11 *Conclusion*

Towards universal, high-quality long-term care: changing the narrative

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11.1 Growing momentum for long-term care on the global development and social policy agenda

The 2020s have seen growing recognition of the need to invest in long-term care systems, with considerable momentum for long-term care reforms building at both global and regional level. The United Nations Decade of Healthy Ageing (adopted in December 2020) identifies investment in long-term care as one of four global priority action areas, unequivocally stating that 'every country should have a system to meet the needs of older people for long-term care' (WHO, 2020: 19). The launch of the European Care Strategy in September 2022 and the ensuing adoption by the European Council of a recommendation on long-term care in December 2022 (European Council, 2023) represent, to date, the most ambitious and comprehensive set of regional initiatives and policy commitments to ensure all those who need and who provide care are protected, supported and facilitated to use quality, affordable and accessible care services. In the same year, the adoption of the Buenos Aires Commitment[1] at the Regional Conference on Women in Latin America and the Caribbean charted a path towards a care society, placing gender equality and sustainability at the core of a transformative recovery plan. Most recently, the UN Department of Economic and Social Affairs dedicated the 2023 World Economic Report to drawing attention to inequality, intergenerational equity and the global crisis of care, concluding that 'effective systems of old-age support will continue to be needed, as will the intergenerational solidarity required to sustain them' (UNDESA, 2023:iv).

[1] Further details available here: https://conferenciamujer.cepal.org/15/en/documents/buenos-aires-commitment

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Spurred by the disproportionate effect of the Covid-19 pandemic on older people and its devastating consequences in long-term care settings and facilities, long-term care has climbed higher than ever before on the policy agenda of countries at all stages of economic development. Severe disruptions to rehabilitative, palliative and long-term care were documented early in the pandemic at global level and persisted throughout the global health emergency phase (WHO, 2023a), adding strain to already pressured long-term care delivery structures. As is extensively documented throughout this volume, the need for transformative reforms in long-term care systems has long predated the pandemic, and the many cracks in care systems which made them vulnerable to the shock of the pandemic have themselves grown to crisis proportions. The rapidly growing demand for care (chapter 2), the accelerated erosion of informal care resources (chapter 8) and persistent shortages of adequately qualified care workers (chapter 4), anachronistic financing mechanisms and limited financial protection (chapters 5 and 8), pervasive fragmentation and unwieldy governance (chapter 4), and poor quality management (chapter 6) have all contributed to a growing prevalence of unmet care needs and have exacerbated equity concerns.

Even as the evidence has steadily grown that long-term care systems, in their traditional structures and underpinnings, are not fit for purpose and that care models will need to be transformed, policy responses have, by and large, not risen to the exigency of the challenges ahead. What is holding back more decisive and more impactful policy responses? And more importantly, what can be done to overcome the policy inertia?

The knowledge base summarised in this volume points to a combination of systemic, societal and economic factors which hinder ambitious long-term care reforms – but equally, it offers a series of evidence-based recommendations for addressing each of these factors and guiding meaningful investment in long-term care delivery. More pernicious still are the lack of clarity of purpose, a public and policy discourse which have overwhelmingly focused on problems rather than on solutions, and a plethora of myths and misconceptions about long-term care systems that must be decisively challenged. In closing this volume, we discuss each in turn, restating in short the case for investment and offering a pathway for the transformation of long-term care systems.

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11.2 Changing the narrative on long-term care

A right to care

The UN Decade of Healthy Ageing (2020), the Buenos Aires Commitment (2022), the European Care Strategy (2022) and numerous other international, national and regional commitments and frameworks for action propose a rights-based approach to long-term care service and system development. Explicitly recognised as a social right in the European Pillar of Social Rights (Principle 18), a right to care is also a corollary of the rights to health, dignity and non-discrimination (European Commission, 2017).

When interpreted as an individual right, long-term care must be recognised not only as an essential pillar of social protection systems, but also as an integral part of the universal health coverage agenda. To aid governments and policy makers responsible for planning and implementing long-term care service provision at the national or subnational level, WHO has developed the 'Package of long-term care interventions for universal health coverage' (WHO, forthcoming). This provides a list of basic long-term care interventions that are essential for all countries to consider, prioritise and provide, in line with their commitments to establish and expand formal long-term care systems. The core interventions are grouped under four categories: preventive and promotive care; rehabilitative and assistive care; palliative and end-of-life care; and caregiver support services. Two key facilitating factors are also identified as essential to high-quality care delivery: person-centred and integrated care processes, and a fit-for-purpose care workforce with the knowledge, skills and competencies to provide safe and quality interventions.

To deliver on this vision of care, the public and policy discourse must evolve from an exclusive grounding in social solidarity and welfare policy measures towards an explicit recognition of the rights of people to care for others, to be cared for and to exercise self-care. At the same time, there is a need to move away from fatalistic attitudes and short-termism. The challenges facing policy makers who wish to transform long-term care systems are daunting, but this should not constitute an argument for delaying meaningful change.

A more positive and constructive policy debate can start by confronting head-on and moving past commonly held but false beliefs about the

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scope for policy intervention in long-term care systems. Based on the evidence presented throughout this volume, five myths of long-term care can be dispelled and replaced with more constructive and evidence-based narratives.

As the population ages, will long-term care costs bankrupt welfare systems?

The myth: Population ageing is frequently described in negative and alarming tones, which focus almost exclusively on the potential downsides and challenges: the grey or silver tsunami, the exploding dependency ratio, the ageing time bomb, the demographic crisis, the burden of ageing, and others. This reflects the commonly held belief that as the population ages, and the proportion of older individuals grows with respect to the working age population, it becomes impossible for public welfare programs to keep up with the exponential increase in costs at the same time as its revenue-generating power diminishes.

***The evidence*:** Indeed, the process of population ageing has long been under way and will continue to deepen (UNDESA, 2019). What is more, we are observing a progressive ageing of the older population itself, as life expectancy continues to increase (the fastest growing age group globally is the oldest old – i.e. 80 years of age or older). It is also true that with increasing age, care needs become more prevalent. We can, therefore, expect a higher share of GDP will need to be allocated for the funding of health and long-term care systems in the future, in addition to other programmes that largely benefit older people (please refer to chapter 2 for a detailed analysis). But the best evidence we have available does not support the conclusion that ageing populations will lead to a rapid and overwhelming increase in health and long-term care costs. Compared to technological innovation and price growth, the effect of population ageing as a cost driver for health expenditure is both modest and gradual (Cylus et al., 2019). Where long-term care services are concerned, a considerable relative increase in spending seems unavoidable but coming from a very low current base, this will not amount to an unsustainable cost pressure. What is more, available projections are highly sensitive to the underlying assumptions. In the EU member states, the demographic effect alone can be expected to lead to a 74 per cent increase in long-term care expenditure (as a percentage of GDP) by 2070, while expenditure

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would more than triple (204 per cent increase) if expenditure patterns and coverage levels were to converge across the EU member states. However, in a scenario where people grow older in better health, so that half of the years of life gained to the horizon of 2070 are spent in good health, the projected expenditure increase can be contained to 64 per cent over current investment (European Commission, 2021).

Taken together, this evidence does not suggest that there is little to no scope for policy interventions in the face of inevitable welfare system collapse, but rather the opposite. Both total expenditure on long-term care and care outcomes in the future will overwhelmingly depend on how quickly policy makers react and how they decide to invest the resources available. The long-term care landscape of the future will be determined by the policy choices made today on volume and coverage of care services, investment in cost-effective technological and social innovation, integration of health and long-term care, and diversifying service provision to facilitate prevention, early intervention and better choices at the end of life[2]. Opportunities to reduce the risks of needing care throughout the life course through primary, secondary and tertiary prevention are well documented (Bennett et al., 2022; Fors et al., 2022; WHO, 2021; Ilinca & Suzuki, 2021) but they require coordinated interventions across health, long-term care, education, housing and social protection systems and must be grounded in a commitment to equity. Similarly, the potential of innovative care models and the increased use of technology hold the promise of cost containment without sacrificing the quality or quantity of care, if appropriate investments and incentives are put in place (chapter 4).

***Changing the narrative*:** Delaying both meaningful reforms and the reorganisation of care models in line with demographic, social and technological trends is placing the sustainability of welfare systems at risk and reducing wellbeing at societal level. The longer countries delay, the greater the challenges will eventually be.

[2] The interested reader is referred to the Economics of Healthy and Active Ageing series, published by the European Observatory on Health Systems and Policies for a structured overview of the evidence available and the policy options that can be derived from it. Available at: https://eurohealthobservatory.who.int/themes/observatory-programmes/health-and-economy/economics-of-ageing

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Is long-term care a sunk cost which limits economic growth?

***The myth*:** Expenditure on long-term care is often described as a sunk cost (i.e. it does not contribute to productive activity and capital accumulation), which diverts considerable resources from more productive sectors of economic activity and limits potential for growth and development. The more long-term care needs increase, the larger the distortionary effect on labour markets. Care is time and labour intensive, and the more people need care the greater the number of caregivers who need to reduce their work hours or leave the labour market altogether. This leads to loss of productive capacity and economic output.

***The evidence*:** The conclusion of this type of argumentation is indeed worrisome, but it does not necessarily follow from the stated premises. Rather, the evidence available points to key levers of intervention that are not considered at all in this over-simplified approach. As discussed at length in chapter 10, an over-reliance on informal caregiving can and does lead to losses in productivity, keeping considerable numbers of caregivers (mostly women) outside the labour market. But this can be addressed through interventions that promote reconciliation of work and caregiving obligations and through investment in formal long-term care delivery, by workers whose skills are better matched to care tasks, who are adequately trained and who provide care in contexts and settings which allow for much higher levels of productivity. Similarly, while labour intensive, there are no a priori reasons why a formal long-term care sector cannot prove to be innovative, productive, gender transformative and cost-effective. In fact, if pervasive issues linked to poor working conditions, low remuneration, work instability and lack of access to training (Eurofound, 2020; The Social Employers, 2022) are appropriately addressed, there is every reason to assume rapid growth in the sector.

***Changing the narrative*:** Investments in the long-term care workforce, innovation, working conditions and competitiveness in the care sector have the potential to trigger flourishing care economies.

Will investment in long-term care crowd out resources for health?

***The myth*:** Due to their overlaps and complementary nature, health and long-term care systems are frequently presented as competing for the

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same pool of resources, including financial, human and technological capital. This concern is more pressing in situations where budget constraints or competing priorities arise within health and long-term care systems. If resources are diverted towards expanding long-term care infrastructure and services there will be a corresponding reduction in available resources for investment in improving health care facilities, personnel and equipment.

The evidence: Such argumentation completely ignores that health and long-term care systems are not only complementary but inter-dependent in their functioning and outcomes. Chapter 7 surveys the evidence available on the ways in which strong long-term care systems benefit, rather than weaken, health care systems through reducing demand for more intensive and more costly health services. While not always consistent in its results due to high variability in the quality and availability of data, the weight of available evidence favours the case for investment in better quality and more responsive long-term care services. When imbalances between health and long-term care capacity are pronounced, inefficiencies or even gridlocks in health care can arise – unable to discharge the bed-blockers[3] who cannot be directed towards more appropriate care settings due to capacity gaps, hospitals are unable to admit patients who could benefit more from the specialised services they offer. The case of England is telling but by no means singular. The Care Quality Commission's 2022 annual assessment of health and social care delivery found more than half of all hospital discharges had to be delayed due to insufficient capacity in social service and community-based care structures, contributing to record increases in emergency department waiting times and health care delays that put patients at significant risk (Care Quality Commission, 2022).

To ensure that resources are allocated efficiently and effectively governments must build capacity for integrated planning approaches that consider both long-term care and health care needs, service delivery and system organisation. Preventing and compensating for

[3] The term 'bed blocker' is used in the health care literature to describe a patient who, due to various reasons, has a delayed hospital discharge, leading to an inefficiency in hospital bed utilisation. The term has come to carry a negative connotation, but in no way implies blame on the hospitalised individual for their prolonged stay. Rather, it is used as shorthand for suggesting an ineffective management of care resources.

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permanent or transient losses of intrinsic capacity are key to maintaining functional ability over time and rely on a series of actions and services across health and long-term care systems (WHO, 2021), which can only be achieved through access to a continuum of care services. Prioritisation and efficiency considerations in such an integrated planning approach must consider care outcomes beyond short-term indicators of efficiency and focus on maximising quality of life, wellbeing and broad societal impact of available resources.

***Changing the narrative*:** Integrated planning and investment in health and long-term care systems will improve system performance and lead to better health and care outcomes at individual and population level.

Does investment in long-term care benefit only older people in receipt of care services? And does it increase intergenerational inequality?

***The myth*:** Considering the limited fiscal space most countries are facing, it has been argued that public spending on long-term care services crowds out investments in infrastructure, in education, in innovation and in economic sectors that contribute more directly to economic development. Such decisions have considerable implications for intergenerational equity, if a disproportionate share of public resources can be seen as benefitting older generations to the detriment of younger age groups.

***The evidence*:** First and foremost, it is misleading to conclude investment in health and long-term care, if used primarily by older population groups, is less of an investment in productive human capital. Older people, when healthy and adequately supported, contribute in myriad ways to our societies, both within and outside labour markets (Greer et al., 2022). These voluntary, informal and formal contributions accrue at societal level, benefit all age groups and enhance both social cohesion and economic development.

Regarding the balance of intergenerational justice in public welfare spending, the evidence at hand points to increases in public spending for older population groups as demographic ageing progresses. However, there remains significant scope of action for policy interventions and shaping public welfare spending despite demographic trends. While most OECD countries spend more on social programmes that benefit

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older age groups (primarily pensions, but also disability benefits and long-term care) than on programmes that benefit primarily younger population groups (e.g., education, active labour market policies, unemployment benefits) this is not strongly correlated with the ageing of their population nor is it a uniform and unquestionable pattern (Vanhuysse, 2013). It suffices to look at examples of countries with similar demographic patterns who have adopted very different policy choices, to conclude that political will and governance cultures determine the shape of welfare policies to a much larger extent than demographics (OECD, 2020).

Nor is it clear that by *not* investing in long-term care systems, governments will be more likely to use whatever resources would be saved in order to address intra and intergenerational equity issues. On the contrary, analyses of the impact on families of underdeveloped social protection schemes for long-term care and the over-reliance on informal care resources (chapter 8) show the detrimental effects on labour supply, income and risk of poverty for caregivers. More worrisome still, it is particularly individuals from lower socioeconomic groups who are likely to be informal caregivers in the first place and see their opportunities for social mobility limited as a result. Large OOP payments for long-term care, even in countries with well-developed care systems, place many families (but especially those in disadvantaged financial situations) at considerable risk of catastrophic payments and of falling into poverty due to care needs. Therefore, the lack of public investment in long-term care systems is more likely to deepen inequalities across the life course (Ilinca et al., 2017) and to act as a vehicle for the intergenerational transmission of inequalities (for example, through the erosion of family assets and the obligation for children to cover costs of care for their ageing parents), which is detrimental to society (chapter 9).

***Changing the narrative*:** Greater consideration of the poverty-exacerbating effects of long-term care for households, particularly those on the lowest incomes, in the design of long-term care systems would improve equity in access and reduce both intra and intergenerational inequalities

Why should the state intervene in long-term care? Wouldn't private markets organise care more efficiently?

The myth: The state's responsibility for long-term care has historically been and continues to be primarily to provide a minimum safety net.

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The state should provide basic care for individuals of limited means and with no access to informal care resources, who would otherwise have to go without needed care. Likewise, market mechanisms can ensure care services are produced and provided in an open, competitive market, leading to greater efficiency, innovation and flexibility to respond to diverse user needs. There are numerous experiences with inefficient and costly direct provision of care by public authorities, burdensome bureaucracy and inability to contain costs, while facing difficulties in mobilising sufficient resources for innovation and investment.

***The evidence*:** The debate on whether older people with long-term care needs are better served if governments play a greater role in providing vs contracting care services is complex (Rodrigues et al., 2014). In practice, recent decades have seen an increase in reliance on market mechanisms for the delivery of long-term care services, including in countries where a traditionally strong public sector has increasingly transformed from a provider to a purchaser and contractor of long-term care. As a result, the weight of the policy debate has shifted towards how contracting and public procurement mechanisms can be strategically used to achieve specific policy goals alongside an efficient and transparent allocation of resources.

But while the role of the state in the direct provision of long-term care can be considered as limited and declining, the same argument cannot be made for its role in regulating private provision and financing long-term care (Costa-Font & Raut, 2022). A purely private unregulated market for care would be unaffordable to most, unavailable to many and often of poor quality. The case for the need to develop public financing for long-term care is built in detail in chapter 5, highlighting how the affordability of care can only be ensured through social protection systems that pool resources across the population. Experiments with private health insurance have proven that well-documented market failures (extensively studied also in the case of health insurance) and rapidly rising costs cannot be avoided without significant regulation (if not compulsion) and considerable subsidies. As there clearly is a role for the state in financing long-term care, the more appropriate question is the extent of the coverage a state should provide and how it can best set eligibility for publicly funded programs. The evidence accumulated in countries with well-established long-term care systems strongly suggests that broader coverage and higher access to care lead to better

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health outcomes and higher wellbeing, and offer opportunities for addressing socioeconomic inequalities in health and access to care (chapter 3).

Further issues of equity in access are also exacerbated by over-reliance on private provision, with limited oversight and regulation. As private providers seek more affluent markets, the geographical distribution of private (especially for-profit) care services in Europe is biased towards urban areas, while rural communities remain severely underserved (Government of Biscay & Age Platform Europe, 2022). The role of public regulation and incentives for quality development in long-term care provision is surveyed in chapter 4, with growing evidence for the role of system-level strategies (e.g., public reporting of quality information, pay-for-performance schemes) and of interventions to diversify care provision and improve the competencies of the care workforce, contributing to higher quality and choice. Promoting quality in long-term care involves a complex set of tasks for regulators (including, but not limited to, legislation development, accreditation and quality assurance mechanisms, needs assessment and social planning, development of monitoring and enforcement frameworks, reporting). Their consistent application over a territory is impractical, if not impossible, to replicate through self-organisation of providers.

Finally, in democratic societies, the question of the involvement of the state in long-term care, as in any aspect of social life, should reflect the preferences of the population it represents. While the evidence on user preferences on long-term care policies and planning remains limited at best, available data from Europe (collected in 2007 and 2021) confirm strong support for increasing the role of the state in the financing and organisation of long-term care, while support for placing financial responsibility for care with the family is declining (Ilinca & Simmons, 2022). A large majority of surveyed individuals, across age categories, believe public long-term care programmes should cover all care costs or a standard package of care services, indicating the societal value of long-term care is well recognised within and across generations.

***Changing the narrative*:** There is a significant role for the state in the financing, regulation, contracting and monitoring of long-term care services, regardless of whether services are provided in competitive (quasi)-markets by public and/or private providers.

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11.3 Conclusion: The value of care and the cost of inaction

Care and caregiving are a universally shared human experience, with profound rooting in and consequences for families, communities and societies. In the broadest sense, care is needed and is provided by every person at least at some point during their life course and therefore affects everyone's wellbeing, participation and opportunities to flourish. More intensive and sustained care spells, associated with declines in intrinsic capacity and functional ability which are the object of this volume, are less frequent and tend to concentrate towards the later stages of life. They are nonetheless common: two out of every three older people are likely to need care and support at some point during their lives. For those who need it, access to appropriate long-term care is essential to maintain quality of life, dignity and social participation, in line with their human rights (WHO, 2022). Whether provided formally or informally, care is a productive activity and an essential contributor and facilitator of human flourishing, economic growth and development.

Viewed through the lens of societal value and by documenting its numerous contributions, the present volume amounts to a case for investment in equitable, affordable and high-quality long-term care. While data gaps limit precision and preclude detailed analyses in large parts of the world (primarily in the Majority World) the evidence at our disposal is sufficient to inform clear policy directions and to sound an alarm over the considerable costs of inaction and delay.

The failure to invest in the development of social protection for long-term care will place increasing numbers of older people and their families at risk of impoverishment and deepening socioeconomic inequalities, limiting potential for economic growth and increasing pressure on social safety nets. Investment in transformative care policies is estimated to lead to net benefits outweighing the costs of implementation for countries at all stages of economic development, and delaying such investments comes with significant opportunity costs (De Henau, 2022).

By imposing stringent eligibility rules for public long-term care services governments may contain expenditure in the short term, but not without wider costs. Restricting access to long-term care will mean that countries fail to take advantage of opportunities to prevent, stabilise and delay functional decline. This short-sighted approach leads to

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higher care needs and correspondingly higher expenditure over the medium and long term. Far from freeing up resources for investment in health care and other economic sectors, weak care systems contribute to the accelerated erosion of human capital, depriving communities not only of the valuable contributions of older population groups but also limiting the social and economic potential of their caregivers.

The systematic undervaluing of care and care work, which effectively means millions of formal and informal caregivers subsidise health and long-term care systems through their underpaid or unpaid work, may keep public sector budgetary allocations for human resources in care artificially low. But their direct and indirect costs to economies and societies are incalculable. At the same time, the continued tolerance of gendered roles in care and the undervaluing of women's work is poised to impede any meaningful progress on gender equity and equal opportunities for women and girls (ILO, 2018).

The reluctance to invest in ensuring decent working conditions and decent pay in the care sector places many millions of care workers at risk of poverty and can be directly linked to unsustainable shortages of personnel. This in turn can be linked with important spillover effects for local economies, which can benefit from stability in a sector with considerable growth potential.

All in all, investment in care systems is an economic and social imperative and a precondition for transforming economies to deliver on the outcomes that most matter: wellbeing, quality of life and health for all. Rather than single-mindedly pursuing growth and expecting wellbeing to follow as a necessary by-product, economic systems and cross-sectoral policies must transform and adapt to place wellbeing (at individual, societal and ecological level) at the core of economic activity (WHO, 2023b; WHO, 2023c). This will require a change in mindset among policy makers, and we hope that this volume helps contribute to that shift.

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