2.61 million at the 1961 Census.

Though the number is significantly lower than the 1841 Census, the 2025 Population Estimate of 5.46 million is the biggest estimate of population for the 26 counties which comprise the current Republic since the 1841 Census.

The usually resident (those that lived in the State for 12 months around the annual reference period) population of Ireland is estimated to have increased by almost 900,000 people in the last 10 years, a percentage increase of 14.9%, and the population has increased by over 30% since the year 2000.

Figure 1. Population at each Census 1841-2022



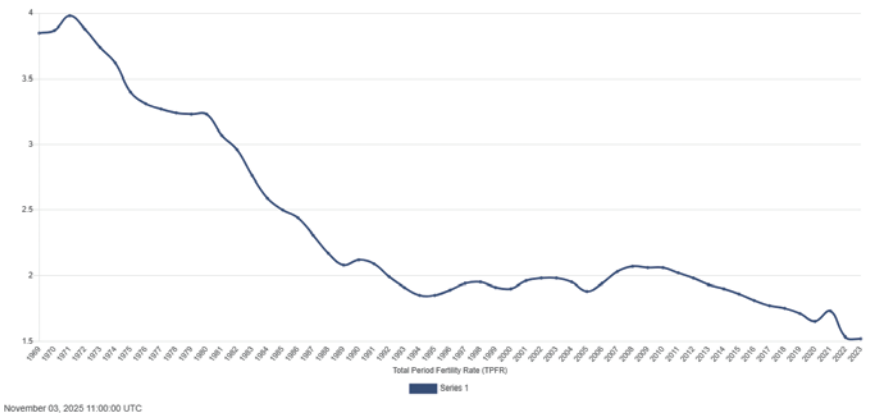
Source: CSO Ireland

2. Demographic Trends

2.1 Declining Fertility

Ireland's TFR has declined from 3.2 in 1980 to 1.5 in 2023. This is far below the replacement rate of 2.1 children per woman. In fact, TFR in Ireland has been below replacement rate every year since 1990. This shows itself in a decline in total number of births from 67,462 in 2014 to 54,062 in 2024 [2]. While Irish fertility is at unprecedentedly low levels, it is in fact still higher than the EU average, which was 1.46 in 2022. The average age at which women are becoming first-time mothers is also rising, from 24.9 years in 1980 to 31.6 years in 2023, while the average age at maternity considering all births increased 4.2 years to 33.2 years in the 50 years between 1973 and 2023.

Figure 2. TFR from 1969 to 2023

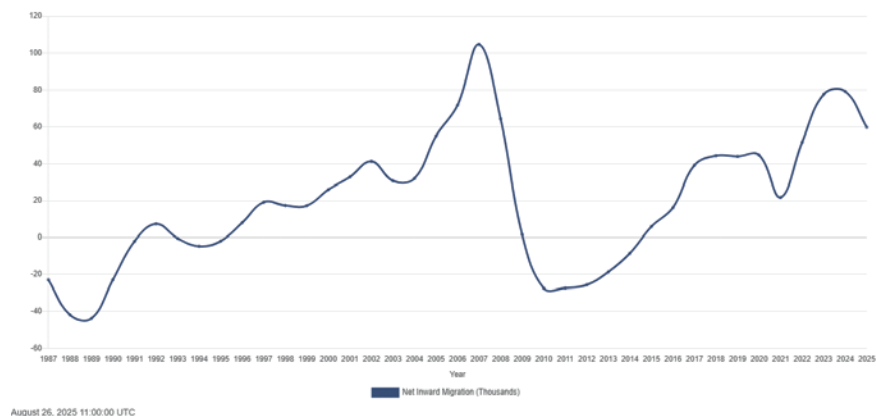


Source: CSO Ireland

2.2 Net Inward Migration

Historically, Ireland has been a country of significant net outflows of migration. Over the past 50 years, this trend has changed and became more cyclical. The 1980s saw several years of strong net outflows each year, but by 1996 this picture had reversed and, for perhaps the first time in the Republic’s history, the 12 years to 2008 saw strong net inward migration. The start of the 2010s saw net migration once again become negative for five years until 2014. However, once again numbers flipped and Ireland once again has been a net receiver of migrants every year since 2015, with immigration surpassing emigration by at least 50,000 for each year since 2022.

Figure 3. Net Migration from 1987 to 2025



Source: CSO Ireland

2.3 2020s so far - War in Ukraine and COVID

So far, the 2020s have produced two major demographic shocks. A big question for demographers worldwide this decade has been the treatment of the first of these, COVID19, in calculations. Mortality rates were impacted in 2020 and 2021, but these effects appear to have had limited impact to overall improvements in mortality.

Likewise, the war in Ukraine and resulting displacement of millions from their homes has had a major impact on inward migration numbers over the past few years. Ireland has been recently seeing net migration at a rate not seen since the mid-2000. A major question for the Expert Group convened to study these projections with the CSO was the long-term level of Net Migration in Ireland. This continues to be reviewed.

3. Population Projections - Expert Group and Assumptions

An Expert Group was convened to consider the assumptions that would be needed to make the 2023-2057 iteration of National Population Projections. Mortality, fertility and migration scenarios in particular had to be considered. In this iteration, just one fertility and mortality assumption were used. However, three migration scenarios were considered. These are delineated below:

3.1 Fertility Assumption

Further decreases in TFR were used as the basis of the Fertility Assumption. The TFR was taken to start at 1.55 in 2023, to decrease incrementally to 1.3 by 2038 and remain constant thereafter to 2057. Many topics were considered in the lead up to this decision, including:

- Trends in births
- ASFR (Age-Specific Fertility Rates)
- Number of Women of child-bearing Age
- Average age of child-bearing mothers and first-time mothers.
- The wider picture in the EU.

3.2 Mortality Assumption

Consensus in demographic circles, as well as indeed the CSO Expert Group, is that life-expectancy will continue to improve for the period of the projections. Short-term mortality is expected to improve by 2.5% year-on-year for those under the age of 90. In the long-term, mortality is assumed to improve 1.5% each year. The short-term rate decreases linearly to the long-term rate each year until 2047, at which point 1.5% is applied each year until the end of the period.

All in all, the assumptions taken result in the following life expectancy improvements:

- 80.2 years in 2022 to 86.2 years in 2057 for males.
- 83.9 years in 2022 to 89.1 years in 2057 for females.

As has always been the case historically, the life expectancy is higher for women than men. However, the difference between the two is set to narrow by almost a year in the 35 year period.

3.3 Migration Assumption

Migration has been very volatile since Covid and a major question facing the Expert Group was one surrounding future trends in this area. While these are not predictions, merely assumptions to illustrate possible future scenarios, the expert group settled on three migration scenarios:

- M1: High Net Migration: Net migration starting at +75,000 in 2022 and decreasing incrementally to +45,000 per annum by 2027 and remaining at this level to 2057.
- M2: Medium Net Migration: Net migration starting at +75,000 in 2022 and decreasing incrementally to +30,000 per annum by 2032 and remaining at this level to 2057.
- M3: Low Net Migration: Net migration starting at +75,000 in 2022 and decreasing incrementally to +10,000 per annum by 2032 and remaining at this level to 2057.

Net Inward Migration was close to 75,000 in 2022, but the sheer size of this net inward flow was due in part to the Ukraine War. With that in mind, that inflow of people is unlikely to be replicated in future, even if Ireland experiences high net inward migration. Therefore, the M1 Scenario of high net inward migration is placed at 45,000, which is 30,000 people below the 2022 figure.

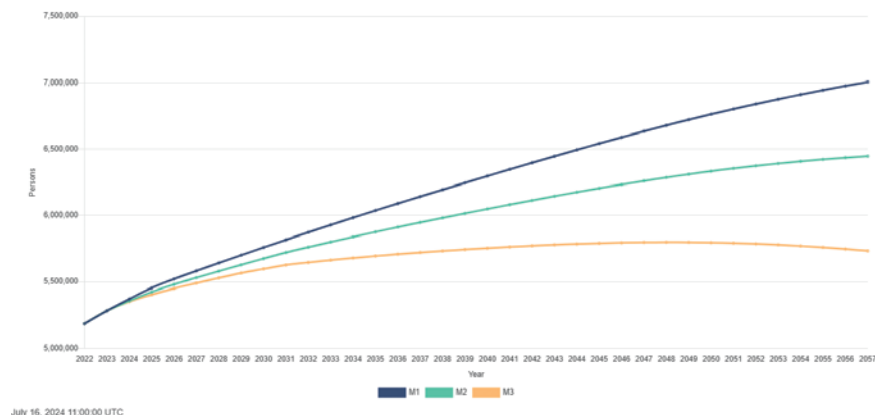
4. Population Projection Results 2023-2057

4.1 2057 Population

The usually resident population of Ireland was 5.18 million people in 2022. Under all three migration scenarios the CSO projects this population to increase significantly over the following 35 years. The population grows as follows under the three scenarios:

- M1: The population grows to 7.01 million in 2057 in this scenario, a volume increase of 1.82 million, and a percentage increase of 35.1%
- M2: The population grows to 6.45 million, representing a rise of 1.26 million people, or 24.4%
- M3: The population grows to 5.73 million people, which is a rise of almost 550,000 people or 10.6%.

Figure 4. Population projected to rise across all three scenarios



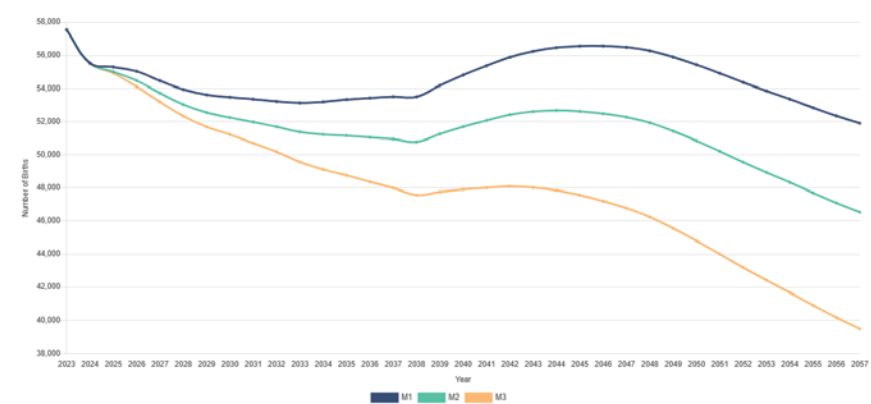
Source: CSO Ireland

4.2 Natural Increase

Annual Natural Increase can be defined as the amount of births subtracted by the amount of deaths on a yearly basis. The natural increase in Ireland stood at 18,679 in 2022 [3]. Under all three scenarios, births are expected to fall and deaths are expected to rise to point where the Natural Increase becomes negative and there is more deaths than births in the State by 2057. Even though ASFR and mortality assumptions are constant across the three migration assumptions, migration has an impact on the number of people who are in the country to experience the fertility and mortality assumptions. Births and deaths under the three migration scenarios are as follows:

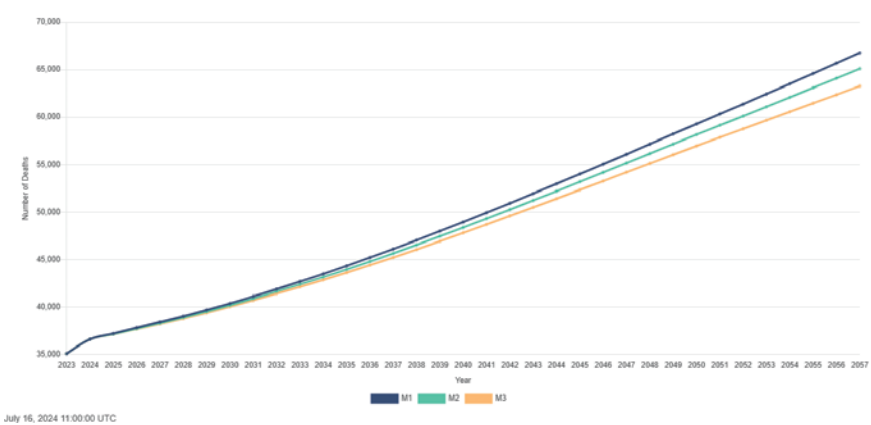
- M1: Births projected to drop to 51,897 by 2057, while deaths rise to 66,772, causing a natural decrease of 14,875.
- M2: Births fall to 46,532, while deaths rise to 65,094, leading to a natural decrease of 18,562.
- M3: Births fall to 39,475 and deaths rise to 63,270 and the natural decrease stands at 23,795.

Figure 5. Births across all 3 migration scenarios projected to fall



Source: CSO Ireland

Figure 6. Deaths across all 3 migration scenarios projected to rise.



Source: CSO Ireland

5. Projected Population by Age Groups of Interest

5.1 Amount of Children aged 0-14 in the State

At the time of the 2022 Census, there was 1,014,300 persons aged 0-14 in the State. Under all three scenarios, this number is projected to be lower in 2057, no doubt in part due to the assumed decline in fertility rates. The projections for the population within this age group in 2057 under each of the migration assumptions are as follows:

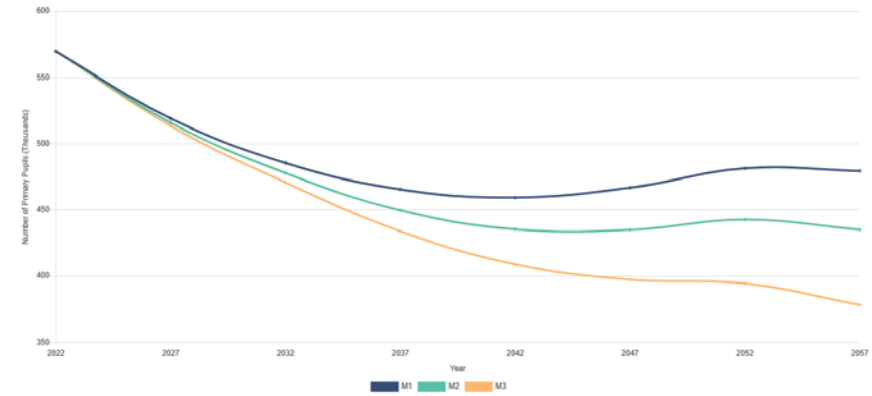
- M1: The population aged 0-14 is projected to fall to 859,400 by 2042, with a small bounceback to a total of 875,300 persons by 2057, which represents a decrease of 13.7% compared with 2022 figures.
- M2: The cohort aged 0-14 is forecast to be 792,600, or a percentage decrease of 21.9% versus 2022, under the M2 assumption.
- M3: The cohort aged 0-14 would fall to 686,400, a decrease of 32.3%.

5.2 Amount of Primary School aged Children

For the purpose of these projections the primary school population is broadly represented by those aged 5-12 years of age. In 2022 there were 569,700 children in this age group. This number is projected to fall heavily in the next 10 years, due to the decline in births post-2010. By 2032, this number is not expected to be above 500,000 under any of our assumptions and it drops as low as 470,733 in our M3 scenario. By 2057, the picture is expected to look as follows:

- M1: The primary-school aged population is projected to be 479,441 under the M1 assumption, a drop of 15.8% compared to 2022.
- M2: The cohort is projected to drop to 435,149, representing a drop of 23.6%.
- M3: Under this assumption, the cohort would fall to 378,409. This is a drop of 33.6% compared with 2022.

Figure 7. Amount of Primary-School Aged Children in the State



Source: CSO Ireland

5.3 Population aged 65 or Over

On the other hand, the population in the oldest age group is expected to increase significantly under all three migration scenarios:

- Under the M1 scenario, the population aged over 65 is going to rise from 781,400 to 1.94 million by 2057, which represents an over two-and-a-half-fold multiplication in this population.
- Under the M2 scenario, the population of this cohort will rise to 1.88 million, while there's a similar rise to 1.81 million under the M3 scenario.

In 2022 the older population accounted for 15.1% of the total population, this will grow to between 27.8% and 31.6% (for M1 and M3 respectively) of the total population by 2057 depending on the scenario used.

6. Dependency Ratios

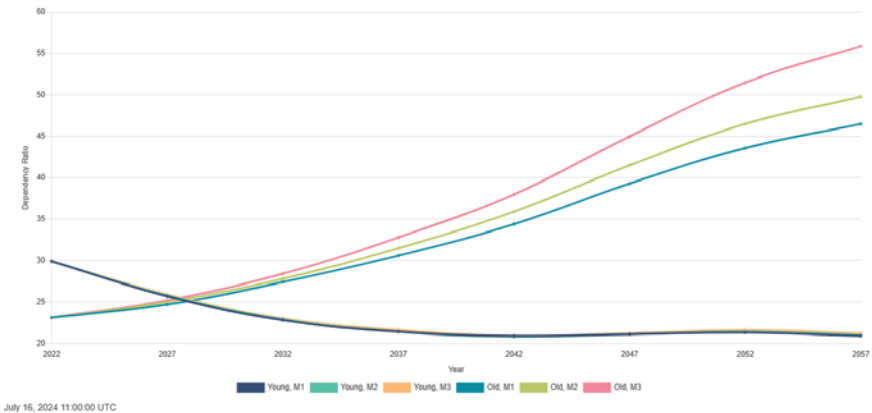
The young dependency ratio (the population aged 0 - 14 years expressed as a percentage of the population aged 15 - 64 years) is projected to fall under all assumptions by 2057. This ratio was 29.9% in 2022 and falls to between 20.9%

(M1) and 21.2% in 2057 (M3). The young dependency ratio is expected to be at its lowest level in the early 2040s.

The older dependency ratio (the population aged 65 years and over expressed as a percentage of the population aged 15 - 64 years) was 23.1% in 2022. This is projected to increase steadily from 2022 onwards, rising by 2 - 7 percentage points every five years. By 2057 this ratio will have more than doubled since 2022 under each different scenario, reaching between 46.5% for the M1 scenario and 55.9% for the M3 scenario.

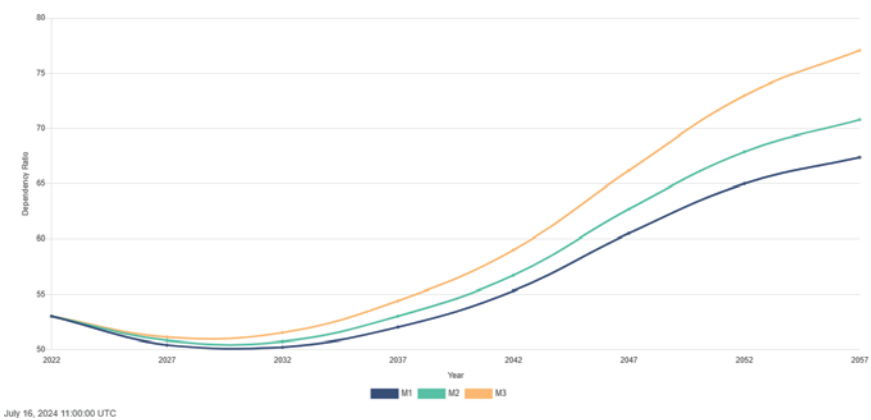
The two ratios combined give the total dependency ratio. In 2022 the total dependency ratio was 53.0%, meaning that there were roughly 2 people of working age for everyone aged 0-14 and 65+. This ratio is projected to rise under all scenarios to reach values of between 67.4% (M1) and 77.1% (M3) by 2057.

Figure 8. Projected Young and Old Dependency Ratios for 2022-2057



Source: CSO Ireland

Figure 9. Projected Total Dependency Ratio under each migration assumption for 2022-2057



Source: CSO Ireland

7. Conclusion

In 2022, Ireland’s usually resident population stood at 5.18 million. Under all three migration scenarios, this figure is projected to rise significantly over the next 35 years. In the case of our high migration assumption, the figure would even surpass 7 million. With this increase, however, will also come a notable aging in our population. In 2022, this population stood at 781,400. We project this figure to rise to over 1.8 million people for all assumptions. While the younger-age dependency ratio will decrease, the old age one will increase significantly. Our projections also indicate that natural increase will become negative over the next 35 years, which will be the first time this has happened in Ireland in recent demographic history.

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2. Care Work, Poverty and Inequality

Susanne Rogers

Introduction

Care embodies a fundamental pillar of the Common Good. It is both a concept and action, transcending mere assistance, central to right relationship between people, institutions and the environment. The giving and receiving of care is woven through the life cycle, in early years, later years and for some, throughout all stages of their lives. The provision of care encompasses a wide spectrum of activities, ranging from care of self, the nurturing of familial and community relationships through to housing and food systems as well as healthcare and democratic systems. However, despite its intrinsic importance, the notion of care has often been undervalued and inadequately addressed within policy frameworks.

As we navigate through an era marked by profound demographic shifts, digital and decarbonisation related economic transformations, and evolving social dynamics, the need to prioritise care within our societies becomes increasingly evident. Whether paid or unpaid, carers in all capacities, contribute significantly to society each year. We must re-imagine care as a central tenet of public policy, acknowledging the multifaceted nature of care, encompassing not only healthcare but also support for systems, families, communities, and individuals across their lifespan. In Ireland, an independent Commission on Care for Older People was established in 2023.¹ While the focus on older people is welcome in light of the changing demographic in Ireland, its limited scope misses all other cohorts that require care and those who provide it.

Whilst Ireland has experienced significant economic growth over the past few decades, persistent inequalities exist. The provision of care is deeply intertwined with social issues like poverty, and inequality. Time and time again, research shows that it is those households unable to engage with full time paid employment due to their caring duties who appear in the deprivation, at risk of poverty, poor health and wellbeing, and housing precarity statistics. By adopting an inclusive approach to care, we can address the diverse needs of individuals and communities while promoting principles of equity, solidarity,

¹ <https://www.gov.ie/en/department-of-health/campaigns/commission-on-care-for-older-people/>

and sustainability. By changing our societal relationship to care, by recognising its centrality to the Common Good and importance in fostering human dignity, we can reaffirm a “care-centric narrative,”² and leave behind a “world in which carelessness reigns.”³ These households must be supported to provide that care.

This paper explores how care structures in Ireland, both formal and informal, interact with poverty and inequality, highlighting gendered dimensions, state responsibility, and social policy shortcomings. We begin by sketching out the current context for care, poverty and inequality and how they interact in Ireland today, followed by an alternative vision for a caring society and the changes that would be required to achieve this. The paper concludes with policy recommendations that provide a pathway to a society in which care is valued, accessible and equitable.

Current Context

How Should We Understand Care?

What do we mean by care? Care is basically expressed and delivered through a wide range of activities and responsibilities that support the physical, emotional, and social wellbeing of others. Fundamentally, it is about recognising and meeting the needs of others. It can be broadly divided into unpaid care and paid care. Note, however, that paid care may be more about buying someone’s time and expertise and less about care as ‘primary nurturing and co-creating work (love labour)’ (Lynch, 2022).

Unpaid care includes domestic tasks and meeting care needs of children and adults without any direct financial compensation, usually directly within households or wider communities. Tasks would generally involve cooking, cleaning, helping children with their school work, caring for sick family members, or assisting elderly relatives. This work is essential for maintaining daily life, the economic and social functioning of society. Yet it is often undervalued and disproportionately carried out by women, reinforcing gender inequalities in the distribution of labour.

Paid care refers to work performed in exchange for a wage or salary, typically within the care sector. Paid care workers often operate within healthcare facilities, private homes, daycare centres, and community institutions. While these roles are vital to public health and social stability, they are frequently

² <https://www.wiley.com/en-ie/Care+and+Capitalism-p-9781509543854>

³ <https://www.versobooks.com/products/2625-the-care-manifesto>

underpaid, lack adequate recognition or workplace protections compared to other professions.

Both forms of care are interdependent. Unpaid care sustains families and communities, while paid care provides professional support and fills critical gaps. Valuing both types is essential for social equity, economic resilience and human wellbeing.

Who needs and provides care?

In Ireland, traditionally and continuing into the present, family members play a central role in providing the vast majority of both childcare and eldercare. The state's reliance on family-based care is rooted in cultural traditions, historical policies, and limited public provision of formal care services. Unpaid care within households is a cornerstone of daily life, with parents, in particular mothers, shouldering the main responsibility for raising children, supporting relatives with disabilities, and caring for older family members.

The Census 2022 Profile 4 - Disability, Health and Carers found that 5.8 per cent of the population provide regular unpaid care, where that caring role is defined as providing regular unpaid personal help or support to a family member, neighbour, or friend with a long-term illness, health issue, or an issue related to old age or disability. This figure equates to 299,128 people, an increase of over 50 per cent from the 195,263 people identified in Census 2016. The dominant caring role played by women was highlighted by the fact that 181,592 (61 per cent) of these care providers were female.⁴ When assessed by length of time, the census found that 46 per cent of carers provided up to 14 hours per week of unpaid help, 14 per cent provided between 15-28 hours, 6 per cent provided between 29-42 hours, and 21 per cent provided 43 or more hours per week of unpaid care.

Care for older adults is often provided informally by adult children, with many older people understandably expressing a preference to remain in their own homes. This model aligns with Ireland's policy emphasis on "ageing in place," but it can also place considerable emotional and financial pressure on family caregivers. While there has been growth in early years childcare services and subsidies, many families still rely very heavily on informal care arrangements

⁴ These proportions are similar to the findings of Census 2016 and 2011 and also echo those from a CSO QNHS special module on carers (CSO, 2010a) and a 2008 ESRI study entitled 'Gender Inequalities in Time Use' (McGinnity and Russell, 2008: 36, 70).

from relatives, especially grandparents,⁵ for support due to both high childcare costs and limited availability of affordable options in many areas, particularly for those on lower incomes.

This deep reliance on unpaid and informal care provided by families reflects the gaps in the formal care infrastructure, meaning care responsibilities can limit workforce participation, especially for women. Indeed, in the Labour Force Survey Q4 2024, among those who stated that they wanted to work but were not seeking work or available for work, 26 per cent cited care responsibilities / personal family reasons as the primary reason.⁶ Care is both ‘fundamental and marginal’⁷ at the same time. That we will care for our family members is presumed. Yet, those engaged in domestic duties, those providing care, are treated as economically inactive, as not producing ‘commodities of direct value to the economy - primary role is vicarious - by servicing others they are enabled to engage in productive economic activity’ (Oakley, 1974). This unpaid work, despite being essential for the functioning of society, is undervalued in economic terms, leading to invisibility in policy and planning. As this work is not regarded as ‘work’, as well as not getting paid for it, no rights to any secondary benefits accrue. In reality, however, no economic activity can take place without the performance of those duties.

Women disproportionately shoulder the responsibility for both paid and unpaid care work. Globally and in Ireland, women provide the majority of childcare, eldercare, and domestic work within households, often without financial compensation. The unequal distribution of care work impacts women’s economic opportunities, limiting their participation in the labour market⁸ and contributing to gender pay gaps. An increase in the cost of childcare provision of just 10 per cent could lead to a 30 minute reduction in a mother’s working hours.⁹ It can also affect their health, wellbeing, and retirement security. Addressing the feminisation of care requires challenging gender stereotypes, investing in professional care services, ensuring fair pay and conditions for care workers, and promoting policies that encourage men to share care responsibilities equally. This shift benefits both gender equality and social sustainability.

⁵ <https://www.growingup.gov.ie/pubs/OPEA121.pdf>

⁶ <https://www.cso.ie/en/releasesandpublications/ep/p-lfs/labourforcesurveyquarter42024/keyfindings/>

⁷ https://platypus1917.org/wp-content/uploads/archive/rgroups/2008-chicago/mitchelljuliet_womenlongestrevolution_nlr40.pdf

⁸ <https://www.irishtimes.com/news/social-affairs/half-of-working-mothers-consider-giving-up-work-over-childcare-costs-1.4189580>

⁹ https://www.esri.ie/system/files/publications/RS73_0.pdf

Women's unpaid work tends to be seen as a costless resource to exploit (Himmelweit, 1995). We see time and time again when austerity hits and Governments curb their spending, it is often women who end up paying the price as whatever supports are in place are withdrawn or reduced. During the last recession Government funding for the Community and Voluntary sector reduced dramatically and this still has not, as yet, been fully restored. The problem is these cuts are not so much savings as a shifting of costs from the public sector to the private sector, primarily onto women because the daily work of care and home still needs to be done.

Meanwhile, in the paid care sector, nursing, childcare services, and home health assistance, women also dominate the workforce. While these roles are socially vital, they are frequently low paid with limited career progression, and precarious working conditions. This undervaluing reflects deep-rooted gender norms that frame care as a “natural” female responsibility rather than skilled work deserving of fair wages and labour protections. Also worthy of note is the crucial role migrant workers play in sustaining Ireland's care economy, filling essential gaps in both paid childcare and eldercare services. As Ireland's population ages, as more women engage in paid work outside the home and with limited domestic labour supply, the demand for care rises accordingly, migrant workers have become an indispensable part of the sector. Strengthening Ireland's care system requires balancing the vital role of families with expanded, accessible professional services, ensuring care is shared more equitably between the state, communities, and households.

Poverty and Inequality in Ireland

An unequal society

Poverty does not occur in isolation and intersects with inequality. The problem of inequality is not merely one of democratic principle, it is materially consequential as has been shown by Kate Pickett, Richard Wilkinson, Joseph Stiglitz and others.¹⁰ Without social transfers, 31 per cent of the population would have been below the poverty line in 2024 (CSO, 2025). Such an underlying poverty rate suggests a deeply unequal distribution of direct income.

A report from Oxfam in 2023 found that the top 1 per cent of wealth-holders owns more than a quarter of the country's total wealth, at €232 billion (Oxfam,

¹⁰ See Pickett, K., & Wilkinson, R. (2010). *The spirit level*. London: Penguin; Stiglitz, J. (2012) *The Price of Inequality: How Today's Divided Society Endangers Our Future*. New York: W.W. Norton & Company

2023). A report from the Central Bank of Ireland shows that the wealthiest 10 per cent of Irish households hold almost half the net wealth in the country (48.6 per cent).¹¹ Analysis presented at *Social Justice Ireland's* conference 'The Social Justice Movement – A Fifty-Year View' demonstrates that income inequality has remained stubbornly stable over the past fifty years. While the total value of income has increased, not much has changed about its distribution. The share of total household disposable income going to the top 20 percent of households between 1973 and 2022 has steadily remained between 40 and 45 per cent. The share going to the bottom 20 per cent of households has remained around 5 per cent (Collins & Kavanagh, 2024).

Uneven progress

During the Celtic Tiger era (from the 1990s to the late 2000s), Ireland experienced unprecedented economic growth driven by a combination of factors such as increased foreign direct investment, a booming construction sector, and increased exports. Rising employment and incomes led to significant reductions in poverty rates, with many households benefiting from improved living standards. However, inequality persisted and certain groups such as lone parents, disabled people and those experiencing long-term unemployment remained at higher risk of poverty despite the country's overall prosperity. In this cohort we can clearly see households with caring needs and duties.

The 2008 global financial crash brought about an abrupt end to this period of growth. Ireland's economy contracted sharply, unemployment soared and Ireland entered an IMF-ECB-EC economic adjustment programme that provided financial assistance, but which required the introduction of austerity measures to substantially reduce public spending. All the cuts to the community and voluntary sector, to social welfare rates, to public services and the impact of reduced wages disproportionately affected low-income households, including those who require care supports. Structural inequalities were deepened as wealthier groups could rely on private healthcare, education, and housing, while others bore the brunt of reduced state provision. Austerity reinforced Ireland's reliance on market-led solutions. Cuts to social housing investment, for example, forced greater dependence on the private rental market, laying the groundwork for today's housing crisis. In education, increased costs and reduced supports widened gaps in participation, particularly at higher levels. The cumulative effect of austerity was a widening of the inequality gap.

¹¹ <https://www.centralbank.ie/statistics/data-and-analysis/household-wealth>

In the mid-2010s, the economy gradually recovered. Poverty rates declined from their post-crash peak, but the benefits linked with economic recovery were unevenly distributed. Rising housing costs and insecure employment meant that economic gains did not fully reach the most vulnerable. The lesson is that whilst Ireland was able to achieve rapid economic growth, without strong social protections in place, any downturn can quickly reverse poverty reduction gains, doing long term damage unless policy actively supports those most impacted.

The austerity measures introduced in Ireland following the 2008 financial crisis had profound and lasting effects on inequality, rooted in structural and systemic factors. To stabilise public finances, successive governments implemented spending cuts, many of which disproportionately affected low to middle-income groups. Public services such as healthcare, education, and social protection were constrained, reducing supports for those most dependent on them. Rather than addressing structural vulnerabilities exposed by the crash, policies prioritised fiscal discipline over social equity. This entrenched systemic disadvantages for already marginalised groups, limiting social mobility and exacerbating intergenerational inequality in Ireland.

Understanding poverty

Where is the poverty line? How many people are poor? On what basis are they classified as poor? These and related questions are constantly asked when poverty is discussed or analysed. In trying to measure the extent of poverty, the most common approach has been to identify a poverty line (or lines) based on people's disposable income (earned income after taxes and including all benefits). The European Commission and the United Nations (UN), among others, use a poverty line located at 60 per cent of median income. The median disposable income is the income of the middle person in society. While the 60 per cent median income line has been adopted as the primary poverty line, alternatives set at 50 per cent and 70 per cent of median income are also used to clarify and lend robustness to assessments of poverty.

The most up-to-date data available on poverty in Ireland comes from the 2024 Survey on Income and Living Conditions (SILC) survey, conducted by the Central Statistics Office (CSO) and published in March 2025 (CSO, 2025). The 60 per cent of median income poverty line is the one adopted in the SILC survey. In that year, the CSO gathered data from a statistically representative sample of 4,885 households containing 12,066 individuals. The data gathered by the CSO is very detailed and incorporates income from work, welfare, pensions, rental income, dividends, capital gains and other regular transfers. Where possible,

this data was subsequently verified anonymously using Personal Public Service Numbers (PPSNs). When gathering income data, the SILC survey uses income from the year before the survey as the ‘income reference period’. Therefore, the data published in the 2024 report refers to income levels in 2023. According to the CSO, the median disposable income per adult in Ireland during 2023 was €29,996 per annum or €574.86 per week.

Consequently, the income poverty lines for a single adult derived from this are:

- 50 per cent of median is €287.43 a week
- 60 per cent of median is €344.91 a week
- 70 per cent of median is €402.40 a week

Updating the 60 per cent median income poverty line to 2025 levels, using published CSO data on the growth in average hourly earnings in 2024 (+6.2 per cent), produces a value for the relative income poverty line at the start of that year (CSO, 2025). In 2025 that figure is €366.30 for a single person. Any adult below this weekly income level will be counted as being at risk of poverty.

The 2024 Survey on Income and Living Conditions (SILC) reported that 11.7 per cent of the population were at risk of poverty, an increase from 10.6 per cent in 2023. To fully grasp the scale of Ireland’s poverty problem, it is useful to translate these poverty percentages into numbers of people. 630,000 people lived below the 60 per cent of median income poverty line in 2024. Looking over the past 30 years, despite a reduction in the headline poverty rate (from 15.6 to 11.7 per cent) there are almost 70,000 more people in poverty (as the population has increased).

The group with the highest risk of poverty and some of the highest rates of deprivation are those who are unable to work due to long-term illness or disability and many incur extra related costs, deepening poverty levels. More than 106,000 older people struggled to make ends meet in 2024, an increase of 64 per cent in a year. This stark figure highlights how vulnerable older people are due to their overwhelming reliance on a fixed income. In 2024, more than 190,000 children in Ireland were living in poverty. The scale of child poverty is alarming, and childhood experiences of poverty are linked with adverse outcomes across almost all areas of life.

The combination of rising rents and unaffordable mortgages force younger generations into precarious living arrangements, including overcrowding, delayed family formation, and prolonged stays in emergency accommodation.

Homelessness, particularly among families and children, has reached record levels, reflecting systemic failures in social protection and housing policy and shows no sign of abating. Those in disadvantaged or marginalised communities are disproportionately affected, as the lack of stable housing undermines access to healthcare, education, and employment opportunities, thus reinforcing cycles of poverty.

The crisis also exacerbates intergenerational inequality. While some households benefit from rising property values, others are excluded from the benefits of homeownership entirely. In effect, housing in Ireland functions less as a common public good and more as a commodity, reproducing inequality through structural and systemic mechanisms.

Regional disparities

In the Irish context, it is also important to acknowledge the differences between urban and rural poverty, a feature of our uneven economic development and recovery. Just over three in ten people in Ireland (36 per cent) live in a rural area, above the European average.¹² Data shows that remote rural areas have the highest total dependency ratio in the State. These areas also have the highest average age in the State, the highest rate of part-time workers in the State (23.8 per cent), and in 2019, at 19.3 per cent, the highest poverty rate (CSO, 2019). This gives an insight into the challenges that face rural and regional communities.

The availability of poverty estimates by region has been inconsistent over recent years. The most recent SILC results provide a breakdown using three regional classifications but did not provide a breakdown for the eight regional classifications (Dublin, Mid-West, South-East etc). Given the relevance of spatial issues to the assessment of progress and societal fairness, we hope this deficit will be addressed in future SILC publications. The available data suggests an uneven national distribution of poverty. Using the latest results, the SILC survey found that poverty levels are below the national average in both the Eastern and Midlands region and the Southern region. The highest rates are in the Northern and Western region, and area corresponding to counties along the border (Donegal, Sligo, Leitrim, Cavan and Monaghan) plus Galway, Mayo and Roscommon. Table 1 shows that the risk of poverty is higher in urban areas compared to rural areas, although the difference is small. By 2024, the risk of poverty had switched, albeit marginally. In urban Ireland, it was 0.8 percentage

¹² <https://data.worldbank.org/indicator/SP.RUR.TOTL.ZS?locations=IE>

points higher than in rural Ireland with at risk rates of 12.0 per cent and 11.2 per cent respectively.

Table 1. Risk of Poverty by Region and Area, 2005 - 2024

	2005	2010	2015	2020	2024
Northern and Western	n/a	n/a	n/a	19.4	18.9
Southern	n/a	n/a	n/a	14.2	10.7
Eastern and Midland	n/a	n/a	n/a	9.7	9.8
Urban Areas	15.9	12.5	15.3	13.0	12.0
Rural Areas	22.2	18.1	18.3	12.5	11.2
Total Population	18.3	14.7	16.3	12.8	11.7

Source: CSO online database

The amount of money required to achieve the Minimum Essential Standard of Living (MESL) ranges from an estimated amount of €156 per week higher for working rural couples with younger children (pre-school and primary age), to €146 per week for rural couples with children of primary and second-level school age, than for their urban counterparts according to the latest MESL figures from the Vincentian MESL Research Centre.¹³ Higher costs are related to household energy, transport, fuel, and food (as has been the case since 2020), however, these costs increased significantly between 2022 and 2024.

Rural and regional policy has to grasp with issues such as higher poverty rates, lower median incomes, higher dependency ratios, distance from everyday services, and a higher rate of part-time employment – issues which have persisted over time. Rural areas are very diverse; not all face the same challenges.

Interaction between Care and Poverty

Care, poverty and employment

In Ireland, we consign large numbers of people who are unavailable for work to poverty. At the same time, we require large numbers of people to forego work to fulfil caring roles. We fail to adequately support people doing that caring work. The 2024 Survey on Income and Living Conditions (SILC) survey, conducted by

¹³ https://www.budgeting.ie/download/pdf/mesl_2025_appendix_tables.pdf

the Central Statistics Office (CSO) notes that those most at risk of poverty report their Principal Economic Status (PES) as either unemployed (34.1 per cent) or by those who are unable to work due to long-standing health problems (32.5 per cent). This compares with the at risk of poverty rate of just 5.4 per cent for those who report that they are employed (CSO, 2025).

The time spent care giving reduces the hours available for paid employment, leading many to work part-time, accept flexible but lower-paid roles, or withdraw from the labour market entirely. Caring responsibilities can significantly limit participation in the workforce, particularly for women, who continue to shoulder the majority of unpaid care for children, older relatives, and family members with disabilities.

In Ireland, limited availability and high costs for any externally sourced formal care puts it out of reach for many lower income families and exacerbates the challenge of juggling care responsibilities with paid employment. For parents of young children, especially mothers, returning to full-time work can make no financial sense as childcare expenses can consume a large portion of wages. Similarly, adult children providing eldercare may reduce their working hours or leave jobs to meet the needs of ageing relatives. These career interruptions have long-term consequences, including reduced income, slower career progression, and smaller pension entitlements. Employers may also perceive those with competing care duties as less committed, which can further limit opportunities.

A lack of affordable childcare is a significant driver of poverty risk for families, especially those headed by a lone parent. When childcare costs are high relative to income, parents, most often mothers, are forced to make choices such as reducing their working hours, take lower-paid flexible jobs, or leave work altogether. This loss of income pushes households into financial insecurity, making it harder to meet basic needs such as housing, food, and utilities. In Ireland, childcare costs remain among the highest in Europe, creating a major barrier to employment for many parents.¹⁴ For lone parents, who typically rely on a single income, the challenge is even greater. Without affordable childcare, they face the difficult choice of foregoing work or taking on unsustainable expenses, both of which increase the risk of persistent poverty. The impact extends beyond immediate finances. Reduced earnings limit opportunities for career advancement and contribute to long-term income inequality.

¹⁴ https://www.esri.ie/system/files/publications/WP708_2.pdf

Paid care work is essential to modern functioning society, yet it is often linked to low pay, precarious conditions, and in work poverty. In Ireland, many care sector workers earn wages close to or at the minimum rate, despite the demanding nature of their jobs, which require skill, emotional resilience, and responsibility for vulnerable individuals. Many care workers can lack access to benefits such as paid sick leave, pensions, or opportunities for professional development. This instability can leave workers trapped in working poverty, where even full-time employment fails to provide a living income. These conditions stem from the historic undervaluing of care as work done by women and from cost-cutting pressures in both private and publicly funded services. Low pay and poor conditions contribute to high staff turnover, affecting the quality and continuity of care.

Many migrant workers are employed in nursing homes, residential facilities, and as live-in carers, providing round-the-clock support to older people. In childcare, they work in early years settings, as au pairs, or as nannies, enabling Irish parents to balance employment with family responsibilities. These roles require skill, empathy, and resilience, yet they are often undervalued and underpaid. Migrant care workers can face challenges such as racism, insecure contracts, limited access to career progression, and dependence on employers for visa status. Cultural and language barriers may add to their vulnerability. Despite these difficulties, their contribution extends beyond labour force participation and contribution to the tax-take, they bring cultural diversity, new perspectives, and vital social connections to the people for whom they care for.

Intersectionality recognises that social inequalities do not operate in isolation but intersect, compounding disadvantages for certain groups. In the context of care-related poverty, gender, class, race, and immigration status interact to shape who does the work of caring, under what conditions, and with what consequences. Women are overrepresented in both paid and unpaid care roles, which are undervalued and often poorly paid. For women from low-income backgrounds, the lack of alternative employment options can push them into precarious care jobs with limited protections. Migrant women, face additional barriers such as language challenges, discrimination, and dependence on employers for visa status, increasing their vulnerability to exploitation.

Class position influences whether individuals can outsource care or must provide it themselves, often at the cost of paid employment. Racial and ethnic inequalities can further limit access to fair wages and secure contracts in the care sector. Immigration status can determine eligibility for social supports, leaving some migrant carers ineligible for benefits despite their essential contributions.

Together, these intersecting factors mean that certain groups, especially low-income migrant women, are disproportionately concentrated in low-paid care work while also carrying heavy unpaid care burdens, perpetuating cycles of economic insecurity and social marginalisation.

Care and structural inequalities and deficits

Healthcare and education are essential forms of care, and access to both in Ireland remain deeply shaped by structural and systemic inequalities. While both sectors are formally available to all, the quality and timeliness of access often depend on a combination of geography and socio-economic status. In healthcare, Ireland operates a two-tier system: those with private insurance receive faster treatment, while those reliant on the public system can face lengthy waiting lists. This structural divide entrenches inequality, as lower-income households, those who are much less likely to afford private cover, experience poorer health outcomes. Rural communities also face systemic barriers, including shortages of general practitioners and limited specialist services.

Education reflects similar patterns. While schooling is free in principle, and we acknowledge that initiatives such as free school books and meals have made enormous differences, systemic factors such as voluntary contributions, transport costs, and access to extracurricular supports create unequal opportunities. Children from wealthier families are more likely to attend fee-paying or well-resourced schools, while disadvantaged areas often contend with overcrowding, fewer supports, and higher dropout rates. At third level, rising accommodation and tuition-related costs reinforce structural barriers, limiting participation for those from lower socio-economic backgrounds.

Both healthcare and education inequalities are rooted in broader systemic issues, including housing insecurity, underinvestment in public services, and policy frameworks that prioritise market-based solutions. As a result, inequality in Ireland is reproduced across generations, undermining social mobility.

The giving and receiving of care within households relies on an appropriate and secure environment in which the conditions for quality care are fostered. Inappropriate housing, insecurity of tenure and homelessness all undermine these conditions. The housing crisis in Ireland is one of the most visible manifestations of deepening inequality, driven by structural and systemic factors that disadvantage low and increasingly, middle-income households. Decades of underinvestment in public housing, combined with a reliance on market-led solutions, have created chronic shortages and soaring rents. This

structural imbalance results in wealth accumulation for property owners while locking many into long-term insecurity. The crisis exacerbates intergenerational inequality. While some households benefit from rising property values, others are excluded from the benefits of homeownership entirely. In effect, housing in Ireland functions less as a common public good and more as a commodity, reproducing inequality through structural and systemic mechanisms.

The combination of unaffordable mortgages and rising rents force younger generations into precarious living arrangements, including overcrowding and delayed family formation. Homelessness, particularly among families and children, has reached record levels, with prolonged stays in emergency accommodation, reflecting systemic failures in social protection and housing policy and shows no sign of abating. Those in disadvantaged or marginalised communities are disproportionately affected, as the lack of stable housing undermines access to healthcare, education, and employment opportunities, thus reinforcing cycles of poverty. Clearly, a lack of access to secure housing, with homelessness as its most extreme expression, impacts significantly on the quality of care experienced in a household.

Childcare policy in Ireland has undergone significant reform in recent years, particularly through the introduction of the National Childcare Scheme (NCS). The NCS was designed to make childcare more affordable and accessible, providing income-related subsidies to families and universal subsidies for all children under a certain age. This marked a structural shift away from fragmented, means-tested supports towards a more streamlined system. However, inequality remains a pressing concern. Families with higher incomes often still have greater access to high-quality providers, while those in disadvantaged areas face shortages, limited availability, and higher relative costs. The average fee for full-time childcare provision is now €186.84 per week, with the highest being in the Dun Laoghaire-Rathdown area (€244.08 per week on average) and the lowest in Carlow (an average of €152.08 per week).¹⁵ High childcare costs present a barrier to employment, particularly among young women with children. An increase in the cost of childcare impacts on the number of paid working hours for mothers. An increase in the cost of provision of just 10 per cent could lead to a 30 minute reduction in a mother's working hours (Russell, McGinnity, Fahey, & Kenny, 2018). Systemically, the reliance on a largely private childcare sector creates uneven provision. Providers in urban areas can command higher fees, while rural areas often struggle to sustain services, leading to geographic inequalities.

¹⁵ https://www.pobal.ie/wp-content/uploads/2022/05/Pobal_22_EY_20-21-Report_final_2.pdf

Furthermore, many childcare workers face low pay and precarious conditions, reflecting structural undervaluing of care work, which in turn affects quality and sustainability.

In Ireland and elsewhere, the outsourcing of care has led to a greater reliance on private childcare facilities, nursing homes, and agency-based homecare services. While it could be argued that this can increase choice and flexibility, it can introduce market pressures that prioritise cost-efficiency and a profit motive over quality. Low wages, casual contracts, and underinvestment in staff training are common in outsourced care settings, undermining job security and service standards. For households, outsourcing care often means paying for carers, frequently migrant or low-paid workers, while unpaid care continues to be shouldered mainly by women. This arrangement reflects and reinforces existing gender and class inequalities. This outsourcing shifts the burden of care provision from the state to individuals and the market, reducing public accountability. Addressing these issues requires rethinking care as a shared social responsibility, backed by strong public investment.

Pathways towards an Alternative Vision for Care

A key aspect of the social contract is solidarity between generations. At different points in the life-cycle, all of us will be either net beneficiaries from, or net contributors to society, and recipients or providers of care. This differs, depending on whether we are children, adults of working age, or old-age pensioners. It depends on whether we are in full-time or part-time education, engaged in caring work or in paid employment, or volunteering in the community. But, at almost all times, we are contributing to and benefiting from society in different ways. Recognising this reality, we must acknowledge the multiple forms of work, including care work, by which people contribute to society. It requires acknowledgement of the work done in our society that goes unpaid, under-recognised and undervalued. This acknowledgement requires that we reconceptualise the interaction between employment, taxation, work and welfare, and give serious consideration to policies such as a universal basic income and universal basic services. All this requires a new approach. The time has come to set a minimum floor of income and services below which no one should fall. The social welfare system and the income tax credits system should ultimately be replaced by a Universal Basic Income which would be far more appropriate during a time of transition and beyond. This should be accompanied by the development of Universal Basic Services to secure the wellbeing of all.

Creating the conditions to support participation in the workforce, in the context of support for carers, must include measures that ensure the adequate provision of care and recognition of the work done in the provision of care. Activation policies are not good enough if they prioritise rapid labour market entry over sustainable, quality employment, especially if they fail to foster a balanced approach for households with demanding caring responsibilities. Future policy directions therefore ought to focus on structural reform rather than piecemeal supports. Adequate welfare must be benchmarked alongside investment in universal public services, housing, childcare, healthcare, which can reduce reliance on cash transfers and build a more equitable social protection system.

Looking at the economics of care from a feminist perspective highlights just how much care work, both paid and unpaid, remains undervalued in Ireland, reinforcing structural and systemic inequalities. Much of this work, disproportionately carried out by women, is either unpaid within households or poorly paid in sectors like childcare, eldercare, and health support. Traditional economic models often exclude or undervalue care, framing it as a private responsibility rather than a public good. This systemic undervaluation contributes to gender pay, wealth and pension gaps, labour market segregation, and reduced economic security for women, particularly in later life. Harsh in light of the fact that no paid economic labour could happen without this care work. Policy responses have begun to address these issues through initiatives like the National Childcare Scheme and improvements to parental leave schemes. However, these remain partial measures within a system still heavily reliant on market provision. Feminist economics argues for structural rethinking. Care must be recognised as essential social infrastructure, on a par with healthcare or education.

Significant public investment in universal, affordable childcare and eldercare, alongside decent pay and conditions for care workers is essential. Expanding flexible and equal parental leave, as well as recognising unpaid carers through stronger social welfare supports and pension entitlements, are also critical. By embedding care into economic policy, Ireland could both reduce gender inequality and strengthen social and economic wellbeing overall.

A new approach that values care requires measures to foster the social conditions in which care is supported. 98,117 people are in receipt of carers allowance.¹⁶ In the context of addressing poverty among carers and those in receipt of care,

¹⁶ <https://www.oireachtas.ie/en/debates/question/2025-01-22/864/#:-:text=The%20main%20income%20supports%20to,be%20over%20%E2%82%AC1.24%20billion.>

it is essential that our social protection system provide an adequate income to live life with dignity, so that those whose participation in the labour force is limited due to caring responsibilities are not left behind. Yet questions remain about their adequacy in tackling structural and systemic challenges. Over the past decade, policy changes have focused on some targeted income supports, activation measures, and housing-related assistance. While these reforms have provided vital relief, they often function as short-term fixes rather than structural solutions. For example, supports like the Housing Assistance Payment (HAP) subsidise rent but ultimately channel public funds into the private market, reinforcing systemic dependence on a housing model that fuels inequality.

Welfare rates, though periodically increased, frequently fail to keep pace with the rising cost of living, especially in areas such as housing, childcare, and healthcare. This creates persistent income inadequacy for many households, leaving them vulnerable to poverty and social exclusion.

Many of the groups in Irish society that experienced increases in poverty levels over the last decade have been dependent on social welfare payments: these include the unemployed, the retired, lone parents and those who are ill or have a disability. Yet we know that adequate social welfare rates make all the difference.

Future policy directions must therefore focus on structural reform rather than piecemeal supports. Adequate welfare must be benchmarked alongside investment in universal public services, housing, childcare, healthcare, which can reduce reliance on cash transfers and build a more equitable social protection system. Table 2 presents the results of an analysis of five key welfare recipient groups performed by the ESRI using poverty data for five of the years between 1994 and 2001. These were the years that the Irish economy grew fastest and the core years of the ‘Celtic Tiger’ boom. Between 1994 and 2001 all categories experienced large growth in their poverty risk. For example, in 1994 only five out of every 100 old age pension recipients were in poverty. In 2001, this had increased ten-fold to almost 50 out of every 100. The experience of widow’s pension recipients is similar.

Table 2. Percentage of Persons in Receipt of Welfare Benefits/Assistance Who Were Below the 60 Per Cent Median Income Poverty Line, 1994-2001

	1994	1997	1998	2000	2001
Old age pension	5.3	19.2	30.7	42.9	49.0
Unemployment benefit/assistance	23.9	30.6	44.8	40.5	43.1
Illness/disability	10.4	25.4	38.5	48.4	49.4
Lone Parents allowance	25.8	38.4	36.9	42.7	39.7
Widow's pension	5.5	38.0	49.4	42.4	42.1

Table 2 clearly highlights the importance of adequate social welfare payments to prevent people becoming at risk of poverty. When payments fail to rise in proportion to earnings and incomes elsewhere in society, recipients slip further behind. It is important that adequate levels of social welfare be maintained to ensure that the mistakes of the past are not repeated.

As a tool to combat inequality, the importance of welfare transfers was also highlighted by the CSO in their assessments of the impact that Covid-19 supports to workers and businesses had on poverty levels. The December 2021 Poverty Insights (CSO, 2021) report estimated that the collective impact of the pandemic unemployment payment (PUP) and the wage subsidy scheme (WSS) was to reduce poverty by 7.7 percentage points, meaning that these supports kept over 380,000 additional people out of poverty in 2020.

Civil society, community and voluntary organisations play a vital role in addressing inequality in Ireland, stepping in where state provision falls short, particularly in the context of care in the broadest sense. These groups provide essential services such as homelessness supports, family resource centres, migrant advocacy, and mental health assistance. Their work not only alleviates immediate hardship but also challenges systemic barriers by amplifying the voices of disadvantaged communities. However, their reliance on short-term or precarious funding streams often limits sustainability and reach. Structural inequality is reflected here too, as many organisations operate under constant financial pressure, while demand for their services continues to rise. Policy responses have increasingly recognised the importance of the community and voluntary sector, particularly through initiatives like the Community Services Programme and Social Inclusion and Community Activation Programme (SICAP). Yet, funding mechanisms often prioritise project-based outcomes over long-term structural change, limiting the capacity of civil society organisations (CSOs) to address root causes of inequality. More secure, multi-annual funding

would facilitate stronger collaboration between the state and the community sector.

Reforms to tackle inequality in Ireland needs investment in the care economy alongside progressive taxation. The care economy, childcare, eldercare, healthcare, and community services provides essential social infrastructure but has historically been undervalued and underfunded. Increased public investment would not only improve access and quality but also create decent jobs, particularly for women, and help to address structural gender and class inequalities. Recognising care as a public good rather than a private burden is essential to building a more inclusive economy.

Progressive taxation is central to financing such investment. Ireland's tax system, while relatively progressive at higher income levels, still relies heavily on indirect taxes like VAT, which disproportionately impact lower-income households. In addition, gaps in wealth and property taxation allow significant concentrations of wealth to go untaxed.

Future demand on resources in addition to those that already exist mean that Ireland's overall level of taxation will have to rise significantly in the years to come – a reality Irish society and the political system need to begin to seriously address, something that *Social Justice Ireland* stressed in our 2022 submission to the Commission on Taxation and Welfare. Together, care economy investment and progressive taxation represent a systemic shift. That of moving away from market dependency towards a redistributive model of social provision. Such reforms would not only reduce inequality but also strengthen social cohesion and resilience in the face of future economic shocks, all of which are necessary if we are to cultivate a sustainable and holistic approach to care across our society and economy.

What is required?

Revising the classification of rural areas and rural typologies would make for more informed policy development and give better indicators of the challenges and opportunities in rural areas (NESC, 2021).

Provide a universal basic income for unpaid carers. Our success in implementing policy to address these challenges will determine how well-placed rural Ireland will be to respond to other challenges such as the transition to a sustainable society and the future of work.

Addressing the many barriers set out above requires affordable, accessible care services, flexible workplace policies, and cultural change that promotes equal sharing of care between men and women, enabling more people to participate fully in the workforce without sacrificing family responsibilities.

Policy responses ought to go beyond subsidies for private sector childcare provision. Substantial public investment in subsidised, high-quality childcare is required, ensuring that all families, no matter what income or structure, are able to access the support needed to work, provide for their children, and break the cycle of poverty. Greater public investment in childcare infrastructure, improved pay and conditions for staff, and targeted supports for disadvantaged communities are essential. A more universal, publicly funded model, similar to healthcare or education, could help transform childcare from a market commodity into a social right, reducing inequality and supporting long-term social mobility.

Improving wages, guaranteeing stable contracts, and investing in training are essential to recognise care as skilled, socially vital work and to ensure both workers and those they care for can thrive.

Recognising the hugely important, indeed vital role migrant workers play in Ireland's care economy means ensuring fair pay, decent working conditions, and pathways to residency. Strengthening protections not only benefits workers but also safeguards the stability and quality of Ireland's care services.

Create the social conditions for a society in which care is valued:

- Benchmark core social welfare rates to 27.5 per cent of average earnings to protect vulnerable households.
- Increase investment in early childhood education and care and after-school care by 0.1 per cent of GNI* each year with a view to reaching 1 per cent of GNI* by 2030.
- Ensure the provision of multiannual funding for the sector.
- Give serious consideration to policies such as a universal basic income and universal basic services.
- Set a new tax-take target on a per capita basis and gradually increase the total tax-take to reach this target.

Policy responses moving forward must therefore go beyond subsidies. Greater public investment in childcare infrastructure, improved pay and conditions for

staff, and targeted supports for disadvantaged communities are essential. A more universal, publicly funded model, similar to healthcare or education, could help transform childcare from a market commodity into a social right, reducing inequality and supporting long-term social mobility.

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3. Out of the shadows: understanding and formalising undeclared care work in the EU

Marianna Baggio and Jorge Cabrita

Introduction

The care economy forms the bedrock of European society, with everyone providing or receiving care at some point in their life. Care fosters wellbeing, which in turn supports the productivity of the workforce and the broader economy. The care economy also has a significant job creation potential, which can drive structural transformation and economic and social development. Yet care work remains profoundly undervalued, both socially and economically. It is also disproportionately shouldered by women (EIGE, 2023). While 48% of women provide unpaid care compared to 42% of men, the true disparity lies in care intensity: women dedicate an average of 32.5 hours per week to caregiving, compared to 26.5 hours for men. In parental childcare specifically, women provide 34 hours per week, while men provide 22 hours, representing 52% more care hours delivered by women (Eurofound, 2025a). This gender care gap - the stark, gendered difference in the provision of care - accounts for one-third to one-half of the gender earnings gap, representing approximately €147-220 billion in forgone economic value across the European Union. The cumulative impact extends throughout women's working lives, contributing directly to the 24.5% gender pension gap and elevated poverty risk in older age (European Parliamentary Research Service, 2025).

The formal care sector employs a growing number of workers in the EU, the majority of which are women, but is also increasingly experiencing staff shortages. Estimates from 2019 show that the formal long-term care (LTC) sector in the EU27 employed approximately 6.3 million workers, accounting for 3.2% of the Union's total workforce; of these, women comprised approximately four-fifths (81%) of all LTC workers (Eurofound, 2020). This gender imbalance has hardly shifted in the past decade, showing a stubborn occupational segregation that reflects the persistent, heavy feminisation of care work.

A significant portion of this essential work takes place in the shadows, operating outside of formal employment structures and regulatory oversight. Undeclared care work is defined as paid work that is lawful in nature but not declared to public authorities. This definition accounts for differences in regulatory systems

across EU Member States, recognising that what constitutes “undeclared” may vary depending on national legal frameworks. Regardless, undeclared care work mirrors many characteristics of both declared and unpaid care work. It remains overwhelmingly female-dominated, systematically undervalued, and characterised by poor working conditions and low pay, having profound impacts on workers’ physical and mental health. Workers in the undeclared care economy, disproportionately composed of third-country nationals and migrant women, face heightened exploitation, abuse and discrimination due to the absence of regulatory oversight, limited or non-existent employment protection, and restricted access to social security provisions. This lack of formal recognition leaves undeclared care workers without adequate health and safety protections, as well as options or mechanisms to challenge abusive employment practices, creating a tier of workers whose contributions to social reproduction and development are simultaneously indispensable and invisible (Eurofound, 2025b).

This article synthesises key findings from the recent Eurofound (2025b) research on undeclared care work. For comprehensive empirical evidence and detailed analysis, readers are encouraged to consult the original study.

Defining care to understand undeclared care work

Care work is remarkably diverse in its scope and responsibilities. It ranges from intimate, personal support, such as helping someone wash, dress, or manage health needs, to routine household tasks, like preparing meals, cleaning, doing laundry and maintaining a home. Social policy generally uses a narrower definition: support provided to people who cannot manage these activities independently, such as older people, those with disabilities, young children, or people who are unwell.

For the purposes of this article, we deliberately adopt the broader conceptualisation of care work. By including the full range of domestic and care activities, we can better trace which tasks are being commodified, outsourced beyond the household, and subsequently rendered vulnerable to informalisation. Moreover, this broader lens reveals the extent of care work operating in the informal economy and captures the blurred boundaries between different types of reproductive labour in practice.

In practice, we distinguish between direct and indirect care work (Figure 1). **Direct care** involves providing personal assistance and immediate support to children, older adults, individuals with disabilities, or those with health

conditions. **Indirect care** includes tasks that enable or support care provision, such as cleaning, cooking and household maintenance, which are essential for wellbeing. The susceptibility of these activities to undeclared work varies considerably across Member States, shaped by differing regulatory frameworks. For example, childcare may be strictly regulated in one country, requiring registration and professional qualifications, whereas it remains largely unregulated in another, making it more vulnerable to informal arrangements (Eurofound, 2025b).

Figure 1. A definition of direct and indirect care work

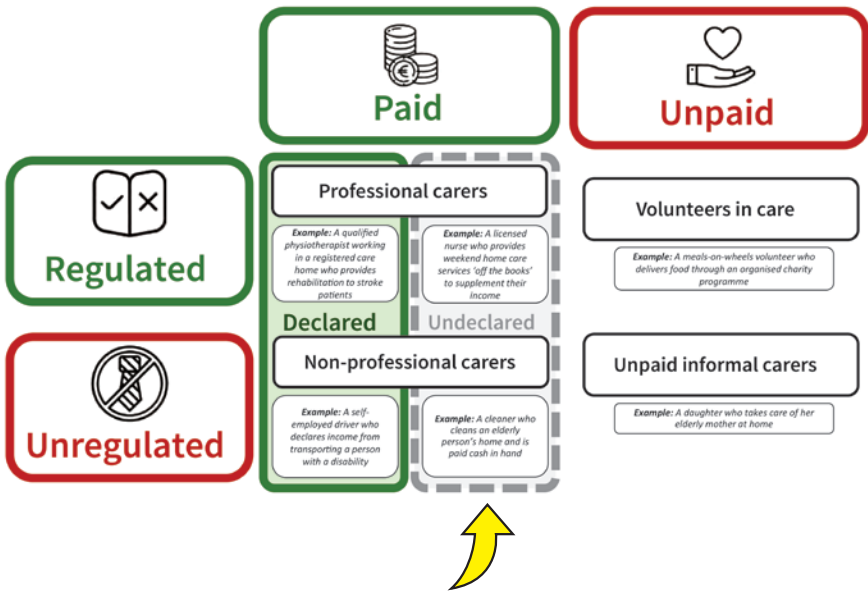


Source: Authors

This example brings another important distinction, between **regulated** and **unregulated** care. Regulated care comprises professional care services delivered by trained practitioners who are paid and operate within formal employment structures, either as employees or self-employed workers. This category also encompasses volunteer care organised through structured programmes and community initiatives, where individuals, though they may lack formal professional credentials, nonetheless work within established regulatory frameworks. Unregulated care, by contrast, is delivered by individuals or organisations operating outside these formal regulatory structures, without the same oversight, standards or protections that govern regulated care provision.

Figure 2 sums up all the main forms that care work can take and highlights where undeclared care work occurs.

Figure 2. A classification of care work



Source: (Eurofound, 2025b)

The scale of undeclared care work in the EU is quite substantial. The European Labour Authority estimates that 6.8 million undeclared workers operate within the personal and household services (PHS) sector across the EU, using a narrow definition of this sector. Of these, 2.1 million work in care services, whilst 4.7 million are employed directly by households. When a broader definition of PHS is applied, the estimated number of undeclared workers rises to 9.2 million. Across both definitions, undeclared work accounts for slightly over half of all employment in the PHS sector on average (ELA, 2021).

Challenges and vulnerabilities of undeclared care workers

Given that undeclared work is inherently difficult to measure, it is no surprise that official statistics on undeclared care work are relatively sparse and not updated regularly. This information gap is critical, as it prevents policymakers from accurately assessing the scope of the phenomenon, the degree of exploitation, and hinders the understanding of the needs of the undeclared carers (Thissen

& Mach, 2023). Despite these challenges, characterising the workforce and the conditions of undeclared care is essential for developing targeted and effective policies to encourage formalisation and protect workers. The available data paints a consistent picture of the sector.

First and foremost, the undeclared care workforce is overwhelmingly composed of **women, frequently middle-aged, migrants, often from non-EU countries**. This profile is consistent across numerous Member States: in **Italy**, the phenomenon of *'badanti'* (live-in carers) is well-known, consisting mainly of migrant women from Eastern European countries like Moldova and Romania, aged over 50. In **Cyprus**, data from 2021 shows that 95% of workers in household activities are female, and an astonishing 97.7% are third-country nationals. In **Spain**, research indicates that 98% of workers in the domestic and care sector are women, with 68% being migrants. In **Slovenia**, most of the women cleaning in private households are mainly from Bosnia and Herzegovina.

The consequences of being part of this undeclared care workforce expose individuals to a series of risks (Eurofound, 2025b):

- **Lack of legal and social protection:** Undeclared workers are excluded from the enforcement of labour standards, rights and social safety nets. They are denied basic rights, including adequate wages and safe working conditions. They also do not have access to unemployment benefits, sick leave, family leaves, and state pensions. Even in systems where domestic work is recognised, protection can be limited, or inferior compared to other sectors. The domestic service regime in **Portugal**, for example, provides workers with a narrower access to benefits compared to other sectors.
- **Financial unsustainability:** Employment is defined by low, irregular pay. For instance, the pay for undeclared cleaning work in **Denmark** was found to be only 65.5% of the average salary for cleaners in the formal labour market. This financial instability is even worse for live-in carers, who might earn a reasonable weekly or monthly amount, but when an hourly rate is calculated for their extensive working hours (often 24 hours a day), their actual remuneration is considerably low. For example, research in **Hungary** has documented live-in carers earning as little as €480–€1,200 per month for what is often around-the-clock work.
- **Physical and mental health challenges:** The work is physically and emotionally demanding, leading to a high risk of burnout, stress,

anxiety, and injuries. In addition, workers often feel they cannot take sick leave, as this is not a right, but also due to fear of losing their income or even their job, forcing them to work while ill and potentially exacerbating health problems. For example, research from **Spain** reveals that over 80% of those working in domestic and care roles experience, or have previously experienced, work-related health issues.

- **High risk of exploitation and abuse:** The informal and isolated nature of the work, often within a private home, creates a high-risk environment for exploitation. Workers are vulnerable to verbal abuse, harassment, and violations of their human rights, on top of their labour rights. In **Cyprus**, documented cases of exploitation include excessive working hours, employers confiscating travel documents, and workers being forced to clean the homes of employers' relatives without additional pay.
- **Social isolation and exclusion:** Live-in carers are particularly at risk of social isolation. Confined to their employer's home with long working hours, they have limited opportunities for social interaction outside of their work environment.
- **Lack of access to worker representation:** Undeclared workers inherently face great barriers to join trade unions and do not benefit from the protections of collective bargaining. Unionisation in the formal care sector is already low, and for undeclared workers, representation is virtually non-existent, leaving them without a collective voice to support them and advocate for their rights.

A complex set of factors on both the supply and demand sides of the market drives the persistence of these conditions. On the one hand, households often turn to the undeclared market not out of a strong desire to break the law, but in response to significant systemic pressures. First and foremost, the lack of accessible and affordable formal care arrangements. When public or private formal care options are unavailable, too expensive, or inadequate, households seek alternatives. The price difference between declared and undeclared work is a powerful incentive. Quantifying this difference enables a preliminary assessment of the problem's scale: according to recent estimates, undeclared care costs an average of EUR 7.70 per hour (Thissen & Mach, 2023). This stands in stark contrast to the cost of declared care, which averages EUR 21.40 per hour through a provider or EUR 13.50 per hour for direct, formal employment (Thissen & Mach, 2023). For many families, this cost differential makes undeclared care the only financially viable option. Last but not least, even when households wish to formalise these

arrangements, they may find formal employment procedures too daunting: navigating tax obligations, social security contributions, and labour contracts can be a significant administrative barrier, making the simplicity of an informal cash-in-hand arrangement more attractive.

On the other hand, workers may prefer undeclared arrangements to receive what would have been the employer's social security contributions as a direct part of their salary. However, the decision for workers to engage in undeclared work is often not a free choice but a response to constrained circumstances. Many individuals accept undeclared work to supplement insufficient income from a primary job or because they lack other employment opportunities. For those on the economic margins, undeclared work can be a crucial lifeline. This is especially true for migrant workers in irregular administrative situations, where undeclared work is often their only available means of subsistence.

Policy pathways to formalise the shadow care economy

Addressing undeclared care work in the EU is a priority because it undermines several fundamental principles of the Union: fair working conditions, the proper functioning of labour markets, gender equality, and social protection, to name just a few. When discussing targeted policy interventions, it is helpful to distinguish between direct and indirect measures.

Direct measures focus first on preventing undeclared care work rather than deterring it (although deterrence remains essential). Direct measures aim to make formal employment more attractive, accessible, and affordable for both households and workers. To achieve this, many Member States have experimented with several solutions, which can be classified into preventative, legitimising and curative.

- **Preventative measures** are designed to reduce motivation and opportunity for non-compliance. These types of measures include administrative simplification and other structural changes that promote compliance from the outset. Digitalisation, for instance, can play a role of enabler, as digital tools and platforms have the potential to streamline processes such as work registration, payments and documentation management.
- **Legitimising measures** encourage the voluntary transition from undeclared to declared work by making formal declaration more attractive, affordable, and accessible. These measures encompass incentives (either in the form of tax schemes or care allowances),

vouchers, flexible arrangements, new legislation, and updated legislative frameworks. The most notable of these are service voucher systems. Pioneered in countries such as France (with its *chèque emploi-service universel*, CESU), Belgium, and Austria (Dienstleistungsscheck, DLS), service voucher systems simplify administration and provide financial incentives. These systems allow households to purchase subsidised vouchers to pay for services, which automatically cover taxes and social security contributions.

- Last but not least, **curative measures** remedy a situation of detected or detectable undeclared care work; examples include amnesties and voluntary disclosures. Amnesties for migrant workers, such as those implemented in Italy and Greece, have provided pathways to legal status for thousands of domestic and care workers. Alongside these measures, broader legislative reforms are crucial. Spain's Royal Decree-Law 16/2022 is a landmark example, aiming to equate the rights of domestic workers with those of all other employees, including access to unemployment benefits and protection against unfair dismissal.

Whilst prevention has become the priority, deterrence - discouragement through penalties ranging from administrative measures, such as fines and back-payment requirements, to penal sanctions in serious cases - remains a key part of the policy mix. The main barrier, of course, is that the majority of undeclared care work is performed in private homes. To improve detection whilst respecting privacy, some Member States have developed innovative methods. **Spain**, for example, launched a letter campaign directly informing households registered as employers of their legal obligations regarding minimum wage and social security. In **Ireland**, the labour inspectorate piloted alternative inspection methods for private households, such as reviewing documents at neutral locations, to monitor working conditions without intrusive home visits. Penalties and fines should not be overlooked, as they can be an integral part of the policy mix. In such a process, it is also important to ensure that workers, as potential victims of exploitation, are protected.

Indirect measures aim to inform citizens about their rights and duties and change the values and norms that fuel the acceptability of the phenomenon. To address this, awareness-raising campaigns are essential. **Poland's** 'I Work Legally!' initiative, for example, informs employers and employees about the benefits of formal work and the risks of undeclared work. However, this should expand to make the value of care work clear and evident. If the job is considered low-status, unimportant, or something that does not require skills (all of which

are false statements), then making any of the direct measures effective becomes very difficult.

Above and beyond different policy solutions, and despite the inherent differences across Member States, addressing undeclared work requires a coordinated policy response. Member States must support cross-border efforts while boosting mutual learning opportunities. Such an approach would facilitate the sharing of best practices, harmonise standards, and ensure more consistent application of labour rights across the European Union.

Conclusions

Undeclared work within the EU's care sector is a challenge driven by complex factors with widespread and systemic consequences. However, a pathway to improve EU and Member States' policy responses exists: on the foundations of clear efforts to make care visible and valued (indirect measures), preventative, legitimising, and curative measures are built, supported by deterrence (direct measures). To implement this policy strategy, two key requirements must be met: coordination and innovation. Coordination is essential given the cross-border nature of the care workforce and the shared challenges across Member States. Innovation means finding new solutions to simplify administrative burdens for households, leverage technology and digital tools to streamline compliance, design inspection methods that balance enforcement with privacy rights, create voluntary quality assurance mechanisms that build trust in formal care arrangements, and experiment with financial instruments that make declared work more accessible and affordable for both care workers and households.

The ultimate objective is to move undeclared care workers out of the shadows, ensuring that they enjoy the same rights as all other workers. Formalising their work is not merely a matter of economic or fiscal policy; it is a matter of social justice and a crucial step toward building a more equitable and resilient Europe.

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4. How do countries compare in their design of long-term care provision? A typology of long-term care systems¹

Ana Llana-Nozal, Jacek Barszczewski, Judit Rauet-Tejeda

Abstract

Models and approaches to long-term care provision vary greatly across OECD countries. This paper reviews existing classifications in the literature and provides a new, comprehensive typology based on five key dimensions: access, availability, funding, governance, and quality. Using a clustering methodology, countries are grouped according to their score across these dimensions, resulting in four distinct long-term care system types. The first cluster includes countries with comprehensive, well-governed, and decentralised long-term care systems that are affordable, offer broad coverage, support family carers, rely on public providers and ensure high quality standards. The second cluster shares many of these features but tends to be more centralised, slightly less generous, more reliant on the private sector, and less likely to use means-testing to restrict access. The third cluster consists of countries with decentralised long-term care systems, characterised by stricter eligibility criteria, fewer public resources, and greater reliance on informal carers. Finally, the fourth cluster comprises countries where public long-term care systems tend to provide limited access and financial support, rely heavily on families, and show weaker quality standards and outcomes.

¹ Previously published https://www.oecd.org/content/dam/oecd/en/publications/reports/2025/06/how-do-countries-compare-in-their-design-of-long-term-care-provision_035a4e96/44f5453a-en.pdf
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This series is designed to make available to a wider readership selected health studies prepared for use within the OECD. Authorship is usually collective, but principal writers are named. The papers are generally available only in their original language – English or French – with a summary in the other.

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Executive summary

International comparisons are an important tool for assessing long-term care (LTC) systems and can raise awareness of the systems' relative strengths and shortcomings, facilitating sharing good practices and stimulating policy debates. Previous attempts to make such international comparisons by classifying LTC systems remain scarce, either focus on one dimension, such as the relative role of the family versus formal public provision, or like funding models; they tend to have a restricted set of countries or a restricted set of either qualitative or quantitative indicators. This working paper attempts a comprehensive characterisation of LTC systems providing support for older people (aged 65 and more) who lose independence due to age by reviewing several dimensions, following the features of interest described in the literature, and a mix of quantitative and qualitative data.

The OECD typology of LTC uses five dimensions to classify countries: access to services, availability, funding, governance and quality. The access dimension focuses on eligibility criteria, the degree of coverage within the target population and the reliance on in-kind services or cash benefits. The second dimension is availability which indicates the supply of formal care and how countries rely on and support informal carers. Funding is the third dimension, which captures the degree of public funding, out-of-pocket expenses on LTC services, and the role of LTC social protection mechanisms to reduce poverty risk among older people with LTC needs. The governance dimension captures the degree of fragmentation and centralisation, the importance of public LTC systems as well as the degree of integration within the different parts of the health systems. Finally, quality focuses on quality measures that capture the importance of human resources in terms of staff ratios and skills, quality assurance and quality outcomes.

Looking at this set of variables, LTC systems across 29 OECD countries reveal a few shortcomings across their features. Access remains limited, with only 28 per cent of older people with needs receiving formal care and modest income- and needs-testing. Availability is constrained, with an average of 40 LTC beds and 4.5 workers per 1,000 and 100 older people, respectively. Public funding covers 66 per cent of costs, but out of pocket expenses still pose a burden, averaging 72 per cent of median income for those with severe needs. Governance is mixed: 60 per cent of systems are decentralised, and only 40 per cent are fully integrated with health care. On quality, most countries have accreditation and assurance frameworks, but educational requirements for personal care workers vary, and only 36 per cent require a high school diploma or higher.

To make valid and useful comparisons, the paper clusters LTC systems across the five dimensions. Clustering is a technique which can be used to form groups of similar LTC systems that share distinct properties. These shared characteristics might not be visible by simply exploring distributions and studying the effect of system features directly on the outcome of choice. The paper uses multiple clustering algorithms to ensure consistency and robustness of the results. At the same time, it is important to note that, while this uses the most comprehensive and up-to-date information, there are limitations in the clustering approach as LTC systems are more nuanced than described in a set of indicators. Boundaries between different groups of LTC policies are rarely clear-cut and the paper also indicates which countries stand out in their cluster.

Four distinct groups of LTC systems are identified through clustering methods, revealing meaningful differences in service provision, funding, governance and quality across OECD countries. Cluster 1 countries combine the most extensive financial support with high-quality, decentralised LTC systems that offer extensive formal care and strong support for informal carers. These countries have the highest formal care coverage - over 50 per cent of older people with needs receive formal services in half of them - and extensive needs- and means-testing mechanisms. Public funding is generous, covering at least 80 per cent of LTC costs for individuals with severe needs in all but one country, keeping out of pocket payments low. These systems are mostly unified in legislation, rely heavily on public providers, and demonstrate strong integration with healthcare. Quality assurance frameworks and accreditation are widespread, and educational requirements for LTC workers are generally high, contributing to overall strong quality outcomes.

LTC systems grouped in Cluster 2 offer extensive formal care availability and high staffing levels, while relying heavily on private provision, featuring limited means-testing, and achieving only moderate quality outcomes. While public financial support is relatively generous - covering 80 per cent or more of LTC costs for older people with severe needs in most countries - means-testing is rarely applied, and only about 30 per cent of older people with LTC needs receive formal care. These centralised systems, largely unified in legislation, rely primarily on private providers and show mixed integration with healthcare. Although staffing levels are the highest across all clusters and informal carers receive policy support, educational requirements for LTC workers are relatively low. Despite widespread use of accreditation and quality assurance frameworks, quality outcomes remain below those of Clusters 1 and 3.

Cluster 3 countries combine decentralised governance with strict needs- and means-testing, which limits public provision and contributes to low formal LTC coverage and mixed quality outcomes. In most countries, less than 30 per cent of older people with care needs receive formal LTC, and public funding is often modest, resulting in high out-of-pocket costs and poverty risks - especially in Estonia, Italy, and the US. Although staffing ratios and quality assurance frameworks are common, and education requirements for LTC workers are relatively high, availability of beds and support for informal carers remains limited. Governance is decentralised in nearly all countries, and integration with health services is partial, while legal frameworks remain fragmented across social and health care.

Countries in Cluster 4 provide the lowest public funding for LTC, resulting in limited formal care coverage, high out-of-pocket costs, and fragmented systems with weaker quality outcomes. Despite minimal use of means-testing, only 20 per cent of older people with care needs receive formal services, and public funding often covers less than 25 per cent of care costs. The availability of LTC workers and institutional beds is low, and informal care is widespread but insufficiently supported by policy. Governance structures are mixed, integration with healthcare is rare, and most systems lack unified legislation. While staff ratios and educational requirements are often in place, the absence of quality assurance frameworks in several countries contributes to overall weaker care outcomes.

While Cluster 1 tends to outperform the others across the five dimensions, there are sometimes trade-offs across some dimensions and distinct features that define some clusters which are not necessarily reflecting higher performance if looking at that indicator alone. For instance, there is a clear gradient across clusters in funding with countries in Cluster 1 providing more generous funding and the level of generosity declining for each cluster and the same holds for coverage. On the other hand, countries in Cluster 2 tend to be centralised while countries in Cluster 1 are the most decentralised followed by countries in Cluster 3 and 4 and the same goes for the share of private providers.

1. Introduction

Population ageing is one of the most significant demographic transitions of the 21st century across OECD countries. While this shift presents opportunities - people can live longer in good health - it also poses growing challenges. In particular, a rising number of older people (defined hereinafter as those aged 65 and over) will require various forms of personal care and assistance, commonly

referred to as longterm care (LTC, a definition is given in Box 1.1). Publicly funded formal care is usually available across OECD countries but differs widely in terms of its scope, reach and composition of providers. In many countries, an important share of care is indeed provided by so-called informal (or unpaid) carers who can be spouses, children, friends, and neighbours. Meeting the rising demand for LTC in old age is becoming an increasing challenge across OECD countries, as population ageing also leads to shortages of both formal and informal carers, alongside rising expectations about the availability, affordability, and quality of LTC services (Ilinca and Simmons, 2022).

Box 1.1. Long-term care in old age: personal care, assistance services and social activities

As people grow older, they are increasingly likely to need help to carry out their every-day activities. These include basic self-care activities, such as washing and dressing, known as Activities of Daily Living (ADLs), as well as more complex/housekeeping tasks like cleaning and shopping, which are referred to as Instrumental Activities of Daily Living (IADLs). As people become more dependent, they may also find it difficult to maintain social relationships and to participate in their community. They may need help with social activities, for example attending a community club or going out for a walk. Finally, people who are dependent on others often need ongoing medical care to manage multiple chronic conditions and to ensure that they remain as healthy as possible. LTC consists of a range of medical/nursing care, personal care and assistance services aimed at alleviating pain and suffering, or at reducing and managing the health deterioration in patients with longterm dependency (OECD, Eurostat and World Health Organisation, 2017). As the emphasis is on long-term dependency, this working paper focuses on LTC needs and use lasting at least six months. Furthermore, as most OECD countries and EU Member States provide universal or quasi-universal health coverage, this work excludes medical nursing care services. Throughout this working paper, the term LTC is used to encompass personal care (help with ADLs), assistance services (help with IADLs) and social activities, for periods of over six months (or until end of life). Although people of any age can become dependent on others through illness or disability, this working paper focuses on older people (aged 65 or more).

In response to the growing demand for LTC services, countries have started to reform their health and social protection systems to expand the provision of benefits and services. The design of LTC systems is often complex, shaped by historical developments, resource constraints, and varying arrangements for

the organisation and funding of care services. Reforms aimed at addressing rising demand should carefully analyse all aspects of LTC system design and understand how these elements interact with one another. A useful tool for such analysis is a classification of LTC systems, which allows countries to compare their own system with others sharing similar characteristics, helping to identify both areas of strength and opportunities for improvement.

To support countries in their reform efforts, this working paper presents a classification of LTC systems based on a comprehensive set of characteristics across multiple dimensions. Countries are grouped into clusters according to the governance structure of their LTC system, the ways in which older people can access public support, the funding and availability of LTC services, and the quality of care provided. Most existing typologies have a much narrower geographic scope, typically focusing on European countries, with only a few including key non-EU countries such as Australia, Japan, and New Zealand, alongside England or the United Kingdom. In addition, the classification developed in this working paper draws on a broader range of variables and dimensions than previous studies, enabling more comprehensive analysis and cross-country comparisons.

The rest of this working paper is structured as follows. Section 2 reviews existing typologies of LTC systems in the literature. Section 3 describes the dataset used for the analysis. Section 4 outlines the methodology employed to identify the clusters. Finally, Section 5 presents the resulting LTC system typology and discusses the characteristics of the different clusters.

2. Typologies of long-term care systems show different types of classifications

This section presents the review of the literature on the typology of long-term care (LTC) systems. It discusses the methods and data used to group countries and summarises the main findings. The typologies discussed in the following paragraphs are organised according to their primary areas of focus.

Many characterisations of LTC systems focus on the responsibility of the family versus public or private provision

One way of classifying LTC systems is by examining the balance between family responsibility and public or private provision of services. This type of classification based on who provides care, stems from the work of Esping-Andersen (1989) on welfare states. Building on this work, Leitner (2003) classified countries based on whether LTC services are provided formally, through paid

carers, or informally, by unpaid carers, typically family members, and whether supportive policies exist for family carers. According to Leitner (2003), welfare systems can either strongly or weakly emphasize familism² or not, which are categorised into four models. The first one is the explicit familism model, which supports the family in the caregiving role but often lacks the provision of formal care. The second one is the optional familism model, where formal care services as well as supportive policies for family carers are provided. Thus, the state strengthens the family while also providing the option to choose partial formal care. The third model is the implicit familism model. This one neither offers formal care services nor actively supports the caring role of the family. Finally, the last one is the de-familism model, which puts emphasis on public or market provision of care services, with minimal support for family caregiving.

Expanding on Leitner's concept of defamilisation, Saraceno (2016) breaks this concept into two types: "supported defamilisation through public provision" and "supported defamilisation through the market". The former is when the state directly provides or funds care services, reducing individuals' reliance on family, such as through minimum income provision. Differently, the second one refers to the provision of income transfers (in the form of cash benefits, vouchers or tax deductions) to help buy services on the market or when the state funds the provision of services via the market.

Ilinca, Leichsenring and Rodrigues (2015) propose another classification by combining the typology of care provision by different actors with the level of care demand. The paper identifies four country clusters: a universal-Nordic one, a standard care one, a family-based one and a transitional one. The criteria for each category consider i) the demand for care (e.g. population in need or at risk of needing long-term care and the role of poverty-driven factors), ii) the provision of informal care (e.g. the share of individuals providing care to a relative and of multigeneration households), iii) the provision of formal care services (e.g. public expenditure on long-term care, share of older people receiving formal care services at home or in institutions) and iv) whether the provision of formal and informal care is considered high, medium, or low.

Similarly, Verbeek-Oudijk et al. (2014) cluster European countries based on the entity that bears responsibility for providing care but also the expenditure on non-residential LTC. The paper identifies three country clusters: a Northern cluster, a Central European cluster and a Southern and Eastern European

² Familism is the set of policies which actively aim at strengthening the family in its caring function.

cluster. Countries in the Northern cluster are characterised by high public spending and low family responsibility for care, the Central European cluster by average expenditure and average family responsibility and the Southern and Eastern European cluster by low public expenditure and high family responsibility. Nonetheless, there is a trend of convergence whereby countries with a large amount of publicly funded care are increasingly shifting the focus towards family or social responsibility, and towards promoting informal care. At the same time, in countries where informal care already dominates, efforts are also being made to improve the quality and access of publicly funded care. In this line, Bihan, Roit and Sopadzhian (2019) conclude that countries have changed with cash-for-care schemes with Southern and Continental countries and England reducing the role of families through the market, whereas the Netherlands introduced more family support.

The dichotomy between formal and family-based care has been also disrupted not only using the market but also using foreign-born carers. In this sense, Simonazzi (2009) argues that the way in which LTC is provided and financed results in differences in the creation of a formal care market. At the same time, national employment models also have an impact on the formal provision through the quantity and the quality of supply and the degree of dependence on care provided by migrants. Salaries, working conditions, and training and credential requirements affect whether workers are primarily low-skilled or more professional. Likewise, working conditions and the type of provision, whether it is in-kind or more via contracting out or through cash-allowances can have an impact on the level of migrant workers. In addition, Simonazzi (2009) suggests that systems relying mostly on unconditional cash allowances or monetary transfers (Austria, Germany, and the Mediterranean countries) may have a greater share of an informal or grey economy relying on migrant or foreign-born workers. This is due to the lack of verifications on the use of the cash allowances and the switch of families from providing care to buy care directly from an unregulated labour market, where foreign-born workers are hired at lower prices than hiring in the formal labour market or where there are shortages of local care workers.

More recent studies discuss the challenge of classifying countries according to the concepts of familialism and finding appropriate indicators to capture such concept. Verbakel et al. (2023) argue that different types of policy instruments can be implemented in a country simultaneously. The paper focuses on the construction of a carer support index and the presence of a cash benefit for carers to measure supported familialism. The study measures defamiliasation through the market by employing the potential use of a cash benefit by the recipient

and an index on the cash benefit for carers. LTC beds are used to measure defamilialisation through public provision. It finds no significant association between supported familialism and supported defamilialisation through the market or between supported defamilialisation through the market and through public provision. However, a significant positive correlation is found between supported familialism and defamilialisation through public provision.

LTC typologies may be based on coverage and funding of long-term care

The provision of LTC services through different actors is intrinsically linked to the funding of LTC. Halásková, Bednář and Halásková (2017) classify LTC systems with respect to the degree of public funding for LTC and the settings of care. The paper finds three types of clusters for countries: 1) a cluster with low overall LTC expenditure and a high share of expenditure allocated to institutional care (Australia, Korea), 2) a second cluster which is similar to the first one but has more dispersion and a lower number of recipients (Czechia, Estonia), and 3) a cluster with the lowest share of expenditure allocated to institutional care (Nordic countries). Along similar lines but adding more dimensions to the analysis, Kraus et al. (2010) classify countries according to the importance of public versus private spending, formal versus informal care use, but also access and targeting, the use of cash benefits and support for informal carers. Based on these criteria, countries can be divided into four different clusters. In the first cluster, public spending on LTC is high, private funding is low, the use of formal care is high, and the use of informal care is low. These countries have generous, accessible, and formalised systems of LTC with still a great deal of support for informal carers. The role of cash benefits is modest. In the second cluster, countries combine a low level of private funding with rather low public spending while the use of informal care and the support for informal carers are both high. Their systems can be seen as more oriented towards informal care, with a low level of private funding. The third group is characterised by a high level of private funding combined with moderate public spending. Access to the formal system is rather limited, while the use of and support for informal care are high. These systems might be described as informal care-oriented systems that also use a rather high amount of private funding. The fourth and last cluster includes countries with a high level of private funding, low public spending, high use of informal care; yet support for informal care is low.

Moreover, LTC funding models may be classified according to the degree of cost-sharing and universality of entitlements. According to Colombo et al. (2011) countries could be classified according to two main criteria: first, the scope of entitlement to LTC benefits – meaning whether there is universal or

means-tested entitlement to public funding; and second, whether LTC coverage is assured through a single or multiple programmes. A somewhat similar typology was discussed by Joshua (2017) who classified countries according to the funding stream and eligibility criteria highlighting the following models: (1) social insurance models such as Germany, Japan and Korea, (2) universal such as Denmark, Finland and Sweden, (3) means-tested such as England and the United States and (4) hybrid such as France. While in many countries there has been a move towards more universal LTC, countries have also searched for a new balance in cost-saving strategies, blurring the lines across countries in some cases. According to Szebehely and & Meagher (2018) in Nordic countries (particularly in Sweden) there is some initial assessment that LTC is becoming less universal, an increase in for-profit provision of publicly funded care services (via policies promoting service marketisation), an increase of family care and declining coverage, as well as of services paid out-of-pocket. Ranci et al. (2019) argue that countries have found different compromises between universalism and selectivity and between coverage and generosity. Some countries have more generous programmes, but they lack progressivity, and therefore, they do not provide adequate support for the most in need. In contrast, others are more restrictive in access to cash for care but providing comparatively high, progressive support for those most in need. The paper also argues that cash-for-care programmes aimed at providing adequate protection to those most dependent had to strictly limit the eligibility, whereas programmes aimed at providing extensive coverage basically fail to protect people with severe needs.

Complementing these typologies, Pavolini (2021) identifies six models of countries based on the extent of state involvement in providing different in-kind services (residential care and home care), as well as cash benefits, whether delivered directly to the beneficiaries or to their informal carers. The first model is the Limited State Intervention. It offers the lowest coverage rates for all kinds of provision and reaches a very limited share of potential beneficiaries. The second and third are Mild State Intervention models, the second through cash benefits and the third through services. The second model offers a higher coverage rate than the first model, whereas the third one provides an even higher coverage rate of needs, mostly through in-kind services, but also through cash benefits for informal carers in some cases. The fourth and fifth models are the Strong State intervention. The fourth is through cash benefits, and the fifth through services. The fourth shares a similar level of coverage to the third one, thanks partially to service provision, but mostly to cash transfers. The fifth and the sixth which is Very Strong State intervention through services attain very high coverage rates through services. These last two models also offer cash benefits as a way of integrating rather than replacing the provisions of in-kind services. In the

fifth group, countries spend a relatively high share of their GDP on LTC policies, using mostly services as a tool of provision.

Comprehensive typologies are based on a mix of indicators

In the literature, there are also typologies following a wider or more comprehensive approach. Dyer et al. (2019) developed a LTC typology of countries based on several key factors, organised in three broad categories. The first category is about organisation and financing. It included access to care, the degree of public versus private funding as well as quality assurance and coordination. The second category is regulation of quality. The focus was on the responsibility for regulation to understand whether it was a centralised or decentralised system and whether responsibilities were divided across different actors (e.g., health and social care). In addition, the paper reviewed the regulatory approach (inspection, reporting mechanisms) and the public availability of quality information. Finally, the third category is additional information on access which included the sources of funding, out-of-pocket payments and types of care providers. As a result, countries are classified according to these three broad categories into four groups. The first group, low access, high consumer spending countries is characterised by means testing and cost sharing, with an important share of the population relying on private funding. The second group, low access, mid consumer spending countries also employ means testing but the reliance on consumer spending is less pronounced. These countries have some common characteristics: they exhibit mid to high levels of quality regulation and integration, regulate quality of both home and residential care and lastly, show a mid-level coordination of LTC services with the health system. The third group, high access, and reliance on consumer spending countries. Finally, the fourth group is the highest performing countries whereby LTC systems provide consumers with the highest levels of access and the lowest cost sharing, and there is a high level of quality regulation and integration with other services including health.

- Following this broad approach, Ariaans, Linden and Wendt (2021) created a LTC typology by analysing quantitative data on supply, public-private mix, health outcomes, as well as institutional information on the access to systems. This results in six clusters, as follows:
- The residual public system. It is characterised by low levels of supply, while access barriers seem low, by applying no means-testing and a low level of choice restrictions. Cash benefits are mainly bound. The share of public LTC expenditure is the highest of all system

types. Outcomes of these systems measured by life expectancy and subjective health status are by far the lowest of all system types.

- The private supply system. It has a medium to high level of supply. Yet, this system shows one of the lowest shares of public expenditure, and cash benefits are unbound. Access restrictions are among the lowest of all systems, with no means-testing and limited choice restrictions. Outcomes in terms of health are medium.
- The public supply system. It is defined by high supply and above-average public expenditure. Benefits are mainly available in kind only. Furthermore, choice is limited in these systems; yet no means-tests apply. The performance indicators in terms of health outcomes of this system are above average.
- The evolving public supply system. It is defined as evolving public supply systems, marked by medium to low supply and public funding and provision. Expenditure and the number of recipients in institutions are at a medium level, the supply of residential beds is below average. Public expenditure is medium, and benefits are only provided in kind. Access to the system is granted without means-testing, but medium to high choice restrictions apply. Performance is highest concerning life expectancy but among the lowest concerning self-perceived health.
- The need-based supply system. Cash benefits tend to be available and are often unbound. Public expenditure is about average. On the other hand, supply is high. In contrast to the private supply type, access is restricted by a high level of means-testing. Like in the private supply countries, choice restrictions rarely apply. Performance in terms of health outcomes is above average.
- The evolving private need-based system. It is labelled evolving private need-based system and shares important characteristics with the need-based supply type. The public-private mix is oriented towards private funding. Performance in terms of health outcomes is rather high. Access is restricted by both means-testing and high choice restrictions. The main difference to the previous system type is low supply, especially low expenditure, but also the provision of beds in residential care and the number of recipients of residential care are at a lower level.

Existing literature is extensive, but it is not comprehensive enough

Table 2.1 summarises the wide range of typologies, already discussed, that have been developed to classify LTC systems. Some typologies focus on who provides care, such as Leitner (2003) and Saraceno (2016). Others incorporate additional criteria such as the level of care demand (Ilinca, Leichsenring and Rodrigues, 2015) or data on non-residential LTC expenditure (Verbeek-Oudijk et al., 2014). A further set of typologies emphasises funding dimensions. Halásková, Bednář and Halásková (2017) assess the degree of public funding and care settings, while Joshua (2017) examines funding streams and eligibility. Pavolini (2021) offers a broader perspective, addressing the state's role in providing both in-kind services and cash benefits.

More recent contributions have adopted a broader approach. Kraus et al. (2010) classify countries based on funding sources, the mix of formal and informal care, access mechanisms, and support for informal carers. Dyer et al. (2019) propose a typology structured around organisation and financing, quality regulation, and access to services. Similarly, Ariaans, Linden and Wendt (2021) use quantitative data to map LTC systems across dimensions such as care supply, public-private mix, health outcomes, and institutional access characteristics.

While these typologies provide valuable frameworks, most concentrate on isolated or only address some dimensions without offering a fully integrated perspective. This gap underscores the need for a more holistic classification that captures multiple system features and outcomes. For example, two systems with similar levels of public support for older people with care needs may differ significantly in the use of formal LTC services due to varying eligibility criteria. Likewise, high rates of informal care use in different countries may reflect either limited access to formal services or strong institutional support for informal caregiving. To address these limitations, the next chapter introduces such a typology, aiming to enhance the comparative analysis of LTC systems by combining within a single analytical framework five key dimensions: access, availability, funding, quality, and governance. While each of these dimensions has been explored in previous typologies, they have not yet been systematically integrated to provide a comprehensive picture of LTC systems.

Table 2.1. Existing research use various criteria to classify LTC systems, but there are few comprehensive frameworks

Author/s	Criteria for Classification	Clusters
Leitner, (2003)	Provision of LTC services (formal or informal) and presence of supportive policies for family carers	<p>Explicit familialism. Supports the family in caregiving but provides minimal formal care services.</p> <p>Optional familialism. Offers both formal care services and supportive policies for family carers, allowing families to choose partial formal care.</p> <p>Implicit familialism. Neither provides formal care services nor supports family caregiving.</p> <p>De-familialism. Focuses on public or market-provided care services, with little support for family caregiving.</p>
Saraceno, (2016)	Source of funding (market-based vs public provision)	<p>Supported Defamilialisation through public provision: when the state directly provides or funds care services, reducing individuals' reliance on family, such as through minimum income provision, unemployment benefits for the young or entitlement to higher education or to receiving care).</p> <p>Supported Defamilialisation through the market: provision of income transfers (in the form of cash benefits, vouchers or tax deductions) to help buy services on the market or when the state funds the provision of services via the market.</p>
Ilinca, Leichsenring and Rodrigues, (2015)	Care demand, informal and formal care provision, and overall intensity of care provision (formal and informal).	<p>Universal-Nordic: Medium care demand, low informal care provision, high formal care provision.</p> <p>Standard Care Mix: High care demand, medium-low informal care provision, medium formal care provision.</p> <p>Family-Based: High care demand, high informal care provision, low formal care provision.</p> <p>Transitional Model: Medium care demand, high informal care provision, medium low formal care provision</p>

Verbeek-Oudijk et al., (2014)	Non-residential LTC expenditure and institution responsible for care provision.	Northern. High public spending and low family responsibility for care Central European. Average expenditure and average family responsibility Southern/Eastern European. Low public expenditure and high family responsibility
Halskov, Bednr and Halskov, (2017)	Degree of public funding for LTC and the settings of care.	Low LTC expenditure, but high share for institutional care (Australia, Korea) Like 1, but more dispersed and fewer recipients (Czechia, Estonia) Lowest share of institutional care (Nordic countries)
Kraus et al., (2010)	Public vs. private spending, formal vs. informal care, access/targeting, cash benefits, and support for informal carers.	High public spending, low private funding, high formal care, low informal care, moderate carer support. Low public/private funding, high informal care, strong carer support. High private funding, moderate public spending, limited formal care, high informal care and support. High private funding, low public spending, high informal care, low carer support.
Colombo et al., (2011)	Degree of cost-sharing and universality of entitlements.	Universal entitlement, single LTC program. Means-tested entitlement, single LTC program. Universal entitlement, multiple LTC programs. Means-tested entitlement, multiple LTC programs.
Joshua, (2017)	Funding stream and eligibility criteria.	Social insurance (Germany, Japan, Korea) Universal (Denmark, Finland, Sweden) Means-tested (England, United States) Hybrid (France)

Pavolini, (2021)	Importance of state support in providing in-kind services (residential and home care), cash benefits to beneficiaries or informal carers.	<p>Limited State Intervention: Offers the lowest coverage rates across all types of provision, reaching a very limited share of potential beneficiaries.</p> <p>Mild State Intervention (Cash Benefits): Provides higher coverage than the first model, focusing on cash benefits to support beneficiaries.</p> <p>Mild State Intervention (Services): Offers even higher coverage, mainly through inkind services, and in some cases, cash benefits for informal carers.</p> <p>Strong State Intervention (Cash Benefits): Delivers similar coverage to the “Mild State Intervention (Services)” model, primarily using cash transfers, with partial service provision. Strong State Intervention (Services): Provides very high coverage through in-kind services, with cash benefits used to complement service provision.</p> <p>Very Strong State Intervention (Services): Offers very high coverage primarily through services, with cash benefits integrated to complement services.</p>
Dyer et al., (2019)	Access, public vs. private funding, quality, responsibility for regulation (centralised vs. decentralized, regulatory approach (inspection, reporting), public quality information, source of funding, out-of-pocket payments, and type of providers.	<p>Low access, high consumer spending, means testing, cost sharing, significant private funding reliance, mid-high-quality regulation, and LTC-health system integration.</p> <p>Low access, mid consumer spending, means testing, lower reliance on consumer spending, mid-high-quality regulation, and LTC-health system integration. High access, some consumer spending, good quality regulation.</p> <p>Highest level of access, lowest cost sharing, high level of quality regulation and integration.</p>

Ariaans, Linden and Wend (2021)	Analysis of quantitative data on care supply, public-private mix, health outcomes, and institutional information regarding system access.	<p>Residual Public System. Low supply, no means-testing, bound cash benefits, highest public LTC spending, lowest health outcomes.</p> <p>Private Supply System. Medium-high supply, low public spending, unbound cash benefits, low access restrictions, medium health outcomes.</p> <p>Public Supply System. High supply and public spending, in-kind benefits only, no means-testing, limited choice, above-average health outcomes.</p> <p>Evolving Public Supply System. Medium-low supply and spending, in-kind benefits, no means-testing, moderate-high choice restrictions, high life expectancy but low subjective health.</p> <p>Need-Based Supply System. High supply, average public spending, unbound cash benefits, strong means-testing, few choice restrictions, above-average outcomes.</p> <p>Evolving Private Need-Based System. Low supply and spending, private-oriented funding, strong means-testing and choice restrictions, relatively high health outcomes</p>
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Source: OECD own analyses.

3. The OECD typology of long-term care systems uses cluster analysis to combine various dimensions

To develop a comprehensive typology of long-term care (LTC) systems, a dataset covering multiple dimensions of system design and performance is required. These data serve as indicators that reflect key features and outcomes of LTC systems. For the typology to be meaningful, the indicators must be specific - clearly defined and unambiguous - and measurable, meaning they should be quantifiable or capable of demonstrating clear evidence of achievement.

This section describes the information and data collection process used to construct the dataset for the LTC systems typology. The dataset covers five key dimensions of LTC systems and services: access, availability, funding, governance, and quality. For each dimension, a set of variables is selected to reflect the full scope of that area. The selection was informed by previous OECD work as well as variables commonly used in the literature reviewed in Section 2.

Some variables are continuous, while others are coded on an ordinal scale, with the scale size determined by the relevance and the availability of data. The analysis draws on a range of sources, including existing OECD LTC indicators, past OECD questionnaires, data collected directly from the countries analysed, and relevant literature. In total, the study includes data from 29 OECD countries. An overview of the variables used to construct the dataset is presented in Table B.1 in Annex B.

Access to LTC services is measured through care needs, financial means, coverage scope, and the form of benefits provided

Access dimension focuses on eligibility criteria (means and needs testing), the degree of coverage within the target population and the reliance on in-kind services or cash benefits. This dimension is measured by four variables.

The first two variables capture the degree of targeted access to LTC services based on care needs and income. The first variable focuses on needs-testing. It is calculated by comparing the share of LTC costs covered by public systems across typical cases³ with varying levels of need. Values range from 0 to 3, representing the number of instances in which public support is higher for individuals with greater care needs.⁴ Specifically, the comparisons include: (1) low needs versus moderate needs, (2) moderate needs versus severe needs, and (3) low needs versus severe needs. The second variable reflects income-testing. It measures the extent to which countries prioritise low-income individuals in providing LTC support. A value of one is assigned for each case in which public support for a low-income individual (at the 20th percentile of the income distribution among older people) exceeds that for a high-income individual (at the 80th percentile), assuming the same level of care needs. Given three levels of need - low, moderate, and severe - the means-testing indicator also ranges from 0 to 3.

The third variable calculates the coverage rate of formal LTC services by comparing the number of formal LTC recipients to the population of older people with LTC needs. This calculation is based on the reporting of ADLs and IADLs and using the OECD measure of needs based on typical cases.⁵ The number of individuals receiving formal care is also derived from self-reported data. An older person is considered to be receiving formal care if they report accessing

³ In this paper, three typical cases of LTC needs are used: low, moderate and severe. For detail description of typical cases, please see OECD (2024).

⁴ Assuming median income and no wealth of compared individuals.

⁵ A detail description of measure of LTC needs is included in the appendix of the report *Is Care Affordable for Older People?* (OECD, 2024).

such services. This includes cases where individuals receive a combination of both formal and informal care.

Finally, the fourth variable looks at the degree to which a country provides services directly through in-kind services, relies only on cash benefits or provides a choice for both, but with the dominating role of in-cash benefits. In the literature, differing perspectives exist regarding the effectiveness of cash transfers versus in-kind benefits. While cash transfers might be beneficial in terms of choice, they do not guarantee service availability, particularly in less populated areas. Moreover, physical or cognitive impairments among older people may hinder their ability to access appropriate care when relying solely on cash benefits. In addition, if cash benefits are unregulated, they might lead to the development of a grey market.

Availability of LTC systems depends on the supply of formal and informal care

The second dimension is availability which indicates the supply of formal care and how countries rely on and support informal carers.

The supply of formal care is proxied by two variables: the number of beds and the number of LTC workers with respect to the older people population. This is calculated with OECD and country-specific data when it is not available in the OECD database.

The countries' reliance and support for family carers is assessed through two variables. The first variable measures the percentage of older people reporting to receive informal care to assess the extent to which informal carers contribute to the overall care supply. The second variable is on familialism and captures the existence of leave and cash benefits for informal carers. It is coded from zero to four based on the availability of the following benefits: cash benefits for informal carers, cash benefits for care recipients who rely on informal care, paid leave and unpaid leave for informal carers.

Funding measures the generosity of public support and its impact on Out Of Pocket (OOP) expenses and poverty rates among LTC recipients

Funding is the third dimension, which captures the degree of public funding, out-of-pocket expenses on LTC services, and the role of LTC social protection mechanisms to reduce poverty risk among older people with LTC needs. It is assessed using three variables. The first variable measures the public share of the costs for LTC for a person with severe needs, a median income and no

wealth. The second variable assesses the degree of OOP spending for the same older person, expressed as a share of the median income. And the third variable calculates the percentage point difference between the poverty rate among older people with severe needs with and without social protection.

These variables capture different elements of the generosity and efficiency of the current funding for LTC. The variable public share of the LTC costs relates to which percentage of the costs is covered by public funding and brings an important precision to the overall LTC expenditure, as it adds the relative importance of spending with respect to the overall costs of LTC. Previous OECD work has shown that unit costs of LTC can vary across countries, particularly in relation to the wages of LTC workers so overall spending does not capture fully the generosity of the system (OECD, 2024). Overall, the total costs of LTC are substantial and represent one to six times the median disposable income of individuals of retirement age or older. The variable OOP costs is complementary as, in some countries, even if public share of costs is generous, because overall costs are high and incomes remain low, the overall burden on users can still be substantial. Finally, the third variable assesses the extent to which social protection mechanisms for LTC reduce poverty risk associated with LTC expenditures. It complements both variables as it shows whether public funding is sufficient to prevent people from falling into poverty.

Governance captures the organisation and legal framework of LTC systems

The overall organisation of public LTC provision is analysed to understand the organisational depth and cohesion of LTC systems. Based on the different typologies presented in Section 2, this dimension should capture the importance of public LTC systems as well as the degree of integration within the different parts of the systems. For this end, it describes LTC systems using four variables.

The first variable assesses whether the legal framework for LTC integrates both health and social care components. In many OECD countries, LTC services are delivered through both sectors. Fragmentation in service provision can lead to overlaps and gaps in access and coverage, potential cost shifting between sectors, and increased complexity for users navigating the system. This can make it difficult for individuals to access the support they need in a timely and coordinated manner. Unifying the health and social aspects of LTC legislation is often a first step towards establishing a single-entry point for the provision of cash benefits and services, based on a standardised needs assessment. Such integration can enhance service delivery and overall system efficiency. To assess

this aspect, countries are classified as “not integrated” if their LTC legislation is not integrated across health and social care sectors, and “integrated” if the legislation is unified.

The second variable captures the level of decentralisation within LTC systems. The literature and existing typologies highlight decentralisation as a key dimension of governance, based on the assumption that organising care provision closer to recipients can result in more tailored and responsive services. Conversely, centralised systems may be better positioned to ensure equity of access and consistency in service provision across regions. However, highly centralised systems may also apply one-size-fits-all approaches that overlook regional heterogeneity, potentially limiting the effectiveness and fairness of service delivery. In this analysis, decentralisation is assessed across three aspects of governance: benefits, services, and eligibility. A system is classified as decentralised if at least one of these aspects is not centrally managed, and as centralised if all three are governed at the national level.

The third variable captures the ownership of public providers in LTC services, measured by their share among all LTC providers. This continuous variable reflects ongoing debates in the familialism literature about whether countries pursue defamilialisation through public provision or rely on market-based solutions. The role of privatisation in LTC is widely discussed, as it raises questions about quality of care and working conditions. Empirical findings on the impact of provider ownership are mixed. Public and private providers often operate under different incentives and management models. For example, research from Sweden suggests that the privatisation of LTC services may yield efficiency gains. In Denmark, evidence indicates that public and private providers differ across several dimensions of care quality. According to Hjelm et al (2018) public nursing homes generally offer better structural quality, especially in staffing, whereas private providers, tend to excel in process quality, such as individualised care (i.e. the times of meals are more flexible). In addition, the paper also shows how although residents' physical health does not differ significantly, public homes often report more adverse events, possibly due to stricter monitoring. In addition, empirical evidence suggests that they contribute to a reduction of care suppliers, and are associated with an increase in some aspects of care quality like for instance choice offered by meals-on-wheels companies (Stolt, Blomqvist and Winblad, 2011), or mortality rates (Bergman et al., 2016). Given its potential implications for other dimensions of the typology, including availability and quality, it is important to include a variable on the extent of public provision in LTC services.

The fourth variable measures the degree of care integration between the LTC sector and the broader health care system, with a particular focus on the use of clinical guidelines, care pathways, and multidisciplinary teams. This indicator, used in previous typologies, aims to capture the organisational depth of care systems, as integration between LTC and health services is associated with improved quality outcomes and greater efficiency from the user's perspective. The variable assesses whether there is meaningful coordination or integration with both primary and acute care, such as through the establishment of joint care pathways or multidisciplinary care teams. Countries are classified as having: (1) integration with both primary and acute care; (2) integration with only one of these healthcare components; or (3) no specific measures in place to support integration with the healthcare system.

LTC quality is analysed through presence of staff ratio, minimum educational requirements and regulatory framework

This LTC system dimension includes variables that measure different aspects of quality. The first two variables capture the structure-based measurement of quality by looking at the quality of the LTC workforce. Structure based assessment of the quality of LTC is based on resources and organisational structure, for example on the facility, equipment and staffing. In recent years, a strong focus is placed on the staffing of LTC due to shortages in the overall level of workers, high turnover rates and a recognition that the quality of staffing is probably related to the quality of care (Mentzakis, McNamee and Ryan, 2008; OECD, 2023). The issues related to staffing stems from, among others, discrepancy of pay between people with the same background in primary healthcare and LTC sector (OECD, 2023).

The first variable examines whether staff-to-resident ratios are in place in each country. This aims to capture the adequacy of staffing in relation to residents' needs. Many studies suggest that during the COVID-19 pandemic facilities with lower numbers of LTC workers were associated with higher infection rates (Sugg et al., 2021; Xu, Intrator and Bowlblis, 2020; Li et al., 2020). In many countries, staffing ratios requirements are implemented as indicators of adequate level of LTC workforce, given that appropriate ratios can contribute to reduced burnout, and better outcomes for care recipients. In addition, ratios have a broader impact as they concern different categories of care staff, including distinctions between professional nurses, personal care workers, and the various sub-categories within each occupational group. However, in some countries staff ratios are not feasible or easy to implement due to the shortage of workers.

The second variable aims to capture the quality of staffing by identifying if there are minimum education requirements for LTC workers. Education requirements for LTC workers vary greatly across OECD countries, often with very low requirements for personal care workers. This variable classified countries in two three categories: no minimum requirements in place, high school diploma or higher, and other i.e. mandatory trainings.

The third and fourth variables within this dimension assess the extent of quality assurance and regulation in the LTC sector. The third variable captures whether mandatory accreditation is required for LTC providers, distinguishing between systems where accreditation is required for both institutional and home care services, for only one type of service, or for neither. The fourth variable reflects the existence of a broader quality assurance framework within the LTC system. Countries are classified based on whether such a framework is in place or absent altogether.

Lastly, the fifth variable in the quality dimension looks at outcomes of care. Outcomes-based assessments focus on the effects of care on the user's health, such as functioning, but also on other indicators related to safety. The OECD has collected indicators on three outcomes: the use of benzodiazepines among the older people, the share of older people with health-related infections in LTC institutions, and the share of older people in LTC institutions with at least one pressure ulcer. Although various indicators exist to assess LTC quality outcomes, these three were selected for this report due to their relatively high degree of international comparability. Since not all countries have data available for all three indicators, countries are ranked on a scale of one (above average) to three (below average) for each indicator available and an average is constructed, although for several countries this measure are based on one indicator alone.

OECD's clusters model provides a comprehensive framework for comparing LTC systems

The contribution of this working paper, considering the different methodologies and data collection existing in the literature (Table 2.1), is its broader scope and increase data coverage. The dataset used in this analysis is more comprehensive compared to those in the LTC typology literature. For example, Kraus et al. (2010) use eight indicators to cluster countries, while Ariaans, Linden, and Wendt (2021) incorporate twelve indicators. In contrast, this working paper includes 20 indicators.

Furthermore, the quality of the typology is determined not only by the number of indicators but also by the breadth and diversity of the dimensions they cover. This working paper categorises its indicators into five key dimensions: access, availability, funding, governance and organisation, and quality. In comparison, Kraus et al. (2010) consider governance, access, funding, and quality, but omit indicators on service availability. Ariaans, Linden, and Wendt (2021), on the other hand, include governance, funding, and access, but exclude both quality-related indicators and those related to the availability and support of informal care.

The dataset created for this working paper provides a more comprehensive framework for comparing LTC systems across countries, allowing for a nuanced understanding of their structures and performance. While it is acknowledged that each LTC system is shaped by unique cultural, policy, and budget constraints, comparative analysis remains valuable. Although the five dimensions used - access, availability, funding, governance, and quality - provide a broad and structured approach, they do not capture all aspects related to ageing and LTC. For example, policies promoting healthy ageing or protecting the rights of care recipients fall outside the scope of this framework. Even within the defined dimensions, some important elements - such as training for carers, policies aimed at increasing the attractiveness of the care profession, denationalisation process, or geographic inequalities in access to LTC services - are excluded due to the lack of internationally comparable data. Furthermore, the dataset reflects the state of LTC systems up to the end of 2025. Given the pace of population ageing, many countries are currently undergoing reforms, and some indicators may become outdated as a result of these dynamic changes.

Clustering serves as an effective analytical tool by grouping systems with similar characteristics. The more comprehensive the clustering framework (in terms of both the number and diversity of indicators) the more robust and meaningful the analysis. This enables the identification of common challenges, emerging patterns, and transferable best practices that can inform policy across different settings.

However, this approach also has limitations. First, cross-country comparisons are complicated by differences in definitions and measurement approaches. Countries may interpret or apply certain indicators differently, which affects data comparability. Second, the use of categorical variables may mask subtle differences between systems. Countries with distinct characteristics could be assigned to the same category if their values fall within similar ranges. These

limitations highlight the importance of careful interpretation when applying clustering techniques to cross-national LTC comparisons.

LTC countries are different across dimensions, but some common challenges emerge

Each dimension of the cluster analysis created for this working paper reveals that LTC systems significantly differ across OECD countries. These cross-country variations become evident when examining the values of each variable within each dimension (see Annex B). At the same time, the average values across each dimension reflect the room for improvement in the LTC systems across the OECD as a whole.

Looking at the first dimension, access, the four variables present potential inequities in access and affordability across OECD countries. Regarding targeting based on needs, the average value of 2.2 out of maximum 3 across all countries suggests that, in most cases, systems provide relatively more financial assistance as needs increase. Moreover, income-testing of public support is limited, with only 1.4 cases out of 3 showing greater generosity for low-income individuals. In terms of coverage, only 28 per cent of older people with LTC needs receive formal LTC services, suggesting limited access and a possible reliance on informal care. Additionally, the type of benefits provided among countries is concentrated in the category only in-kind or predominantly in-kind benefits (72%), while a 27 per cent with predominantly in cash and cash only benefits.

Regarding the availability dimension, the first two indicators on formal care supply show an average of 40.5 LTC beds per 1,000 older people, and 4.5 LTC workers per 100 older people. These numbers suggest a lack of workforce and bed capacity, indicating that the average LTC system may struggle to meet the growing demand for care. Concerning the other two variables related to informal care, 61 per cent of countries rely on informal carers, but the support provided to them is limited. The average level of support and benefits is 1.96 out of 3, highlighting insufficient resources and assistance for informal carers.

In terms of funding, variables suggest that countries provide moderate public support that helps reduce poverty risk associated with LTC, but significant gaps remain, as OOP expenses remain high for individuals with severe needs. On average, public support covers 66 per cent of total LTC costs, which reflects a moderate level of generosity, but individuals are still responsible for covering around one-third of the costs themselves. Looking at the OOP expenses, they amount on average to 71 per cent of median income for an older person with

severe needs and no wealth. In this line, there is a substantial financial burden, and gaps in affordability despite existing public support. Finally, the impact of LTC benefits on poverty, on average, these benefits contribute to a 37.9 per cent reduction in the poverty rate among older people with severe needs.

When it comes to the governance dimension, countries exhibit differences in the structure of their systems, with identifiable groups emerging across most variables. Most countries' LTC systems are decentralised (62 per cent), while the remaining 38 per cent have centralised ones. Moreover, 45 per cent of countries have a unified LTC law that combines health and social aspects, while 55 per cent have more fragmented systems. The average share of public providers is 34 per cent, which indicates that while a fair portion is provided by public entities, there is reliance on private providers. In terms of integration, 41 per cent of countries integrate LTC with both hospitals and primary care, 35 per cent integrate it with only one, and 24 per cent have no integration at all.

Finally, the quality dimension, similarly to the previous one also reveals identifiable groups emerging across some of its variables. The first two workforce-related variables highlight differences between two or three groups of countries. Looking at staff ratios, most countries (72 per cent) have them in place, while 28 per cent do not. When examining educational requirements for personal care workers, most countries have established some minimum standards. About 38 per cent of countries require at least high school education or higher, and 52 per cent of countries education other than high school, i.e. mandatory trainings. Only a 10 per cent of countries have no minimum educational requirements to work as personal care workers. Regarding the next two quality variables, most countries require mandatory accreditation for both home and institutional LTC services (65 per cent) or for just one of these (31 per cent). Only one country does not have mandatory accreditation in place. Similarly, quality assurance frameworks are present in most countries (90 per cent), with only 10 per cent lacking them. Lastly, regarding the final variable on quality outcomes, the average score is 2.11 out of 3, indicating that, overall, the values are like the OECD average.

4. Methodology

This section outlines the methodology employed to cluster long-term care (LTC) systems across OECD countries. First, it explains the standardisation of the variables and the dimensionality reduction applied to the dataset. Next, it describes the methods used to derive the cluster assignments. Finally, the section details the approach taken for the additional analyses conducted post-clustering.

Data dimension reduction is needed to increase efficiency and effectiveness of clustering algorithms

Before applying a clustering algorithm, the dataset is modified through the application of dimensionality reduction techniques. It includes 20 variables, grouped into five dimensions of LTC systems, as described in Section 3. Given the relatively small number of observations (29), the dataset can be classified as high-dimensional. In such high-dimensional spaces, the data become sparse, and traditional indexing and algorithmic techniques often struggle in terms of efficiency and effectiveness perspective (Aggarwal, Hinneburg and Keim, 2001). As a result, the literature commonly combines clustering algorithms with dimensionality reduction techniques to improve clustering outcomes (Liu et al., 2020).

The dataset consists of mixed-type data, requiring the use of different dimensionality reduction techniques. Some variables are continuous, while others are categorical. For instance, the generosity of the LTC system is measured as the share of LTC costs covered by public support for an older person with severe needs, making it a continuous variable. In contrast, the classification of whether LTC governance is centralised or not is a categorical variable. The standard dimensionality reduction technique for continuous data is Principal Component Analysis (PCA) (Abdi and Williams, 2010), for categorical variables is Multiple Correspondence Analysis (MCA) (Nenadic and Greenacre, 2005), and for mixed type data, the appropriate technique is Factor Analysis of Mixed Data (FAMD) (Saporta, 1990).

To preserve the original data structure, the dimensionality reduction is carried out in two stages. Since the data are originally collected within five broad dimensions of LTC systems, the reduction is first performed within each of these five dimensions. The scores obtained are then used for a second round of dimensionality reduction to derive the final score. This approach ensures that common variation is captured first within the dimensions and then across them, preventing from the domination of one dimension in the final score. In the first stage, Principal Component Analysis (PCA) is applied to the Availability and Funding dimensions, while Factor Analysis of Mixed Data (FAMD) is used for the remaining three dimensions. The continuous data are normalised before applying the dimensionality reduction techniques to prevent variables with high variance from dominating the factor loadings.

The number of components retained from the dimensionality reduction varies across the five dimensions of the LTC system. The optimal number of

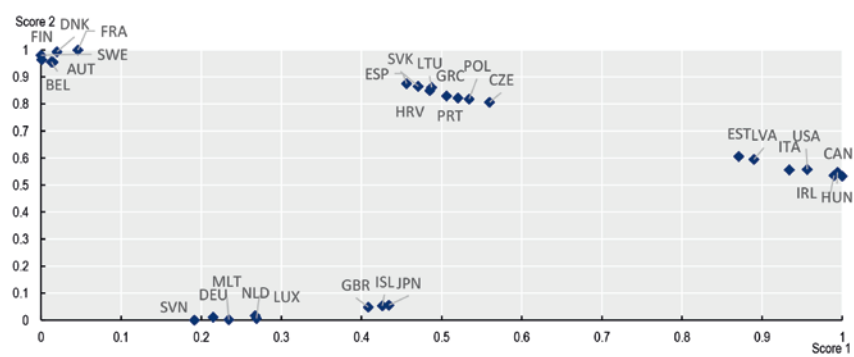
components is determined using the “rule of thumb”: only components with eigenvalues greater than one are retained. This rule is commonly used in the literature as it ensures that only components that explain more variance than a single original variable are retained (Girden, 1996). As a result, two components are retained for access, two for availability, one for funding, three for governance, and five for quality. Consequently, the first stage of dimensionality reduction reduces the number of variables from 20 to a total of 13, highlighting the need for further reduction in the second step.

The second stage of the dimensionality reduction is performed using Uniform Manifold Approximation and Projection (UMAP) (McInnes et al., 2018). As the scores obtained from the first dimensionality reduction are continuous, this allows for the application of a wide range of dimensionality reduction techniques. UMAP is a versatile technique that does not assume a linear relationship between the scores, enabling it to capture nonlinear relationships effectively. The algorithm is applied with the following parameters: two components are retained, a minimum distance of 0.02 is set to control the balance between local and global structure, three neighbourhoods are used to define the local structure, and the cosine metric is employed to measure similarity, which is often effective for high-dimensional data with sparse relationships. These parameters are chosen to optimise the capture of both local and global structures within the data, ensuring that the reduced dimensionality retains as much of the original structure as possible. The scores obtained from this second stage are then normalised.

Analysis of the scores suggests that LTC systems can be clustered into either four or five groups. Figure 4.1 presents the scores obtained from the dimensionality reduction for the 29 analysed countries. Based on this figure, four or five distinct clusters are visually identifiable. This clustering can later be confirmed using appropriate clustering methods. It is important to note that the obtained scores should not be interpreted in terms of their sign or absolute value. Rather, they serve as suggestive evidence of the relative distances between LTC systems - specifically, the smaller the distance between two points, the higher the likelihood that the corresponding LTC systems belong to the same cluster.

Figure 4.1. Distribution of countries across reduced dimensions describing LTC systems

Based on scores obtained from two-stage dimensionality reduction



Note: The scores are predicted using the UMAP and normalize to lie between 0 and 1.

Source: OECD own analyses.

Multiple clustering algorithms are applied to ensure the consistency of the results

Cluster analysis is used to classify LTC systems based on their key characteristics. The goal of cluster analysis is to divide a dataset into groups (or clusters) such that the data points within each group are more like each other than to data points in other groups. Cluster analysis can be performed using a variety of algorithms, reflecting the various concepts of what constitutes a cluster and how it should be defined.

Four clustering algorithms have been used in this working paper (see Table 4.1 for comparison) to group LTC systems. They belong to two broad classes of clustering methods: distance-based clustering and probabilistic clustering. Distance-based algorithm groups data points into clusters based on the similarity between them, which is calculated using a distance metric. The fundamental idea is to place data points that are close to each other in the same cluster, reflecting the proximity in the feature space. Probabilistic clustering is a clustering approach that assigns data points to clusters using probabilistic models or probability distributions. These methods assign probabilities to indicate the likelihood of data points belonging to each cluster. This approach is particularly useful when data points

can potentially belong to multiple clusters or when there is uncertainty in cluster assignments.

Table 4.1. Comparison of four clustering algorithms used to group LTC systems

Algorithm name	Algorithm class	Description
K-means	Distance-based algorithms	Assigns data points to clusters such that the distance between a data point and cluster centroid is smallest. Initial centroids of specified number of clusters are randomly selected. While the advantage is its simplicity, the algorithm is sensitive to the initial random selection of cluster centroids. Besides, finding the optimal number of clusters lacks a general theoretical solution.
Hierarchical clustering	Distance-based algorithms	Groups similar data points into clusters that form a hierarchical structure, reflecting the order in which clusters are merged or divided. It does not require to specify the number of clusters beforehand and is not sensitive to the initial selection of cluster centroids. Yet, it can be sensitive to outlier observations and is influenced by the choice of distance metric and linkage method.
Self-Organising Map	Distance-based algorithms	Is a type of artificial neural network designed to reduce the dimensionality of data while preserving the topological relationships between data points (Kohennen, 1982). The algorithm is robust to noise and outliers in the data but can be sensitive to the initial configuration of neurons. Additionally, its outcome depends on the selection of parameters such as the grid size, learning rate, and neighbourhood size

Gaussian Maximization Method (GMM)	Probabilistic algorithms	Assumes data points are generated from a mixture of several Gaussian distributions, each corresponding to one cluster. GMM employs an Expectation-Maximization technique to estimate parameters (the mean and the covariance) for each of these distributions. It allows for the calculation of the probability of belonging to each cluster. This makes GMM a more flexible approach compared to k-means. However, it also lacks a general theoretical framework for determining the optimal number of clusters and is sensitive to initial parameter guesses.
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Source: OECD own analyses.

The OECD methodology described in this working paper differs from those described in the literature because it synthesises results of several algorithms. Ariaans, Linden and Wendt (2021) employed a similar approach, but they relied on outcomes of two clustering algorithms only while the methodology used in this working paper uses four different clustering methods. The OECD methodology has several advantages. First, different clustering algorithms have varying assumptions and characteristics. Applying multiple clustering methods helps to assess and validate the robustness of the clusters. Since multiple algorithms produce similar results, it adds confidence in the validity of the clusters. Second, since various clustering algorithms handle outliers differently, running multiple algorithms ensures that identified clusters are not significantly affected by extreme data points. Finally, clustering algorithms might identify patterns based on data noise (e.g. including a lot of variation in the data), leading to overfitting so the identification of clusters that do not exist. Employing multiple algorithms reduces the risk of overfitting since each clustering method has a unique approach to classify data points and it is less likely that all algorithms will result in the same overfitted solution.

5. The results of the OECD typology show four country clusters

This section presents the results of the OECD typology of long-term care (LTC) systems. It begins by outlining the outcomes of the clustering exercise. It then discusses the key characteristics of each cluster, highlighting how they differ

from one another. Finally, it examines how individual countries compare to the average profile of their respective clusters.

Clustering algorithms identify four groups of LTC systems

The number of clusters is set to four based on the analysis of silhouette scores (where a higher value indicates better clustering quality), Davies-Bouldin scores (where a lower value is preferable), and the elbow method. The elbow method involves plotting the total within-cluster sum of squares against the number of clusters, helping to identify the point at which adding more clusters results in only marginal improvements - this point, often called the elbow, indicates an appropriate number of clusters. Three alternatives are considered: three, four, or five clusters. The allocation into three clusters results in a lower silhouette score and a higher Davies-Bouldin score compared to the four- and five-cluster solutions, indicating a poorer fit. The comparison between four and five clusters is more nuanced. While the elbow method suggests that four clusters provide an optimal balance between model complexity and explanatory power, the silhouette and Davies-Bouldin scores are very similar for both cluster solutions. Given the relatively small number of observations (29 countries), and to avoid overfitting and to ensure meaningful interpretation, the four-cluster solution is selected as the most appropriate.

All four employed clustering algorithms lead to the same allocation of countries into clusters. The clusters are numbered from 1 to 4, and the allocation of countries is shown in Table 5.1. The cluster numbering is arbitrary and does not correspond to any specific feature of the LTC system. The size of the clusters varies, ranging from six countries in Cluster 1 to eight countries in Clusters 2 and 4. Within each cluster, countries are listed in alphabetical order. The fact that all four algorithms grouped countries into the same clusters confirms that the allocation is robust and consistent, despite the differing assumptions and methods underlying each clustering technique.

Table 5.1 Clustering of countries based on their LTC system characteristics

Cluster 1	Cluster 2	Cluster 3	Cluster 4
Austria	Germany	Canada	Czechia
Belgium	Iceland	Estonia	Croatia
Denmark	Japan	Hungary	Greece
Finland	Luxembourg	Ireland	Lithuania
France	Malta	Italy	Spain
Sweden	Netherlands	Latvia	Poland
	Slovenia	USA	Portugal
	United Kingdom		Slovak Republic

Note: All four clustering algorithms: K-means, Hierarchical clustering, Self-Organization Map, and Gaussian Maximization Method yield to the same LTC systems grouping. Countries are ordered alphabetically within the cluster.

Source: OECD analysis based on the data sources listed in the Annex C.

The number of LTC workers per older population and the share of total LTC costs covered by public support are among the most important variables influencing group assignment. To assess the importance of each variable in the clustering, a random forest classifier is trained using the original variables and the cluster assignments. For each variable, impurity-based feature importance is calculated. Following the number of LTC workers per older population and the generosity of the LTC system, other influential variables include the share of public providers, the number of LTC beds per older population, out-of-pocket expenditures, and the share of older people with LTC needs receiving informal care. Among the least impactful variables are the presence of a staff ratio requirement, the form of benefits (in-cash versus in-kind), and the existence of a quality assurance framework.

Clusters differ across all dimensions of LTC systems, although the degree of variation varies across dimensions. Figures in Annex A present the averages of all variables used in the clustering, disaggregated by cluster. LTC systems show significant variation across clusters in terms of the number of LTC beds and LTC workers per older population, as well as in variables related to funding, the centralisation of governance, and the share of public providers of LTC services. By contrast, patterns are noticeably less distinct when it comes to the type of LTC benefits offered or the presence of a quality assurance framework. These findings are consistent with the earlier analysis of variable importance: variables with

greater variation across countries have a stronger influence on the clustering, while variables with lower variation appear to have a smaller impact.

Cluster 1 countries have the highest financial support, high formal public provision yet offer high support to informal carers, and have high-quality, unified but decentralised systems

Countries in Cluster 1 are characterised by the highest coverage of formal LTC services, and access to public support is often both needs- and means-tested. In half of the countries in this cluster, the share of older people with care needs who receive formal care exceeds 50 per cent. Only in Sweden is this share below 25 per cent, aligning more closely with the levels observed in Clusters 3 and 4. Needs-testing is widespread: in four countries, the share of LTC costs covered by public support increases with the severity of needs, with the exceptions of France and Denmark. Similarly, some form of means-testing is present in all countries in this cluster, except for Denmark. Lastly, the type of LTC benefits varies across countries— Austria and France rely more heavily on in-cash benefits, whereas the remaining countries predominantly provide LTC services directly

The availability of formal LTC and support for informal carers is high in LTC systems grouped in Cluster 1 although staffing levels are somewhat lower. The number of beds in LTC institutions per older population is, on average, relatively high compared to other clusters, with Denmark being the only country in the group where this number is significantly lower (more than 20 per cent below the average). The number of LTC workers per older population, on average, is significantly lower than in Cluster 2, largely due to lower staffing levels in Austria, Finland, and France. However, in countries such as Denmark and Finland, the number of LTC workers per older population is significantly above the cluster average, and more comparable to levels observed in Cluster 2. The share of older people with LTC needs receiving informal care is, on average, like that in Clusters 2 and 4, though the prevalence of informal care is particularly low in France and Sweden. Most LTC systems in Cluster 1 offer at least two policy measures supporting informal carers, suggesting relatively strong institutional support for this form of care.

LTC systems grouped in Cluster 1 provide, on average, the highest level of funding for formal home care, resulting in low out-of-pocket expenses and a reduced risk of poverty for individuals receiving formal LTC. In all countries except France, public support covers at least 80 per cent of the LTC costs for older people with severe needs. As a result, out-of-pocket expenses are below 50

per cent in all countries except France, which leads to a significant reduction in poverty associated with LTC expenditures.

LTC laws are mostly unified in the systems within Cluster 1, while all these systems are decentralised and primarily rely on public providers. The only exception in this cluster is Belgium, which does not have a unified LTC law. Public providers account for around 50 per cent or more of all providers in every country, except for Belgium, where this share is significantly lower, at 29 per cent. All countries in Cluster 1 integrate LTC with hospitals and primary care units; however, in Austria and Belgium, integration occurs only with one of these services, not both.

Accreditation for LTC providers and quality assurance frameworks are common instruments used to ensure high-quality outcomes, while some countries opt not to mandate staff ratios. A quality assurance framework is present in all countries within Cluster 1, and accreditation is mandatory for both home and institutional LTC providers in all countries, except Austria, where mandatory accreditation applies only to one type of provider. Educational qualifications for LTC workers are generally high, with at least a high school diploma required in all countries except Denmark and France. This level of educational requirement is much higher than in Clusters 2 and 3 and is comparable to that observed in Cluster 4. However, to provide greater flexibility to LTC providers facing labour shortages, some countries, including Denmark, France, and Finland, have opted to forgo mandatory staff ratios. As a result of these relatively high-quality measures, the quality outcomes are generally high, except for France.

Cluster 2 comprises of LTC systems that offer high financial support, are centralised, rely more on private providers and have less means-testing

Access to LTC services is less frequently needs- and means-tested in countries grouped in Cluster 2 compared to other clusters, and public support is provided predominantly or exclusively in-kind. Public funding as a share of LTC costs is higher for all cases only in the UK, Iceland, and Malta, which is much less common than in the other clusters. Additionally, four countries - Germany, Iceland, Luxembourg, and Malta - do not use means-testing for any typical case, and none of the countries in Cluster 2 apply means-testing to all typical cases. As a result, means-testing is much less prevalent in Cluster 2 than in Clusters 1 and 3, and is more in line with countries in Cluster 4. The share of older people with LTC needs receiving public support is, on average, 31 per cent, with the UK,

Malta, and Slovenia having coverage rates below 25 per cent. This is significantly lower than in Cluster 1, but higher than in Clusters 3 and 4.

The availability of formal LTC is very high in Cluster 2, accompanied by a high prevalence of informal care and relatively strong support for informal carers. The number of LTC beds per older population is the highest among all clusters, with only Germany and Japan having fewer beds per older population. On average, the number of LTC workers per older population is also the highest in Cluster 2 compared to all other clusters, with Slovenia being the only country with several LTC workers significantly below the cluster average. The prevalence of informal care is also high, like Cluster 1 and 4, with more than 60 per cent of older people with LTC needs receiving informal care, except in Iceland. Informal carers receive institutional support in all countries, with policies in place to support them. Only Iceland offers fewer than two policies for informal carers.

LTC systems in Cluster 2 are relatively generous; however, out-of-pocket expenses and the risk of poverty among formal care recipients are, on average, slightly higher than in the LTC systems of Cluster 1. Slovenia is the only country in this cluster that cover around 50 per cent or less of the cost of LTC for an older person with severe needs, while other countries in the cluster cover around 80 per cent or more of the costs. This disparity has implications for out-of-pocket expenses and the poverty risk among care recipients, as these are higher in Slovenia compared to other countries in Cluster 2 and Cluster 1.

Most countries in Cluster 2 have a unified LTC law and centralised LTC governance, while relying primarily on private providers. All countries, except Malta and the Netherlands, have a unified social and health component in their LTC laws. Governance is largely centralised, with the exceptions of Iceland and Japan. All LTC systems in this cluster, except for Slovenia, rely predominantly on private providers. Two out of the three LTC systems are integrated with both primary care and hospitals, with Iceland being the only country lacking integration with both elements of the health sector. Some countries lacking integration with primary care or hospitals recognise the limitations of insufficient coordination. In response to that, for example, France is planning structural reforms to improve coordination between the health, medico-social, and social sectors.

Education requirements for LTC workers are lower in Cluster 2 compared to all other clusters, while LTC systems in this group mostly rely on staff ratios, accreditation for LTC providers, and quality assurance frameworks to ensure high-quality care. The UK and the Netherlands are the only countries in Cluster

2 that do not use staff ratios. Additionally, the UK, along with Iceland and Japan, does not have specific educational requirements for LTC workers, whereas the other countries have some requirements, although none mandate a high school diploma or higher. Accreditation is mandatory for both institutional and home care providers in all countries in Cluster 2, except Iceland. All countries have some form of quality assurance framework; however, the quality outcomes measured in these countries are, on average, lower than those observed in countries grouped in Clusters 1 and 3.

Cluster 3 groups countries with decentralised governance where strict needs and means-testing limit public provision of LTC

Means- and needs-testing are widely used in countries grouped in Cluster 3, which contributes to lower coverage of formal LTC. In all countries except Italy (for two cases) and Canada (for one case), the share of LTC costs covered by public support increases with the severity of needs. Similarly, means-testing is widespread: only Canada and Ireland do not apply it in any of the typical cases, while all other countries in the cluster apply it in two or more cases. As a result, in all countries in this cluster - except Ireland and Canada - less than 30 per cent of older people with LTC needs receive formal care, a coverage rate lower than in Clusters 1 and 2. Public support is typically delivered through a mix of in-cash benefits (as in Hungary and Italy) and in-kind benefits (in all other countries), with in-kind support being more prevalent overall.

The number of LTC beds and workers per older population is generally slightly below the overall average and the prevalence of informal care is also low, with only one or two policies supporting informal carers and care recipients. The number of LTC beds per older population is particularly low in Italy and Latvia, with around 20 or fewer beds per 1,000 older people. In terms of LTC workers, availability is especially low in Latvia and Hungary, while Estonia has a relatively high number of LTC workers per older population, comparable to the average in Cluster 1. The relatively low prevalence of informal care in Cluster 3, compared to other clusters, is primarily driven by Canada, Hungary, and Ireland. However, other countries in this cluster also have a prevalence of informal care below the average observed in the other clusters, suggesting a relatively low reliance on informal carers overall. This might be partly due to the limited support for informal carers - four countries have only two policies, and Italy, the USA, and Latvia have just one.

The generosity of public support for LTC is average in Cluster 3, resulting in, on average, higher out-of-pocket expenses and a higher poverty rate among care

recipients compared to Clusters 1 and 2. The share of total LTC costs covered by public funding for an older person with severe needs and median income is relatively high in Canada and Hungary, aligning with the average of Cluster 1, which has the highest generosity. In contrast, it is very low in Estonia and the US, where public funding covers around 20 per cent or less. This has implications for out-of-pocket expenses, measured as a share of median income, which are high in Estonia and in Italy who faces a high overall cost of LTC. As a result, only Canada, Ireland, and Hungary effectively limit the risk of poverty among formal care recipients.

Countries in Cluster 3 lack a unified social and health component of LTC law and predominantly have decentralised LTC governance systems. The governance is centralised only in Ireland within this cluster, while the other countries have decentralised systems, like those in Cluster 1. The share of public providers of LTC services varies countries such as Estonia and Latvia rely mostly on public providers, while countries like the US, Italy, and Ireland depend largely on private providers. Most countries integrate their LTC systems with either hospitals or primary care, except for the US, which has integrated both elements of the health sector.

LTC systems in Cluster 3 often use staff ratios, and all have implemented quality assurance frameworks while imposing relatively high educational qualifications for LTC workers to ensure quality care. More than 70 per cent of countries in this cluster have mandatory staff ratios for LTC institutions, with the exceptions of Canada and Ireland. Canada and Estonia also require a high school diploma or higher for LTC workers, while the remaining countries require some other form of qualification. Countries in Cluster 3 typically require accreditation for either LTC institutions or home care providers, with the exceptions of Estonia and Latvia, which require accreditation for both. The quality outcomes of LTC systems in Cluster 3 are, on average, like those in Cluster 1, with Canada, Hungary, and Latvia achieving very high outcomes, while Italy and the US have relatively low outcomes.

Countries in Cluster 4 offer the lowest public funding for LTC, resulting in low formal care coverage and have fragmented systems with lower quality

Even though Cluster 4 comprises LTC systems that rarely use means-testing, the coverage of formal LTC care remains relatively low. Six out of eight countries in this cluster provide higher public funding for more severe needs, while only Poland and Portugal do not employ means-testing. Lithuania, Spain, and Greece

are the only countries that use means-testing for some typical cases, while the remaining countries do not apply means-testing for any typical case. Despite the limited reliance on meanstesting, only 20 per cent on average of older people with LTC needs receive formal care, with the share exceeding 30 per cent only in Spain and Greece. The form of public support varies considerably: countries like Czechia, Spain, and Croatia provide mostly or entirely cash benefits, while others, such as the Slovak Republic and Portugal, rely primarily on in-kind benefits.

The low number of LTC workers and beds in LTC institutions contributes to the high prevalence of informal care in Cluster 4, despite the limited number of policies supporting informal carers. The number of beds in LTC institutions per older population is below the average of all four clusters in Greece, Croatia, Poland, and Portugal, with only Spain and Slovakia having numbers closer to the averages observed in Clusters 1 and 2. The number of LTC workers per older population is even lower compared to other clusters, with only Spain having a number close to the Cluster 2 average. As a result, the provision of informal care is very high, exceeding 50 per cent, with Poland and Portugal being the only countries where the prevalence of informal care is below 60 per cent. This high reliance on informal care is not supported by policies, as most countries offer one or no policies to support informal carers, with Spain being the exception, offering a set of four policies.

Countries in Cluster 4 offer relatively low public support for older people with LTC needs, resulting in high out-of-pocket expenses and insufficient reduction of the poverty risk associated with care expenditures. Lithuania is the only country that covers more than 50 per cent of the LTC costs for an older person with severe needs and median income, while Czechia, Croatia, Poland, and Portugal cover less than 25 per cent of the cost. As a result, only in Greece are out-of-pocket expenses for an older person with severe needs and median income below 50 per cent, making care largely unaffordable for most older people with needs in the remaining countries. This is further confirmed by the fact that only Greece, Portugal, and the Slovak Republic reduce the poverty risk associated with LTC expenditures in any meaningful way.

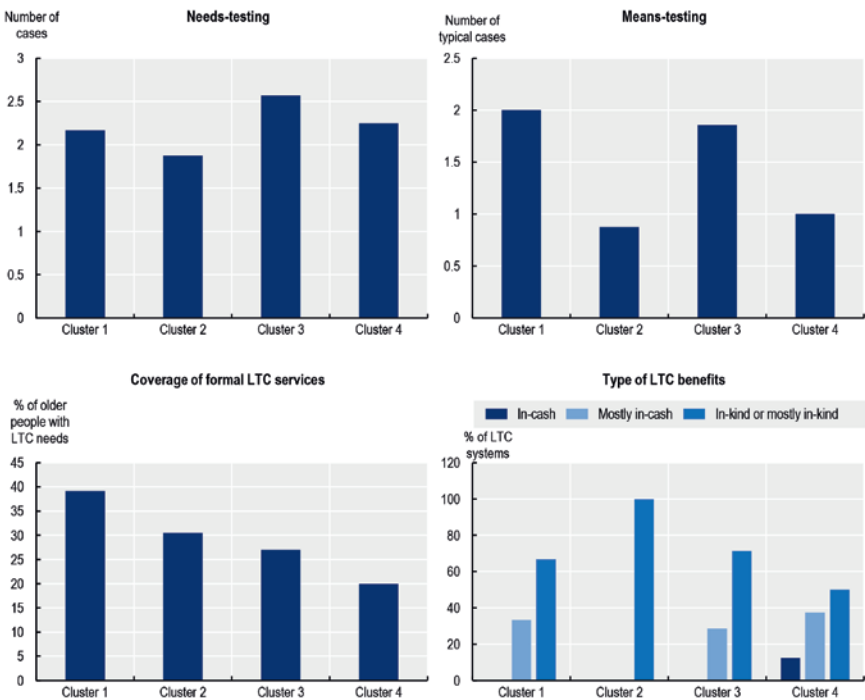
In Cluster 4, the social and health components of the LTC system are mostly not unified, and LTC systems are largely unintegrated with the broader healthcare system. Portugal and Spain are the only countries that have unified the social and health components of their LTC laws. The governance of LTC is mixed: half of the countries have a centralised LTC system, while the others opt for decentralisation. LTC service providers are primarily private, with the exceptions

of Czechia, Poland, and the Slovak Republic, where the share of public providers is slightly above 50 per cent. Integration of LTC with hospitals and primary care is absent in most countries, except for Greece (which integrates LTC with one of these services) and Portugal, which has fully integrated its LTC system with both elements of the healthcare system.

Most countries in Cluster 4 rely on staff ratios and have high educational requirements for LTC workers, although some countries lack a LTC quality assurance framework. Mandatory staff ratios are in place in all countries except Czechia. Five out of eight countries require LTC workers to have at least a high school diploma, while the remaining three require some other form of educational qualification – similar values as observed among countries in Cluster 1. All countries in Cluster 4, except Portugal, require accreditation for LTC home and/or institutional service providers. Greece, Poland, and Portugal are the three countries (among all countries) that lack a quality assurance framework, which may impact the quality of care provided. As a result, on average, quality outcomes in Cluster 4 are below those in other clusters, and Lithuania and Slovakia are the only two countries with high quality outcomes.

Annex A. Characteristics of LTC systems across clusters

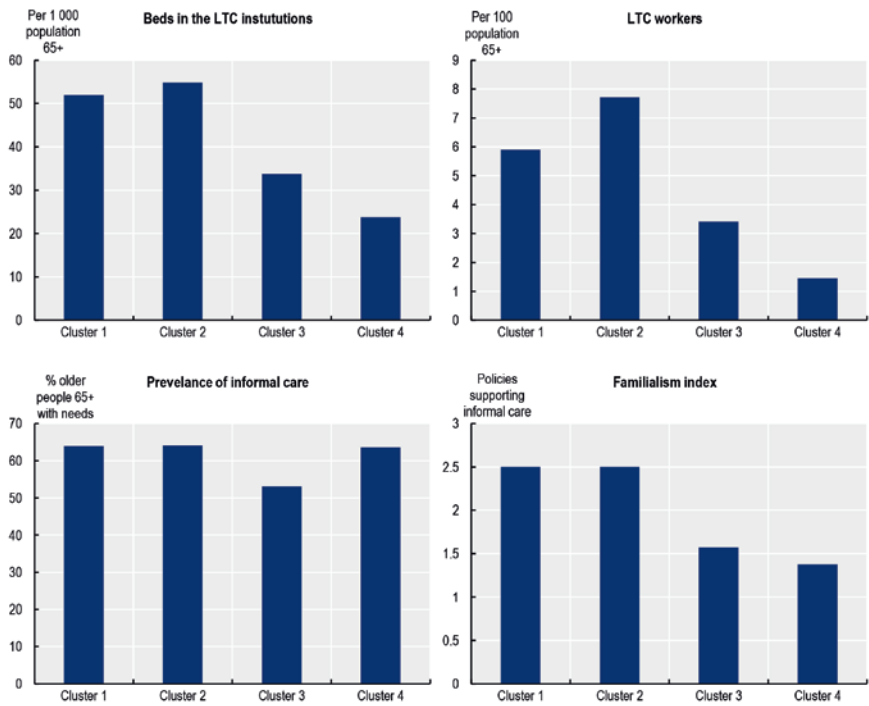
Figure A.1. Characteristics of access to LTC services by cluster



Note: The detail description of variables presented on the figure is included in Chapter 3.

Source: OECD own analyses based on data sources listed in Annex C.

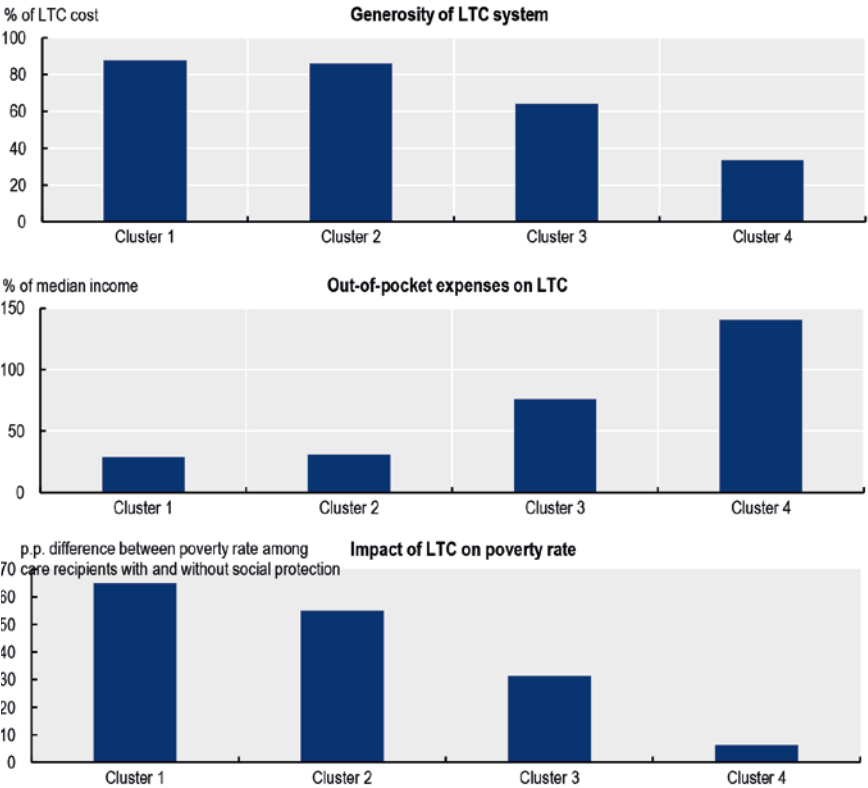
Figure A.2. Characteristics of availability of LTC across clusters



Note: The detail description of variables presented on the figure is included in Chapter 3.

Source: OECD own analyses based on data sources listed in Annex C.

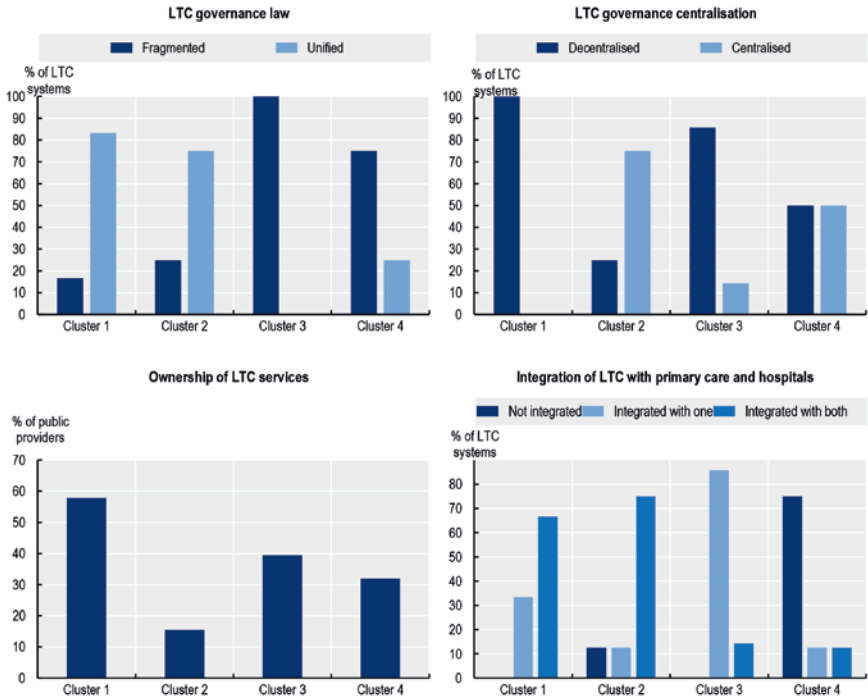
Figure A.3. Characteristics of funding of LTC across clusters



Note: The detail description of variables presented on the figure is included in Chapter 3.

Source: OECD own analyses based on data sources listed in Annex C.

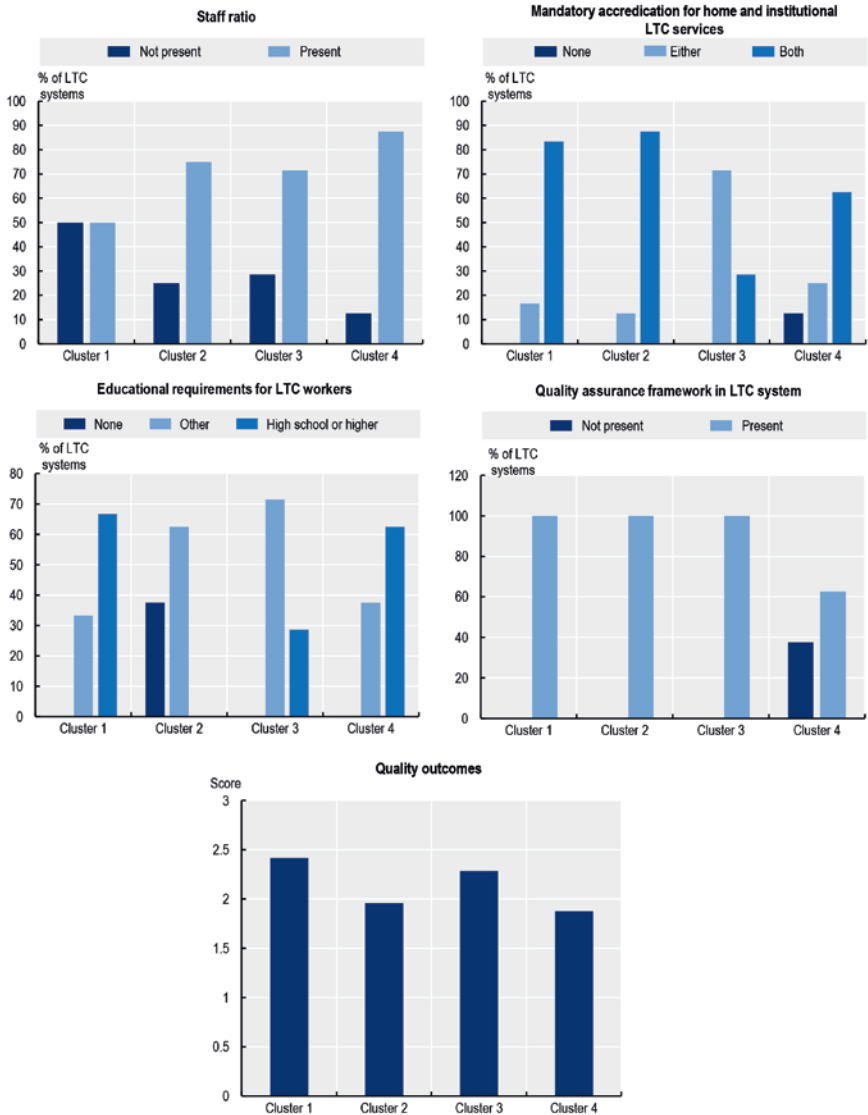
Figure A.4. Characteristics of governance of LTC systems across clusters



Note: The detail description of variables presented on the figure is included in Chapter 3.

Source: OECD own analyses based on data sources listed in Annex C.

Figure A.5. Characteristics of quality of LTC across clusters



Note: The detail description of variables presented on the figure is included in Chapter 3.

Source: OECD own analyses based on data sources listed in Annex C.

Annex B. Data used to cluster long-term care systems across OECD countries

This annex presents data that are used to classify the long-term care (LTC) systems. Data are divided into five dimensions. The sources of the data presented in the tables below are described in Annex C. The detailed description of variables presented in the table is included in Section 3.

Table B.1. Overview of all indicators used to create typology of LTC systems

Area	Indicator	Measure
Access	Needs-testing: number of comparisons in which support for an older person with more severe needs is higher	Extent to which public support for LTC varies with the level of an older person's care needs
	Means-testing: number of typical cases for which support for a person with low income (20th percentile of income distribution of older population) is higher than for a person with high income (80th percentile)	Extent to which public support for LTC varies with the income of an older person's care needs
	Coverage of formal LTC services (% of older people with LTC needs receiving formal care)	Extent to which the LTC needs of the older population are met through formal care provision
	Type of LTC benefits: in-cash vs in-kind	Extent to which the LTC system relies on public support provided in cash versus in kind

Availability	Number of beds in the LTC institutions (per 1 000 older people)	Availability of institutional care
	Number of LTC workers (per 100 older people)	Availability of formal care
	Prevalence of informal care (% of older people with LTC needs receiving informal care)	Extent to which the LTC provision relies on informal care
	Availability of benefits for informal carers (number of available benefits for informal care)	Extent to which countries support for informal carers
Funding	Public support for older person with severe needs, median income and no wealth (as a share of LTC cost)	Generosity of LTC system
	Out-of-pocket expenses of older person with severe needs, median income and no wealth (as a share of median income)	Financial burden of LTC expenditures on care recipients
	Poverty reduction due to the social protection for LTC (percentage point difference between poverty rate among older people with severe needs with and without social protection)	Impact of LTC expenditures on poverty among care recipients
Governance	Unification of health and social components of LTC law	Unification between health and social care laws
	LTC system governance and management centralisation	Extent to which the governance of the LTC system is divided between central and local governments
	Public providers of LTC services (% of LTC providers)	Ownership of LTC facilities
	Integration of LTC with primary care and hospitals	Degree of integration between LTC services, primary care providers and hospitals

Quality	Guidelines for the staff ratio in the institutional LTC	Extent of regulatory oversight of staff in institutional LTC facilities
	Educational requirements for LTC workers (personal care workers)	Qualifications of LTC workers
	Mandatory accreditation for institutional and home LTC services	Extent to which LTC service providers are subject to formal regulation
	Quality assurance framework in LTC system	Extent to which monitoring of quality of LTC services is regulated
	Quality outcomes in the LTC (average of three quality outcomes): 1) Use of benzodiazepines among older people, 2) Share of older people in LTC institutions with at least one healthcare-associated infection, 3) Share of older people in LTC institutions with at least one pressure ulcer	Quality outcomes of LTC

Note: Older people refer to people aged 65 and more.

Table B.2. Data on access to LTC system

Country	Needs-testing: number of comparisons in which support for an older person with more severe needs is higher as a share of total LTC cost	Means-testing: number of typical cases for which support for a person with low income (20 th percentile of income) is higher than for a person with high income (80 th percentile)	Coverage of formal LTC services (% of older people with LTC needs receiving formal care)	Type of LTC benefits
Austria	3	3	31	Predominantly in-cash
Belgium	3	3	53	Only in-kind or predominantly in-kind
Canada*	1	0	49	Only in-kind or predominantly in-kind
Croatia	3	0	25	Predominantly in-cash
Czechia	3	0	15	Only in-cash
Denmark	1	0	49	Only in-kind or predominantly in-kind
Estonia	3	3	11	Only in-kind or predominantly in-kind
Finland	3	2	28	Only in-kind or predominantly in-kind
France	0	3	51	Predominantly in-cash

Germany	2	0	37	Only in-kind or predominantly in-kind
Greece	3	2	30	Predominantly in-cash
Hungary	3	3	21	Predominantly in-cash
Iceland	3	0	43	Only in-kind or predominantly in-kind
Ireland	3	0	36	Only in-kind or predominantly in-kind
Italy	2	3	28	Predominantly in-cash
Japan	2	2	28	Only in-kind or predominantly in-kind
Latvia	3	2	15	Only in-kind or predominantly in-kind
Lithuania	3	3	13	Only in-kind or predominantly in-kind
Luxembourg^	1	0	31	Only in-kind or predominantly in-kind
Malta	3	0	22	Only in-kind or predominantly in-kind
Netherlands	1	1	44	Only in-kind or predominantly in-kind
Poland	0	0	18	Only in-kind or predominantly in-kind

Portugal	0	0	16	Only in-kind or predominantly in-kind
Slovakia	3	0	12	Only in-kind or predominantly in-kind
Slovenia	0	2	16	Only in-kind or predominantly in-kind
Spain	3	3	31	Predominantly in-cash
Sweden	3	1	23	Only in-kind or predominantly in-kind
United Kingdom	3	2	23	Only in-kind or predominantly in-kind
United States of America	3	2	29	Only in-kind or predominantly in-kind

Note: The detail description of variables presented in the table is included in Section 3. Older people refer to people aged 65 and more.

** Data for Ontario only for Needs and Mean testing indicators, Types of LTC benefits. The data for Coverage of formal LTC services covers only home care, therefore not including residential long-term care. In addition, the data is drawn from a volunteer population participating in a time consuming longitudinal study (Canadian Longitudinal Study on Ageing), and there is likely a strong self-selection bias.*

^ Data for Luxembourg do not include older people in LTC institutions.

Source: OECD own analyses based on data sources listed in Annex C.

Table B.3. Data on availability of LTC services

Country	Number of beds in the LTC institutions (per 1 000 older people)	Number of LTC workers (per 100 older people)	Prevalence of informal care (% of older people with LTC needs receiving informal care)	Availability of benefits for informal carers (number of available benefits for informal care)
Austria	45.7	4.1	73	3
Belgium	66.9	5.5	62	3
Canada*	46.7	3.8	40	2
Croatia	10.7	0.2	66	1
Czechia	34.9	2.4	66	1
Denmark	37.1	7.4	69	2
Estonia	41.4	5.2	62	2
Finland	50.8	4.3	65	2
France	47.4	2.4	59	2
Germany	53.9	5.5	63	3
Greece	1.8	0.3	72	0
Hungary	42.6	1.8	47	2
Iceland	51	11.5	44	1
Ireland	43.1	3.6	42	2
Italy	21.3	3.7	61	1
Japan	26.5	6.8	80	2
Latvia	12.4	1.3	59	1
Lithuania	38.5	1.1	64	0
Luxembourg	78.9	7.5	62	3
Malta	63.59	10.5	60	2
Netherlands	73.9	8.2	71	4
Poland	10.7	0.6	53	2
Portugal	4.0	0.8	59	1
Slovakia	46.2	1.3	69	2
Slovenia	49.5	1.7	67	2
Spain	43.4	4.9	60	4

Sweden	63.9	11.7	56	3
United Kingdom	41.3	10.0	66	3
United States of America	28.9	4.5	61	1

*Note: The detail description of variables presented in the table is included in Section 3. *Data for Ontario only for Availability of benefits for informal carers. Older people refer to people aged 65 and more.*

Source: OECD own analyses based on data sources listed in Annex C.

Table B.4. Data on funding of LTC

Country	Public support for older person with severe needs, median income and no wealth (as a share of LTC cost)	Out-of-pocket expenses of older person with severe needs, median income and no wealth (as a share of median income)	Poverty reduction due to the social protection for LTC (percentage point difference between poverty rate among older people with severe needs with and without social protection)
Austria	87	45	50
Belgium	95	10	90
Canada (Ontario)	97	6	70
Croatia	23	137	0
Czechia	12	482	0
Denmark	99	3	90
Estonia	0	189	10
Finland	100	0	90
France	47	103	0
Germany	76	39	50
Greece	46	49	20
Hungary	85	25	70
Iceland	99	1	90
Ireland	93	18	70

Italy	75	162	0
Japan	90	37	50
Latvia	75	50	0
Lithuania	60	81	0
Luxembourg	97	9	90
Malta	95	5	70
Netherlands	98	12	80
Poland	6	143	0
Portugal	23	84	10
Slovakia	46	55	20
Slovenia	51	102	10
Spain	52	92	0
Sweden	98	11	70
United Kingdom	83	41	0
United States of America	22	81	0

Note: The detail description of variables presented in the table is included in Section 3. Older people refer to people aged 65 and more.

Source: OECD own analyses based on data sources listed in Annex C.

Table B.5. Data on governance of LTC

Country	Unification of health and social components of LTC law	LTC system governance and management centralisation	and management centralisation Public providers of LTC services (% of LTC providers)	Integration of LTC with primary care and hospitals
Austria	Unified	Decentralised	55	Either
Belgium	Fragmented	Decentralised	29	Either
Canada*	Fragmented	Decentralised	46	Either
Croatia	Fragmented	Centralised	1	None

Czechia	Fragmented	Decentralised	65	None
Denmark	Unified	Decentralised	84	Both
Estonia	Fragmented	Decentralised	51	Either
Finland	Unified	Decentralised	50	Both
France	Unified	Decentralised	48	Both
Germany	Unified	Centralised	5	Both
Greece	Fragmented	Centralised	5	Either
Hungary	Fragmented	Decentralised	39	Either
Iceland	Unified	Decentralised	9	None
Ireland	Fragmented	Centralised	20	Either
Italy	Fragmented	Decentralised	14	Either
Japan	Unified	Decentralised	4	Both
Latvia	Fragmented	Decentralised	100	Either
Lithuania	Fragmented	Centralised	43	None
Luxembourg	Unified	Centralised	29	Both
Malta	Fragmented	Centralised	12.5	Both
Netherlands	Fragmented	Centralised	0	Both
Poland	Fragmented	Decentralised	55	None
Portugal	Unified	Decentralised	2	Both
Slovakia	Fragmented	Centralised	56	None
Slovenia	Unified	Centralised	57	Either
Spain	Unified	Decentralised	28	None
Sweden	Unified	Decentralised	81	Both
United Kingdom+	Unified	Centralised+	7	Both
United States of America	Fragmented	Decentralised	6	Both

*Note: The detail description of variables presented in the table is included in Section 3. * Data for Ontario only for Integration of LTC with primary care and hospitals. + The value is decentralised as Scotland, Wales, Northern Ireland and England have different laws and governance systems, but each is centralised in each region.*

Source: OECD own analyses based on data sources listed in Annex C.

Table B.6. Data on quality of LTC

Country	Guidelines for the staff ratio in the institutional LTC	Educational requirements for LTC workers	Mandatory accreditation for institutional and home LTC services	Quality assurance framework in LTC system	Quality outcomes in LTC (average of three quality outcomes)
Austria	Present	High school education or higher	Either	Present	3.0
Belgium	Present	High school education or higher	Both	Present	2.0
Canada*	Not present	High school education or higher	Either	Present	3.0
Croatia	Present	High school education or higher	Both	Present	2.0
Czechia	Not present	High school education or higher	Either	Present	2.0
Denmark	Not present	Other	Both	Present	3.0
Estonia	Present	High school education or higher	Both	Present	2.0
Finland	Present	High school education or higher	Both	Present	2.0
France	Not present	Other	Both	Present	1.5
Germany	Present	Other	Both	Present	2.5
Greece	Present	High school education or higher	Either	Not present	1.5
Hungary	Present	Other	Either	Present	3.0

Iceland	Present	None	Either	Present	1.5
Ireland	Not present	Other	Either	Present	2.3
Italy	Present	Other	Either	Present	1.7
Japan	Present	None	Both	Present	3.0
Latvia	Present	Other	Both	Present	3.0
Lithuania	Present	Other	Both	Present	3.0
Luxembourg	Present	Other	Both	Present	2.3
Malta	Present	Other	Both	Present	1.0
Netherlands	Not present	Other	Both	Present	2.3
Poland	Present	High school education or higher	None	Not present	1.5
Portugal	Present	High school education or higher	None	Not present	1.0
Slovakia	Present	Other	Both	Present	3.0
Slovenia	Present	Other	Both	Present	1.0
Spain	Present	Other	Both	Present	1.0
Sweden	Not present	High school education or higher	Both	Present	3.0
United Kingdom	Not present	None	Both	Present	2.0
United States of America	Present	Other	Either	Present	1.0

*Note: The detail description of variables presented in the table is included in Section 3. *Data for Ontario only for the Mandatory accreditation for institutional and home LTC services.*

Source: OECD own analyses based on data sources listed in Annex C

Table B.7. Quality outcomes data calculation

Countries	Index (1- above average, 2- around the average, 3- below average)			Average/ Result
	Use of benzodiazepines among the older population	Share of older people in LTC institutions with at least one health-care associated infection	Share of older people in LTC institutions with at least one pressure ulcer	
Austria	-	3	-	3.0
Belgium	-	1	3	2.0
Canada	3	-	3	3.0
Croatia	-	2	-	2.0
Czechia	-	1	3	2.0
Denmark	3	-	3	3.0
Estonia	1	3	-	2.0
Finland	3	1	2	2.0
France	-	2	1	1.5
Germany	-	3	2	2.5
Greece	-	1	2	1.5
Hungary	-	3	3	3.0
Iceland	2	1	-	1.5
Ireland	2	2	3	2.3
Italy	3	1	1	1.7
Japan	-	-	3	3.0
Latvia	3	3	-	3.0
Lithuania	-	3	3	3.0
Luxembourg	2	2	3	2.3
Malta	-	1	-	1.0
Netherlands	2	3	2	2.3
Poland	-	2	1	1.5
Portugal	1	1	1	1.0
Slovakia	-	3	3	3.0

Slovenia	1	1	-	1.0
Spain	1	1	1	1.0
Sweden	3	-	3	3.0
United Kingdom	-	1	3	2.0
United States of America	-	-	1	1.0

Note: The detail description of variables presented in the table is included in Section 3. Older people refer to people aged 65 and more.

Source: OECD own analyses based on data sources listed in Annex C.

Annex C. Data sources

Table C.1. Data sources for all indicators under the access dimension

Countries	Sources	Comments
Needs-testing of LTC benefits		
2022: BEL, CAN, CZE, DEU, DNK, ESP, EST, FIN, FRA, GBR, GRC, HRV, HUN, IRL, ISL, ITA, JPN, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVN, SWE, USA. 2021: AUT, SVK	Own calculations based on Is Care Affordable for Older People? (OECD, 2024)	BEL: Data for Flanders only CAN: Data for Ontario only EST: Data for Tallinn only GBR: Data for England only ISL: Data for Reykjavik only ITA: Data for South Tyrol only USA: Data for California only

Means-testing of LTC benefits

2022: BEL, CAN, CZE, DEU, DNK, ESP, EST, FIN, FRA, GBR, GRC, HRV, HUN, IRL, ISL, ITA, JPN, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVN, SWE, USA. 2021: AUT, SVK	Own calculations based on Is Care Affordable for Older People? (OECD, 2024)	BEL: Data for Flanders only CAN: Data for Ontario only EST: Data for Tallinn only GBR: Data for England only ISL: Data for Reykjavik only ITA: Data for South Tyrol only USA: Data for California only
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Coverage of formal LTC benefits

2019: AUT, BEL, CZE, DEU, DNK, ESP, EST, FIN, GRC, HRV, HUN, IRL, ITA, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVK, SVN, SWE.	European Commission: Eurostat (2020) European Health Interview Survey (EHIS wave 3): methodological manual: 2020 edition (re-edition). Publications Office.	
2010-2015: CAN*	Idler et al. (2023)	
2013: FRA	European Commission: Eurostat. (2013) European Health Interview Survey (EHIS wave 2): methodological manual: 2013 edition. Publications Office	
2019: GBR	Banks et al. (2024) English Longitudinal Study of Ageing (ELSA) Wave 9, [data collection]. 40th Edition. UK Data Service. SN: 5 050	GBR: Data for England only
2008: ISL	Sigurdardottir and Kåreholt, (2014)	

2017: JPN	Tokyo Metropolitan Institute of Gerontology, Institute of Gerontology (University of Tokyo) and University of Michigan (2024), Japanese Aging and Health Dynamics Study (JAHEAD), Wave 9, 2017.	
2018: USA	Health and Retirement Study (HRS) (2018) Wave 14, RAND HRS Products public use dataset. Produced and distributed by the University of Michigan with funding from the National Institute on Ageing (grant number NIA U01AG009740). Ann Arbor, MI	

Types of LTC benefits

2024: AUT, BEL, CZE, EST, FIN, GBR, GRC, HUN, IRL, ITA, JPN, LUX, MLT, SWE.	OECD (2024)	BEL: Data for Flanders only ITA: Data for South Tyrol only EST: Data for Tallinn only GBR: Data for England only
2020: CAN, HRV, ISL, LTU, LVA, NLD, SVN	Oliveira Hashiguchi and Llena-Nozal (2020)	CAN: Data for Ontario only ISL: Data for Reykjavik only
2024: DEU, FRA, POL PRT, USA.	OECD long-term care questionnaire	USA: Data for California only

*Note: *This source is focussed on home care, therefore not including residential long-term care. In addition, the data is drawn from a volunteer population participating in a time-consuming longitudinal study (Canadian Longitudinal Study on Aging), and there is likely a strong self-selection bias.*

Table C.2. Data sources for all indicators under the availability dimension

Countries	Sources	Comments
Number of beds in LTC institutions		
2021: AUT, BEL, CAN, CZE, DEU, DNK, ESP, EST, FIN, FRA, GBR, HRV, HUN, IRL, ISL, ITA, JPN, LTU, LUX, LVA, NLD, POL, SVK, SVN, SWE, USA	OECD (2023a)	
2019: GRC	OECD (2021)	
2020: MLT	European Commission, Eurostat (2014 (updated 2022))	
2015: PRT	Lopes, Mateus and Hernández-Quevedo (2018)	
Number of LTC workers		
2021: AUT, CAN, CZE, DEU, DNK, ESP, EST, FIN, HRV, HUN, IRL, JPN, LUX, NLD, SVK, SVN, SWE, USA	OECD (2023)	
2019: BEL, FRA, GRC, ISL, ITA, LTU, LVA, POL 2012: PRT	OECD (2021)	
GBR	Banks, French and McCauley (2023)	GBR: Data for England only
2019: MLT	Eurofound (2020)	

Prevalence of informal care

2021/22: AUT, BEL, CZE, DEU, DNK, ESP, EST, FIN, FRA, GRC, HRV, HUN, ITA, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVK, SVN, SWE	SHARE-ERIC (2024) Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 8. Release version: 9.0.0. SHARE-ERIC. Data set	
2010-2015: CAN*	Idler et al. (2023)	
2019: GBR	Banks et al. (2024) English Longitudinal Study of Ageing (ELSA) Wave 9, [data collection]. 40th Edition. UK Data Service. SN: 5 050	GBR: Data for England only
2003: IRL	McGee et al. (2008)	
2008: ISL	Sigurdardottir and Kåreholt (2014)	
2017: JPN	Tokyo Metropolitan Institute of Gerontology, Institute of Gerontology (University of Tokyo) and University of Michigan (2024), Japanese Aging and Health Dynamics Study (JAHEAD), Wave 9, 2017.	
2018: USA	Health and Retirement Study (HRS) (2018) Wave 14, RAND HRS Products public use dataset. Produced and distributed by the University of Michigan with funding from the National Institute on Aging (grant number NIA U01AG009 740). Ann Arbor, MI.	

Availability of benefits for informal carers		
2020: AUT, BEL, CAN, CZE, DEU, DNK, ESP, EST, FIN, FRA, GBR, GRC, HRV, HUN, IRL, ISL, ITA, JPN, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVK, SVN, SWE, USA	Rocard and Llena-Nozal (2022)	BEL: Data for Flanders only CAN: Data is for Ontario only (some of the benefits are nationwide) GBR: Data for England only ISL: Data for Reykjavik only
2023: MLT, LVA	EuroCarers (2023)	

*Note: *This source is focussed on home care, therefore not including residential long-term care. In addition, the data is drawn from a volunteer population participating in a time-consuming longitudinal study (Canadian Longitudinal Study on Aging), and there is likely a strong self-selection bias.*

Table C.3. Data sources for all indicators under the funding dimension

Countries	Sources	Comments
Public support for older person with severe needs, median income and no wealth		
2022: BEL, CAN, CZE, DEU, DNK, ESP, EST, FIN, FRA, GBR, GRC, HRV, HUN, IRL, ISL, ITA, JPN, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVN, SWE, USA 2021: AUT, SVK	OECD data published in Is Care Affordable for Older People? (OECD, 2024)	BEL: Data for Flanders only CAN: Data for Ontario only EST: Data for Tallinn only GBR: Data for England only ISL: Data for Reykjavik only ITA: Data for South Tyrol only USA: Data for California only

Out-of-pocket expenses of older person with severe needs, median income and no wealth

2022: BEL, CAN, CZE, DEU, DNK, ESP, EST, FIN, FRA, GBR, GRC, HRV, HUN, IRL, ISL, ITA, JPN, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVN, SWE, USA 2021: AUT, SVK	OECD data published in Is Care Affordable for Older People? (OECD, 2024)	BEL: Data for Flanders only CAN: Data for Ontario only EST: Data for Tallinn only GBR: Data for England only ISL: Data for Reykjavik only ITA: Data for South Tyrol only USA: Data for California only
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Poverty reduction due to the social protection for LTC

2022: BEL, CAN, CZE, DEU, DNK, ESP, EST, FIN, FRA, GBR, GRC, HRV, HUN, IRL, ISL, ITA, JPN, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVN, SWE, USA 2021: AUT, SVK	OECD data published in Is Care Affordable for Older People? (OECD, 2024)	BEL: Data for Flanders only CAN: Data for Ontario only EST: Data for Tallinn only GBR: Data for England only ISL: Data for Reykjavik only ITA: Data for South Tyrol only USA: Data for California only
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Table C.4. Data sources for all indicators under the governance dimension

Countries	Sources	Comments
Unification of health and social components of LTC law		
2022: DEU, DNK, EST, FIN, FRA, GBR, LTU, LVA, MLT, NLD, PRT, SVN, SWE	OECD (2022)	GBR: Data for Scotland
2018: AUT, BEL, CZE, GRC, HRV, HUN, ISL, ITA, LUX, POL, SVK	Spasova et al. (2018)	
2023: CAN	Sullivan-Taylor et al (2022)	
2019: ESP	Marban Gallego (2019)	
2024: IRL	OECD long-term care questionnaire	
2020: JPN	Yamada and Arai (2020)	
2015: USA	Kaiser Family Foundation (KFF) (2015)	
LTC system governance and management centralisation		
2022 : AUT, BEL, DNK, ESP, EST, FIN, GBR, LTU, NLD, SWE	OECD (OECD, 2022)	
2024: DEU, FRA, IRL, MLT, PRT	OECD long-term care questionnaire	
2020: CAN	Royal Commission into Aged Care Quality and Safety (2020)	
2018: CZE, SVK	Spasova et al. (2018)	
2022: JPN	Jin et al., (2022)	
2019: POL	European Commission: Directorate-General for Employment, Zigante and King (2019)	
2023: SVN	Health Systems and Policy Monitor (HSPM) (2024)	
2023: USA	Colello and Sorenson (2023)	

Public providers of LTC services (% of LTC providers)		
2022: ISL, PRT, SWE	OECD data collection on ownership of LTC facilities	
2021: CZE, DEU, DNK, ESP, EST, FIN, HRV, HUN, IRL, JPN, LUX, LVA, NLD, SVK, SVN,		
2020: ITA, USA		
2019: FRA		
2022: AUT, BEL, GBR, LTU		
2021: CAN	Canadian Institute for Health Information (2021)	
2024: GRC	OECD data acquired during Greek SG REFORM project	
2020: MLT	Fenech, Vella and Calleja (2020)	
2024: POL	Rejestr Domów Pomocy Społecznej (Urzędy Wojewódzkie, 2025)	POL: data collected from regional offices and aggregated
Integration of LTC with primary care and hospitals		
2020: BEL, CAN, CZE, EST, FIN, FRA, GBR, GRC, HUN, IRL, LTU, LVA, POL, SVN, USA	OECD long-term care COVID-19 questionnaire	CAN: Data for Ontario only
2024: DEU, DNK, JPN, LUX, MLT, NLD, PRT	OECD long-term care questionnaire	
2016: ISL, SWE	Iversen et al. (2016)	ISL: Data for Reykjavik only
2010: AUT	Riedel and Kraus, (2010)	
2019: ESP	European Commission (2019)	
2020: HRV	The World Bank (2020)	

2020: ITA	Notarnicola et al. (2020)	
2010: SVK	Radvanský and Páleník (2010)	

Table C.5. Data sources for all indicators under the quality dimension

Countries	Sources	Comments
Guidelines for the staff ratio in the institutional LTC		
2020: BEL, CAN, CZE, DEU, FIN, GBR, GRC, HUN, IRL, JPN, LTU, LUX, LVA, POL, PRT, SVN, USA	OECD long-term care COVID-19 questionnaire	
2024: DNK, EST, NLD, SVK	OECD long-term care questionnaire	
2019: AUT, MLT	Eurofound (2020)	AUT: Data for Vienna only
2022: ESP	Ministerio de Derechos Sociales y Agenda 2030, (2022)	
2019: FRA	Libault (2019)	
2023: HRV	OECD (2023[78])	
2016: ISL	Sigurdardottir, Kristmundsson and Hrafnisdottir (2016)	ISL: Data For Reykjavik City only
2023: ITA	Brugiavini, Carrino and Pasini (2023)	
2012: SWE	Harrington et al. (2012)	
Educational requirements for LTC workers		
2020: BEL, CAN, CZE, DEU, EST, FIN, FRA, GBR, HUN, IRL, JPN, LUX, LVA, NLD, PRT	OECD long-term care COVID-19 questionnaire	
2024: DNK, GRC, LTU, MLT, SVK, SVN, USA	OECD long-term care questionnaire	

2016: AUT, HRV, SWE	OECD (2020)	
2020: ISL		
2023: ITA		
2022: ESP	Costa-Font et al (2022)	
2014: POL	Golinowska, Sowa and Kocot CASE NETWORK (2014)	
Mandatory accreditation for institutional and home LTC services		
2024: DNK, HRV, LVA, MLT, POL, PRT	OECD long-term care questionnaire	
2013: ISL, DEU, JPN	OECD/European Union (2013)	ISL: Data for city of Reykjavik only
2017: SWE	OECD (2017)	
2019: AUT, BEL, CZE, FIN, GBR, IRL, ITA, LTU, LUX, NLD	Cès and Coster (2019)	
2019: FRA	European Commission: Directorate-General for Employment, Zigante and King (2019)	
2019: CAN	Royal Commission into Aged Care Quality and Safety, (2020)	Data for Ontario only
2023: EST	Kasekamp et al. (2023)	
2024: GRC	Global Observatory of LTC (2024)	
2016: HUN	Gaál et al. (2011)	
2004: SVK	National Council of the Slovak Republic (2004)	
2021: SVN	Republika Slovenija (2021)	
Quality assurance framework in LTC system		
2010: CZE, EST, SVK, SVN	Kraus et al. (2010)	
2012: LTV	Plakane (2012)	

2013: FIN, IRL, ISL, ITA	OECD/European Union (2013)	ISL: Data For city of Reykjavik only
2019: DEU, DNK, JPN, LUX, NLD, SWE, USA	Royal Commission into Aged Care Quality and Safety (2020)	
2019: FRA, POL	European Commission: Directorate-General for Employment, Zigante and King (2019)	
2021: AUT, BEL, HRV, HUN	Comas-Herrera A, (2022)	
2022: ESP	Ministerio de Derechos Sociales y Agenda 2030 (2022)	
2024: MLT, PRT	OECD long-term care questionnaire	
2024: GRC	Karagiannidou (2024)	
2024: CAN	Government of Ontario. (2021), British Columbia Ministry of Health. (2024)	Data for Ontario and British Columbia
2024: GBR	NHS England Digital (2024), Care Quality Commission (2025)	
Quality outcomes in LTC (average of three quality outcomes)		
Use of benzodiazepines among the older population		
2019: CAN, ESP, IRL, ITA, LUX, NLD, SVN, SWE,	OECD (2021)	
2020: DNK, EST, FIN, ISL, LVA, PRT		
Share of older people in LTC institutions with at least one healthcare-associated infection		

2016-17: AUT, BEL, CZE, DEU, ESP, EST, FIN, FRA, GBR, GRC, HRV, HUN, IRL, ISL, ITA, LTU, LUX, LVA, MLT, NLD, POL, PRT, SVK, SVN	European Centre for Disease Prevention and Control (2023)	
Share of older people in LTC institutions with at least one pressure ulcer		
2016-17: BEL, CZE, DEU, DNK, ESP, FIN, FRA, GBR, GRC, HUN, IRL, ITA, LTU, LUX, NLD, POL, PRT, SVK, SWE, USA	OECD (2019)	
2016: JPN	Ishizawa (2023)	

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5. Caring for the Carers. Balancing the rights of Carers and the Cared for Person in Ireland: Implications for Policy and Practice

Dr Sarah Donnelly

For my presentation, I am going to be talking about something a little bit different. It is primarily focused on the topic of what we are calling ‘Carer Harm’. This is very much a poorly understood but also a sensitive topic so I want to acknowledge that from the outset. I also want to acknowledge that many of you here may be a carer, have been a carer, or will be a carer in the future and so I think that this is an issue that is of interest to us all. With my presentation this morning, my intention is not to offend; it is really to try and open up the conversation and heighten awareness about this topic that we really know very little about.

I am primarily going to be reporting on some research that I carried out with Family Carers Ireland in 2023, where we received a small amount of funding from the Irish Research Council. I am also going to be drawing on some ongoing work that I am carrying out with what we are calling, the ‘Five Nations Working Group’, which is a group of academics with expertise in domestic violence, adult safeguarding and family carers from across the five nations of the British Isles. We are really trying to progress our understanding around this issue in order to influence changes to current policy and practice. Everybody is very well versed in the context for caregiving, and while I know that some figures have been disputed, Eurocarers (2024) estimates that 80 per cent of all care across Europe is now provided by unpaid family caregivers. Frazer (2016) would argue that since the 1980s, we have really seen the responsibility for care shift nearly entirely away from formal services and onto family caregivers themselves. Some of the drivers are our ageing population, as well as increasing numbers of children and working-age adults with long-term health conditions. We also know that caregiving is becoming more complex and more time-consuming. Carers are supporting people with more complex conditions and multimorbidity such as dementia. We have to ask ourselves, firstly, is it right or is it safe that we ask our family carers to do so much? Secondly, is it ok that younger people with a disability or older people should be reliant on their family carers for care and support in our current society? The other important thing that my research suggests is that carers are expected to continue to care under almost any

circumstances. Again, we know that we have growing numbers of older carers and also younger carers. We will examine some Irish-specific data later in the presentation.

Research from Care Alliance Ireland estimates that about 14 per cent of our population are providing care, that's just over 600,000 people. That is estimated to save the Irish Government about €20bn a year (Care Alliance Ireland, 2025). The economic impacts are important to note. Our current policy is underpinned by a utilitarian logic that frames family carers as an unpaid economic resource. The Centre For Care in the UK has calculated the value of care for all the UK at approximately £184bn. They estimate that there has been a significant increase since the 2011 data they collected, primarily due to the increase in the number of care hours that family carers are providing (Petrillo et al. 2024). Irish census data would suggest that approximately 29 per cent of our carers here in Ireland are providing care for 43 hours or more per week. Many family carers are providing for one or more relatives (Census, 2022). Petrillo et al. (2024) from the Centre For Care have suggested that if unpaid carers stopped providing care, our health and social care systems would entirely collapse. That claim could also be made in respect of Ireland.

We know there are huge benefits to being a family carer, people find it very rewarding. We also know there can be some negative and adverse outcomes such as being at a higher risk of living in poverty. We also know that our family carers experience significant levels of loneliness which has knock on impacts of that on physical and mental health and wellbeing. 41 per cent of family carers also have long term health conditions themselves. It is estimated that family carers have approximately 38 per cent higher probability of experiencing depression than the average population.

The indirect impact of caregiving are quite well established. In terms of the care needs of someone, if they have more complex needs, if they have long term care needs, if they require intensive caring, these can all be associated with a range of adverse outcomes. O'Dwyer et al. (2024) have done some work in the English context and have found that 42 per cent of parent carers of a disabled or chronically ill child have experienced suicidal thoughts at some stage. We know that carers can struggle to afford some of the essentials, including food. Carers can also experience social isolation' (Carmichael & Ercolani, 2016). There is a well established research base and it is well acknowledged that harmful situations can arise when carers are under extreme stress. They do not have any support from formal services. In these circumstances, sometimes carers can lash out as a result of care burden or care stress (Momtaz et al., 2013). To date, however, there

has been very little recognition of any harm or abuse of the carer. What is direct care harm? This may be a term that many are unfamiliar with and there is not currently an accepted definition. Dr. Louise Isham (2021) has done seminal work around this in the UK. She looked at dementia dyads and has defined carer harm as when carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in some form of physical, psychological and/or sexual harm. My own work would suggest a slightly different definition that we are still struggling with. The major difference between my own empirical work and Isham's is around intentionality. Within our working understanding of this, the behaviour may be caused intentionally or unintentionally by the person with care and support needs. In some situations, there can be instances of bi-directional harm and some of these patterns of harmful behaviour may predate the need for care. For example, in domestic abuse situations, that caregiving role can either exacerbate or bring to light some of these harmful behaviours. Sometimes, there can be certain stages in terms of an illness trajectory. Some of the work I have undertaken has shown that puberty or for people with dementia, when they begin to develop intimate care needs, could often be a trigger for some of these harmful behaviours starting to develop (Donnelly and O'Brien, 2023). We really have very little knowledge or research on the impact of direct harm. Carers to date are rarely conceptualised as victims of harmful behaviour so this is a very new language, it is a very new narrative and it is very sensitive. Part of the difficulty we have is that we have very limited evidence about its nature and prevalence. I am only aware of two studies to date that have specifically looked at this topic. My own interest in this area really developed from some earlier work that Family Carers Ireland did in 2019 in conjunction with the College of Psychiatrists and my colleague Dr. Deirdre O'Donnell in UCD. They surveyed 1,052 family carers in Ireland, 44 per cent of whom reported regularly experiencing either physical aggression or verbal or emotional abuse or harm from the relative they were caring for (Family Carers Ireland, College of Psychiatrists of Ireland and University College Dublin 2019). From my own work which I have to state at the outset was at very small scale and very qualitative and cannot be generalised from. When we did some secondary data analysis of the 2019 study, that showed that there were two main cohorts who were reporting experiencing carer harm. That was parents or carers of children or adults with autism and carers of people living with dementia. It is really important to stress that these parents or family carers for the autism cohort, the people they were caring for did not just have autism, they also had very complex health care needs such as rare genetic conditions or mild to moderate intellectual disabilities. Likewise, with the dementia dyads, they also had other complex health and care needs which very much contributed to these harmful behaviours.

The family carers reported a wide range of harmful behaviours. This included shouting and screaming and damage and destruction of personal possessions or the family home. Also, significant levels of knock on physical violence and the psychological distress caused by that. There is a strong gendered component to this, most of the victims were women. We know that most carers are female and that intimate care tends to be done more by women than men. We also know that some of these carers that are at risk of harm tend to be embedded in dyadic, intimate relationships or are in a very demanding care context. Many are isolated and certainly many of the carers we have spoken to had very little access to support services and help (Donnelly et al. 2025).

So why do we know so little about this? Why is this so taboo? First and foremost, many people do not define themselves as carers and they never will. They see themselves as a mum or dad, a sibling or a cousin. The terminology of family carer or carer does not resonate with everyone. The term then 'carer harm' is not easily recognisable. It isn't often accepted by professionals or carers. The terminology itself is very problematic. We struggled with it throughout the course of the research, in terms of finding a terminology that really captured this phenomena and these behaviours. The other big consideration is that for many family carers this was very much taboo, it was sensitive. They were not comfortable opening up or speaking about this so recruitment was incredibly difficult. Carers that we did speak to felt guilty, embarrassed or really felt like they were being disloyal to their loved one or child who were exhibiting the harmful behaviour. There is a private nature to family life. People are not comfortable speaking out about this. There can be concerns about contravening either familial or cultural norms or disrupting domestic patterns within the home. For many, one of the biggest barriers and fear around disclosure, again, I would argue that these were very real and valid fears, was about either unwanted or unwelcome care or criminal interventions as a result of disclosure (Donnelly and O'Brien, 2023).

In Isham's work, this quote from Mary who cared for her husband with dementia sums up some of the complexity and challenge for family carers in terms of speaking out, *"For me, it's about recognising that a lot of people are suffering as I did. How can you be critical of someone who is ill? It's not the illness but the effect that that it has on you. I think we need a word to describe the effect on the person, on the caregiver, rather than on the service user being an abuser. That is what I would like to try and find. This very binary, overly simplistic language of victim and perpetrator or abuser and abused does not fit this situation"* (Isham et al. 2021).

From our Irish work what was quite powerful and quite striking was the knock on impacts, not only on the family carer but also on younger siblings and other

family members. Lana's quote about her situation speaks very strongly to this. Lana is a carer to her son who has many complex needs and she talked about *"When D was about nine years of age, I was at home on my own. My husband was at work. D came back from school and had a tremendous meltdown. He pulled my hair, even though he usually doesn't do that. But that day he did. He was only eight or nine but he pulled me with such force that he pulled me to the ground and I hit my head and was there for a few seconds. Then my eldest child came home from school. So imagine that D was nine, so my eldest was eleven. Can you imagine what it is like for an eleven year old child to restrain his brother on the sofa to give me a chance to get up? I'll remember this 'til the day I die. My eldest was crying saying, 'Mummy, I don't know how much longer I can restrain him'"* (Donnelly and O'Brien, 2023).

Lana's situation was not an isolated one. Several of the family carers we spoke to talked about the need to develop safety plans within the family home to ensure that all members of the family were safe during these kinds of situations. In Lana's situation, she recognised she had a younger child who was three and Lana felt she could not ensure the safety of all the children in her family home. She reported herself to TUSLA, the Child and Family Agency, really as a cry for help, as a cry for support. The response of the Child and Family Agency was to offer to remove the two children who were not exhibiting the harmful behaviour to foster care with the expectation that Lana would continue to care for her child exhibiting the harmful behaviours with little or no support. Again, this was not an isolated narrative from the family carers we spoke to. It wasn't isolated to the carers themselves. We spoke to many professionals who spoke about the hopelessness and helplessness of their inability to provide support and care, even in what was sometimes life-threatening situations (Donnelly and O'Brien, 2023).

Of equal importance is the very harmful role of the care system and the whole issue of what we might call dangerous care. Colleagues in Scotland have done some very important work around this where they talk about the role played by the welfare policy but also services which can both create and aggravate the stress within care relationships. And also the responses to these (Sherwood Johnson et al. 2023). Across the British Isles, carers very much face an opaque, complex and fragmented health and social care system where it is very unclear who they should turn to ask for help, with little or no recognition of this issue and its impact (Donnelly et al. 2025a). Many of the carers we spoke to in the Irish context spoke about having to fight and beg for help in order to stay safe. Even when they did that, they were made to feel like they were undeserving. Some of the narratives were around, *'Well, there's people worse than you out there'*. Very much, the problem was put back on them to resolve and sort out.

Aligned with that, there was very often unrealistic and unhelpful expectations placed on carers and these were constantly re-enforced by health and social care professionals, with carers just being expected to cope in any situation. Often, the solution offered was around more training or behavioural interventions rather than concrete supports like respite or educational places. There is a whole systems piece to this in terms of, for the autism cohort that we spoke to, very early problems like delays in diagnosis, lack of access to educational places, really had a knock-on impact in terms of the family's ability to cope. What we saw was those who had more social capital, who had access to finance, to education, who could pay for private assessments, were able to get help and support a little bit earlier. What we also saw was for many of our family carers, the supports and services they had pre-Covid were never reinstated to the full extent after the pandemic so they continue to struggle to cope (Donnelly and O'Brien, 2023). There may be a case for arguing that system-related harm is a type of social harm.

In terms of the unrealistic expectations, there is a perception that once you are in receipt of carers allowance, you have signed your life away. *"What exactly does it mean to be a family carer? I think of parents of children with additional needs who are really good at vocalising this – my child needs 24/7 care. Amplifying those voices to say that nobody can provide care 24/7 and it's not that you are paid to work 24 hours a day, 7 days a week"*. Again, these unrealistic expectations from care providers, from services, from disability managers were incredibly unhelpful and exacerbated the harm in many situations. We also had situations of unhelpful responses. Mairead's situation speaks to this very well. Mairead was the carer to her dad who had moderate dementia. And required two (carers) for all activities of daily living and transfers. Mairead talks of an instance where a carer was hurt. This was the paid home care professional. *"There were just two carers in the room at the time, we were obviously not there to see what happened and a carer was injured. And the next day at 4 o'clock in the afternoon, I got a phone call from the manager of older persons' services advising me that all care had been withdrawn with immediate effect for my dad. She advised that there had been a physical assault within the home, that my dad needed a psychiatric assessment and that it wasn't safe for her employees to be coming into the home and that we could also expect a call from the Gardaí"*. Again, in this situation, that harmful behaviour, which was very much an expression of unmet need was then criminalised. For Mairead, the situation was she was left to provide full time care to her dad along with her 80 year old mother. These unhelpful responses really adding to the hurt and injury in these very difficult caregiving relationships (Donnelly and O'Brien, 2023).

There are a number of significant terminological but also conceptual issues. Carer harm very much challenges a number of our dominant narratives that currently

underpin our policy and practice relating to carers and their relatives. Some of this constraining, binary discourse about who can legitimately be regarded as a victim or perpetrator of abuse or harm is problematic (Donnelly et al. 2025a). For example, the Care Act 2014 in England, only identifies the person with care and support needs as possibly being at risk within caregiving relationships. The family carer themselves is never constructed as possibly being at risk of harm. What is quite challenging about this is that it does unsettle our persistent framing of family caring as virtuous and natural and carer relationships as always positive. The big issue is around the organisation and focus of intentionality. It really obscures some of that complexity of caring and can act as a barrier in terms of help seeking. What our study really firmly showed was that most carers are incredibly reluctant to describe the person with care and support needs as abusive, especially if this behaviour is unintentional (Donnelly and O'Brien, 2023). For example, arising from a condition such as dementia. In terms of our Five Nations Working Group, our collective has been trying to analyse the care strategies, adult safeguarding legislation, domestic violence legislation and really looking at that intersection of care and harm across the five nations of the British Isles (Donnelly et al. 2025a). Some of our early findings have concluded that England, Ireland and Northern Ireland have very much a focus on the discourse of duty and familial responsibility. Wales and Scotland have moved somewhat more to a rights-based recognition orientation framing. In everything we have analysed so far, unpaid care remains largely established as a family responsibility, with the most demanding, unequal and emotionally complex aspects largely unacknowledged. Care relationships are presented implicitly as almost entirely positive with carers portrayed as virtuous and heroic. This implicit assumption that everybody is able, willing, and capable of caring is very much inbuilt in everything we have looked at. Whilst interdependency and those direct harms are really not explicitly recognised so we really need to look at our policy and legislative framework going forward. So what might help in terms of policy? Some of our recommendations are around the need for intersecting, enforceable legal rights which would help to ensure that carers and the cared for person or child are better protected and supported (Donnelly et al. 2025; Donnelly et al. 2025a). That statutory entitlement to services for both the carer and the person with care and support needs is paramount. That does exist in the Care Act 2014 in England, we do not have anything like that currently in Ireland. There should also be a legal right for carers to be protected from harm. Paid carers are protected under employment legislation. Our family carers currently are not. There is no meaningful limit on the demands placed on carers, including what they are expected to tolerate in terms of harmful behaviours. We need to consider carer harm as of equal importance to other types of harms such as domestic abuse. So this is a social justice as well as a welfare issue. For our working group, we feel

that family care is currently a privatised risk, where families bear all of the cost and responsibilities for care. We feel there is a need to shift and look at this as more of a social risk.

In terms of the study and the work done with Family Carers Ireland, we were very committed from the outset to not just look and understand more about this issue, but to also develop resources or supports that might better help support family carers and to raise awareness. We ran several co-design World Cafes¹ where we developed awareness-raising leaflets, one on caring for someone with dementia, a generic one on ‘What is carer harm?’, one on caring for a child or adult with autism and additional needs and one on best practice considerations (see Family Carers Ireland website and ‘Carer Harm’ section. There is a Creative Commons licence on all of these outputs. We have seen many local authorities in England and other organisations take these up and adapt them for their own use. We hope this will help people to open up and speak out about these situations. Going forward, we really need to accord family carers and the cared for person or child equal rights to be protected from harm. This is really about the balancing of rights and ensuring that all family members are safe, protected and supported. However, given our projections around the need for increased care, we do anticipate the abuse of unpaid family carers could flourish, where the demand for care is great but also where there are complexities in relation to the needs of the cared for person and a lack of concrete formal supports. In the Irish context, given the lack of legislative underpinning and a statutory right to home care, the right to a legislative fulfilment of disability assessments and a family carers right to a standardised assessment of need is critical. My understanding is that the interRAI² single assessment tool, which Ireland has been piloting for the last 10 years, we are not sure when we are ever going to see that rolled out, but inbuilt in that is an assessment of need for the cared for person and the family caregiver. That is really what we need to advocate for going forward. The concept of interdependence was referenced earlier. Considering and embracing the interdependent nature of everyday living and recognising at every stage, that at some point in our lives, every one of us will require or need care is an important starting point.

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ANNEX

The priorities for care organisations in the years ahead

Clare Duffy

Public attitudes towards care, including views on sectoral priorities and where responsibility for care should lie, have been significantly shaped by the deliberations of the Citizens' Assembly on Gender Equality (2020–2021), the subsequent Oireachtas Committee on Gender Equality (2022), and, most recently, the Government's 2024 care referendum. Together, these mark a major shift in Ireland's understanding of care as a collective societal responsibility rather than solely a private or family duty. A priority for care organisations in the years ahead will be in bringing this broader understanding of care responsibility to life by campaigning for the State to play a greater role in supporting family carers through tangible supports and enforceable rights.

The Citizens' Assembly on Gender Equality (2020–2021) provides a crucial reference point when considering the future priorities of care organisations. Amongst its recommendations was the need to improve terms and conditions for those in professional caring roles; ensure choice and independence for older persons and persons with disabilities; reform Carer's Allowance; provide greater respite options and an individualised pension for family carers. The Assembly's most notable conclusion however was that Article 41.2 of the Constitution be deleted and replaced with language that obliges the State to '*take reasonable measures to support care*'. In 2022, the Oireachtas Joint Committee on Gender Equality ratified the Citizens' Assembly recommendation, advising Government to hold a Referendum to replace Article 41.2 with wording that obliges the State to '*take reasonable measures to support care within and outside the home and Family*.'

When Government finally published its wording for the amendment of Article 41.2 (Article 42B) just three months before the care referendum on March 8th, 2024, there was a notable departure from the Citizens' Assembly and Oireachtas Committee's recommendation with a commitment only to '*strive to support*'

family carers – a term deemed by many as non-justiciable and ultimately lead to the overwhelming defeat of the referendum.

Voters opposition to the wording of the care referendum should not be interpreted as their rejection of care, or a dismissal of its profound importance. Rather, it reflected the Irish people's unwillingness to endorse weak and ambiguous constitutional wording that undermined the recommendations of the Citizen's Assembly and Oireachtas Committee on Gender Equality and risked allowing the State to shirk its responsibility to carers and those they support.

For advocates and organisations, including Family Carers Ireland, who campaigned for a Yes vote, the outcome was a sobering but valuable lesson. While we recognised that the wording of the proposed amendment was imperfect, we believed that having care recognised in the Constitution could be a foundation for future progress - a dimmer switch that could be turned up over time. While our intentions were well meaning, we mis-read family carers and settled for less than they deserve.

Advocates for Yes were chastised for settling for wording that was unlikely to provide carers, people with disabilities or older people with any new enforceable rights or obligations on the State to improve supports. The public expected more than a government that would merely *strive* to support carers. They demanded real change, real ambition. The more modest approach accepted by campaigners for Yes, was not what the public wanted. They wanted care organisations to listen more, demand more and hold government to a higher standard.

To determine the priorities for care organisations in the years ahead, we must reflect on the lessons learned from the referendum. Not least of which is that it is the people who care organisations serve who should decide these priorities. It is them — not us — who should set the agenda.

The priorities for care organisations in the years ahead – from the perspective of family carers.

While most organisations involved in the delivery of care, or in advocacy for carers, will understandably list the operational priorities they will endeavour to achieve in the coming years - a right to home care, sustainable funding, a skilled workforce, robust regulations etc, it is perhaps more appropriate to focus on the aspirations and needs of the people who rely on our supports and what they

expect us to aspire to in the years ahead. Namely, family carers, older people and people with a disability expect care organisations to:

- **Push for bold and ambitious policy reform:** While Constitutional recognition for care is important, so too is immediate, practical change. Carers and the people they care for deserve bold and ambitious policy reform that delivers tangible supports and enforceable rights including the right to an adequate income that reflects the immense contribution of carers, a right to appropriate and regular respite delivered in the way carers and the people they care for want, flexible working arrangements and accessible, quality healthcare. Our policy ambitions must keep pace with the lived reality of care and be based on what carers need, not what we believe Government will concede to.
- **Guarantee access to supports when, where, and how they are needed:** In line with *Sláintecare's* vision of providing *the right care, in the right place, at the right time*, carers and the people they support should not have to accept substandard services or wait indefinitely for essential supports to become available. Services must be accessible when, where, and how they are needed. This requires delivering care as close to home as possible, engaging in proactive planning, and future-proofing services to ensure that support is timely, coordinated, and person-centred.
- **Do nothing about us without us:** Carers and those receiving care want to be actively involved in decisions about the services they rely on. They don't just want care delivered to them; they want to help shape how it is delivered, ensuring that services reflect their needs, preferences, and lived experiences.
- **Unite around a shared vision and champion autonomy and inclusion:** The care sector is diverse, spanning family carers, disability advocates, and older persons' groups. To achieve transformative change, organisations must present a united, coordinated voice that articulates a common goal - a society that truly values and supports care and delivers rights-based services that uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), ensuring that people with disabilities can live independently and participate fully in community life.
- **Champion care worker rights:** Care workers are the backbone of a compassionate and effective care system. Championing their rights is essential to ensuring quality, continuity, and dignity in the delivery of support. This means recognising care work as skilled, valued, and vital

to society; providing fair pay, secure employment, and opportunities for professional development; and ensuring safe, supportive working conditions. When care workers are respected, empowered, and properly supported, the people they care for experience better outcomes and stronger, more person-centred services.

- **Hold government to account:** The referendum result was not a green light for political complacency. It was a mandate for stronger action. Care organisations must insist that care becomes a central pillar of social and economic policy, not an afterthought. True recognition of care requires more than legislation. It requires a cultural shift—where care is seen not as private sacrifice, but as a public good essential to the wellbeing and sustainability of society.
- **Be ‘chameleons of care’:** Care is not stagnant. It is dynamic and constantly evolving to meet the changing needs of individuals and communities. It requires adaptability, innovation, and a willingness to embrace new ideas, approaches, and technologies. By recognising that care is never fixed or one-size-fits-all, organisations and workers can respond proactively, delivering services that are timely, person-centred, and future-ready. Care organisations and their workers must demonstrate the agility and versatility required to navigate the evolving landscape of modern care fostering a culture of innovation, leveraging assistive technologies, collaborating and co-designing services with carers and the people they support and embracing continuous learning and development.

In conclusion

Ireland’s care system faces significant challenges in the years ahead. Our population is ageing - by 2040, 22% will be over 65 - and demand for care services, which is already growing, is expected to accelerate. At the same time, the sector is experiencing unprecedented difficulties in staff recruitment and retention, resulting in long waiting lists and significant unmet need. The Government’s current funding model exacerbates these issues, allocating 1.5 times more to long-term residential care (€1.23bn) than to home support services (€838m).

This persistent imbalance undermines the principle of person-centred care and limits real choice for individuals and families, many of whom would prefer to receive care at home. To achieve the ambitions set out in Sláintecare—particularly the goal of moving care out of hospital settings and closer to home—significantly increased supports for family carers, including financial payments, respite, and home support, will be essential.

The care referendum defeat provided a moment of clarity. The Irish people did not reject care, they demanded better. Meeting that demand will require ambition, unity, and courage from all who champion the cause of carers and the people they support.

When we talk about autism and the needs of autistic people, for so long within our community, at the very core of how autistic people were treated in society, was a stigma. Very often that stigma related straight back to the mother, or parents or to blame. Over last number of decades, where we have seen an increase in public awareness, if not yet understanding or acceptance of autism, we like to think we are moving beyond that. Yet, over the last year to two years in particular, we have seen a real regression in that regard. We have a double edged sword, on the one hand we have seen the return of horrific misinformation around autism, that absolutely stigmatises autistic people, that absolutely creates broader public health concerns in many instances but once again, places blame back on parents and carers for the failures of society to meet the needs of autistic people and to plan to meet those needs as well. The other side of that sword is a real return to gaslighting around the experiences of autistic people. Just last year, I attended a policy consultation where at a roundtable a senior official said with enormous confidence that ‘we have heard that people are just getting diagnoses of autism in order to access domiciliary care allowance for their child’. If that is a belief at a senior officials level, how are we possibly going to move forward when it comes to meeting the needs of autistic people?

Sometimes in this discussion there can be that sense of conflict that we have to talk about the rights of autistic people or the rights of carers. But they are much more intrinsically linked than that because if we place the autistic person or the autistic adult at the centre, really what we are talking about is creating a family life that works for everybody. In taking a rights based approach towards meeting the needs of autistic people, a word that we hear a lot is neuroaffirmative. What does that really mean? People have different definitions as to what that word means but affirm means belief. So often the barriers autistic people face in society and those who provide care for us comes back to that idea of simply not being believed and simply not being validated in the huge barriers people face in every aspect of life.

When we talk about what we mean by care, it is really important on the one hand that we recognise the huge work that carers do and in many instances that the family carer is the only advocate for the autistic person and plays a huge role in meeting need. It is also important to recognise that this is no substitute for the role of the State in terms of enabling autonomy. We see that in terms of the need for greater personal assistance services. We see that in terms of the huge gaps in public services where, for example, the failure to provide therapeutic

supports, the failure to provide adequate school places, essentially creates additional care needs where they do not necessarily need to arise if the State was doing its job. What we are seeing as a result is a mutual failure of rights. What is very concerning and is another example of how we see that is mutual failure is the fact that very often to vindicate the rights of the autistic person in terms of their right to access public services, or indeed to vindicate the rights of the carer, the only recourse families have or feel they have, is to go to media. The lack of dignity that goes with that, the intrusion on the privacy of family life, is so awful and yet very often that is what families and individuals find themselves having to do as a last resort.

Sometimes in the narrative, what can also get lost is we try and neatly segment is, that you are either autistic and a recipient of care or non-autistic and a provider of care. Very often, in our organisation, those we see who face the greatest barriers in society, are those autistic adults who are also caring for someone in their family who is autistic or who has another care need as well. It is important to recognise that isn't just people who have a diagnosis their whole lives. We know that 90 per cent of autistic adults are undiagnosed, who have grown up in a society where there wasn't that understanding of autism. And so often, if the system can be intractable for all, for those who have grown up with those experiences, it can pose even greater barriers. Equally, when we talk about supports and meeting the needs of autistic people in the community, autistic professionals are particularly well placed to inform and provide that care. So I think it is important that in our discussions we don't see these things one dimensionally. All of these failures are also leading to sticking plasters in the system which in and of themselves is an attack on the rights of autistic people. Just two examples of that is over medication of autistic people, often without appropriate supervision, and very concerning, a reality where State agencies and State funded agencies continue to promote behavioural based approaches and so-called interventions which are not rights compliant and very often de-humanise autistic people and autistic experience.

In concluding, some priority issues that AsIAM is working on at the moment is the launch of a new strategy in January, setting out our stall for the next five years, looking at how we can expand and the progress we want to make. Also recognising that at the moment, it very much feels like we are in a defensive position, it's about protecting the progress that has been made when we see very worrying shifts in the narrative. For us, one of the most important issues to address is the huge link between being autistic or having a family member who is autistic and living in poverty. We were very frustrated to see the failure to introduce a cost of disability payment in the Budget. We need to definitely see

the full abolition of the carers means test. We also would like to see a scenario where the domiciliary care allowance both increased and extended to the age of eighteen, to break that link in so many instances between autism and poverty.

The other issue that I think it's worth talking about is the huge power imbalance that exists between those providing care and the system and to just give three examples of that. The issue of school places, where families are asked to go around the country often trying to identify a school place or people are often accepting either an unsuitable school place or unacceptable practices within school on the basis of 'well, where else will I go if I don't take this placement'? An example of how out of touch the system is often with the experience of carers, across the country at present we have children who don't have school places or who are on reduced timetables, or who are being unfairly suspended or expelled because their care needs are not being met. At the same time, the State has invested a large sum of money in the month of September to run a billboard campaign to tell parents that every day out of school is a day that counts for autistic children. Where is the public awareness campaign about your rights around reduced timetables or your rights around inappropriate suspension or expulsion? It's a real disrespect, a slap in the face, and a point we have made directly to the Child and Family Agency. But unfortunately to no avail.

The issue of seclusion and restraint, unfortunately in recent times we have seen very serious cases before the courts around the inappropriate use of restraint in the classroom. We know that when that restraint takes place that very often carers do not have a voice and the strain those scenarios have place on family units has been extraordinary. While that is one example, there is a broader piece around how the system in general responds to complaints and issues of concern from families and the huge power imbalance that exists. We do need to see a dedicated advocacy service to support parents in engaging with the system and supporting carers.

The very final point I would say is there is a need to talk about future proofing. So we know about the existing failures but we are also looking in the face of a huge demographic shift, of a generation of autistic people ageing out of school, of issues around housing, the criminal justice system and older persons care for autistic people. We should not be surprised when these become issues in the next decades. We need to be planning now.

Ireland ratified the UN Convention on the Rights of the Child (UNCRC) in 1992. In 1998, the UN Committee on the Rights of the Child expressed concern that Ireland lacked an independent monitoring mechanism that would be accessible to children and would deal with complaints in relation to violations of children's rights. More than any other country, the urgent need for an Irish office was highlighted by the decade of devastating revelations in relation to the abuse and neglect of children that preceded our establishment. Following huge efforts by Non Governmental Organisations (NGOs) and children's rights advocates, the Government committed to establishing an Ombudsman for Children here and the Ombudsman for Children's Office (OCO) opened its doors in 2004. In 2012, Ireland passed the children's referendum where there was constitutional recognition of children's rights.

While the State has made a commitment to children's rights in principle, which is to be welcomed, in practice there remain significant difficulties that lead to violations of children's rights. This is most clearly demonstrated when we look at the situation of children who rely most heavily on the State in their care and protection.

- **Children in care** – almost 6,000 children are living in State care and over 100,000 child protection referrals were made to Tusla last year. The acute shortage of appropriate care placements; the lack of interagency collaboration; insufficient supports and safeguards for unaccompanied minors; the repeated failures of special care and the placement of vulnerable young people in unregulated settings are just some of the challenges facing a system at crisis point.
- **Children in poverty** – one in five children now experience enforced deprivation, with the number in consistent poverty doubling last year.
- **Children in homelessness** –in 2019, when the OCO published No Place like Home, the number of homeless children was approximately 3,000, the number now exceeds 5,200.
- **Children seeking asylum** – over 9,500 children living in direct provision, often in sub-standard accommodation, and with further risks to children's rights coming down the tracks as Ireland implements the EU Migration Pact. We are also witnessing an increase in anti-immigration sentiment which is not only impacting migrant

children experiencing discrimination but also shaping the views of children who are more exposed to extremism.

- **Children with disabilities** – over 18,000 are overdue their assessment of need, as waiting lists for therapeutic services continue to grow. There still a lack of forward planning for school places and we are falling well short of providing truly inclusive education.

It is clear we still have a long way to go to ensure that the principles that inform children's rights and the rights themselves are embedded in legislative and policy frameworks so that the State meets its obligations under the Convention on the Rights of the Child and delivers for children in Ireland. At a time when we are seeing a backslide on human rights globally, Ireland must resist and put children's rights at the centre of decision making.

Ireland has already committed to the rights in the UNCRC, but this has not been made clear in Irish law. Incorporation is the next step to fully implementing the UNCRC in Ireland. Putting children's rights into law shows that Ireland values children and will place them at the heart of everything the State does. This is why the full and direct incorporation of the UNCRC is the number 1 goal of the OCO's new strategic plan. Ireland would be following Scotland, Sweden, Norway and South Africa who have already incorporated the UNCRC into their domestic legislation.

For legislators and policy makers, it will improve the policy making process as children's rights are baked in from the start, leading to greater savings for the state further down the line. It would mean these rights are not an add on but are fundamental into how we develop and design laws, policies and deliver public services for children.

We are not starting from scratch as the 'Young Ireland, National Policy Framework for Children and Young People', already commits to indirect incorporation of the UNCRC through commitments in relation to child budgeting, child rights capacity building and training and Child Rights Impact Assessments (CRIAs). Full and direct incorporation would mean that these commitments are mainstreamed throughout Government departments.

Incorporation will address the root of gaps in children's rights, prevent or mitigate infringements of rights before they happen by ensuring children's rights are considered upstream, at their source, and lead to a steady flow of positive changes in law, policy and practice.

Introduction

Ireland is at an important moment in shaping how we think about care and disability support. One million people now live with a disability or disabling condition, and around 100,000 rely on specialist supports. This reality requires a modern, fair, and sustainable approach; one that values care, guarantees support, and enables full participation in society. The Government's National Human Rights Strategy for Disabled People 2025– 2030, alongside renewed national discussion on care, creates a real opportunity to move from a system built on dependency to one based on rights and inclusion.

Care and Support: Connected but Not the Same

Care and disability support are too often treated as interchangeable. They are not. My view is that care is personal and relational, usually rooted in family and community. Care is given and received at different points in the life cycle. Support is structural, essential for independence, access, decision-making, and participation. When policy merges these concepts, families are left to fill gaps that should be met through properly designed supports. Disability Federation Ireland (DFI) Bridging the Gap research shows the consequences: reduced independence for disabled people, and pressure, exhaustion, and financial strain for families.

Today's Landscape

Ireland's conversation on care has gained momentum, supported by consistently strong research from Family Carers Ireland and Care Alliance Ireland. Their work highlights the toll on families who provide intensive, often invisible, care. At the same time, Budget 2026 recognised carers but did not sufficiently acknowledge disabled people as citizens with rights and ambitions of their own. This imbalance reflects a wider issue: disabled people's support needs are still not at the centre of policy design.

Families Carry the System - But Should Not Carry It Alone

Families have kept the system going for decades. Their contribution has been extraordinary, but a rights-based model cannot depend on unpaid labour. Families sometimes face stark choices: leaving employment, reducing hours, absorbing costs, and navigating complicated systems alone. A sustainable future

requires shared responsibility across families, communities, providers, the State, and society as a whole.

Priorities for the Years Ahead

1. Adopt a Whole-of-Society Approach to Care and Support

Care and support do not sit within any single department or sector. A whole-of-society approach; spanning Government, community and voluntary organisations, families, employers, and local communities is essential. Shared understanding and shared accountability must underpin this framework.

2. Invest in Independent Living Supports

Personal assistance, community-based housing, supported decision-making, and social inclusion supports are fundamental. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) sets out the right to live independently; our policies must deliver it. Stronger supports ease pressure on families and give people real choice over how they live.

3. Build Collaboration Across the System

Collaboration must be a defining feature of the next phase of reform. This means joint planning between disability, care, health, housing, and community services; shared learning across organisations; coordinated approaches at local level; and transparent communication between the State, providers, disabled people, and families.

4. Support and Value the Workforce: Paid and Unpaid

Ireland needs secure pay and conditions for care and support workers, and fair recognition for family carers. We must also remove barriers preventing disabled people from employment within the sector.

5. Co-Design Policy with Disabled People and Carers

Real change requires co-production, not consultation. Disabled people and carers must have a direct role in shaping, monitoring, and evaluating policies and services.

Conclusion

Ireland now has an opportunity to build a system where care is valued, support is guaranteed, and inclusion is the foundation. With a whole-of-society effort

and stronger collaboration across all sectors, Ireland can create a future defined by rights, participation, and genuine equality.

The notion of care has often been undervalued and inadequately addressed within policy frameworks. Yet, the receiving and giving of care is woven through the life cycle, in early years, later years and for some, throughout all stages of their lives. It is essential to human dignity and well-being. Carers, whether paid or unpaid, in all capacities, are the lynchpin of this fundamental pillar of the Common Good, and contribute significantly to society each year. As we navigate through an era marked by profound demographic shifts, economic transformations, and evolving social dynamics, the imperative to prioritise care within our societies becomes increasingly evident.

Fundamentally, care is a value-laden practice that covers a broad spectrum of actions, responsibilities, and attitudes that foster the well-being and development of individuals, communities, and environments. Examining care from the perspective of social justice and equity and attempting to cover a broad spectrum of issues and adopt an inclusive approach to care, we discuss:

- The demographic shifts likely to impact on future needs for care.
- The intersection of care and poverty.
- Care structures, both formal and informal in Ireland.
- The rights of carers and those cared for.
- What policies Ireland needs to implement now to meet the challenges that lie ahead.

The chapters in this book were presented at a 2025 social policy conference on the topic of 'Care in a Changing World' organised by *Social Justice Ireland*.



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