Learning from Long-Term Care practices for the European Care Strategy

The meanings of inequalities in long-term care in Portugal

National report

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List of Acronyms

ADLs	Activities of Daily Living
CACI	Occupational Centre for Persons with Disabilities
CNIS	Confederation of IPSS
ECCID	Home-based Teams of Continuous Care
EGA	Hospital Discharge Teams
ERPI	Residential Care Facilities for Older Persons
IADLs	Instrumental Activities of Daily Living
IPSS	Private Institution of Social Solidarity
INE	National Statistics Office
LTC	Long-Term Care
RAI	Autonomous Residences for Persons with Disabilities
RNCCI	National Network of Continuous Integrated Care
RRP	Recovery and Resilience Plan
SAD	Homecare for Older Persons
SCM	Holy House of Mercy
SNS	National Health Service
UC	Convalescence Unit
ULDM	Long Duration and Maintenance Unit
UMDR	Medium Duration and Rehabilitation Unit

Executive summary

The expression “Long-Term Care” (LTC) is still today an expression that has no straightforward translation into Portuguese apart from the strict language translation – *Cuidados de Longa Duração*. Traditionally LTC in Portugal has developed from social assistance and therefore the concept in use more commonly is “social care”. But even this, that would translate as ‘*Cuidados sociais*’, is used mostly in the scientific literature. In legal and policy documents the term in use is ‘*Respostas Sociais*’, that translates as Social Responses. In 2006, it was created a new system, the National Network of Integrated Continuous Care (*RNCCI – Rede Nacional de Cuidados Continuados Integrados*), bringing together the Ministry of Health and the Ministry of Labour, Solidarity and Social Security, to create a new type of service under the National Health System (*SNS – Serviço Nacional de Saúde*) that would focus on securing continuous, long-duration and focused on rehabilitation and reablement care, as well as on palliative care.

Care is primarily understood as the other side of the coin against needs. The two notions end up being rather circular as they imply each other. In that sense, understandings of care are tied to how the system is organised in terms of programmes and services that provide care.

Despite the references to the term quality to discuss care services, interviewed stakeholders struggle with offering a clearly outlined definition of what quality of care means. Even if probed to be more explicit about the meaning of quality of care, it was not possible to get such a definition. Explanations remain fuzzy and at a very abstract level.

In Portugal, the data and regulatory infrastructures related to LTC provisions reflect the system fragmentation that separates social care from the RNCCI. Regarding the most pressing problems in provision of care, views collected in interviews and the literature offer a high level of consensus around some main ideas: low coverage rates and long waiting lists signal a need for fast expansion of the system; underfunding of the care system is preventing good quality of care; shortages of workers and of qualifications have a strong impact in quantity and quality of care.

The system draws on a one-size-fits-all approach, with national regulations applying to the entire country in the same manner. This includes issues of funding, types of services and regulations on licensing and operations.

The ongoing political debate is vague, mostly reacting to the occasional news in the media but showing no signals of any systematic holistic discussion taking place soon about LTC. Negotiations between the state and care providers is almost exclusively focused on funding issues.

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Introduction

This report is part of the European research project **LeTs-Care: Learning from Long-Term Care practices for the European care strategy**, a collaborative research project that engages and supports policy makers and other stakeholders in addressing the challenges posed by long-term care (LTC) across the European Union countries.

LeTs-Care brings together a consortium of seven European academic institutions, a unique European Network of Cities and Regions, and several social economy organisations operating in Austria, Denmark, Italy, Lithuania, the Netherlands, Portugal, and Spain. The project is coordinated by Ca' Foscari University of Venice, and in Portugal the research is conducted by University of Porto. The project started in April 2024 and will run until December 2027. It is funded by the European Union under Horizon Europe as stipulated in Contract 10113270.

Long-term care (LTC) systems across EU countries are facing important challenges and are trying to strike a balance between ensuring affordable, accessible and good quality care; high quality of work in the care sector and financial sustainability. According to the European Union's "care strategy", we should invest in practices that promote integrated and person-centred care to address these challenges.

However, to date, there is little systematic knowledge of the specific LTC challenges and of the meanings of, for instance, quality of care and quality of work in care across national and local contexts. In addition, we know that "good practices" are difficult to transfer or to extend because their outcomes are highly dependent on the context.

Furthermore, while "good practices" in care provision are frequently promoted across Europe, experience shows that their transferability is limited. What works effectively in one context may not yield the same results elsewhere, because outcomes are strongly shaped by local governance models, policy environments, available resources, and community networks. This complexity calls for a comparative, context-sensitive approach to the study of LTC systems — an approach that LeTs-Care aims to provide.

LeTs Care has three aims:

1. To provide a new, in-depth, reflexive understanding of LTC challenges across national and local contexts, for and with stakeholders and policy makers.
2. To understand how "integrative" and "innovative" practices work in context and to highlight the possibilities and limitations to their transfer.
3. To develop a new model for policy learning with and for stakeholders.

To achieve the first aim, the LeTs-Care team set out to understand the meanings of five structuring concepts within long-term care systems: *needs; care and quality of care; work and quality of work; sustainability;* and *inequalities*. Methodologically, LeTs-Care adopted a mixed-methods approach, combining the analysis of secondary data (including a review of national literature, both academic and grey literature, as well as policy documents) with the collection and analysis of primary data obtained through interviews with *stakeholders* and *policy makers* at national and subnational levels.

For each of the five key concepts, every national research team produced a dedicated report focusing on a contextualised understanding of its meaning within the respective long-term care system. The present document is one of these reports, forming part of the series of five national reports developed by the Portuguese research team within the framework of LeTs-Care. Specifically, this report focuses on the concept of long-term care needs in Portugal, examining how it is understood, articulated, and addressed within the national policy and care landscape. Equivalent

reports were produced by all research teams in the other participating countries. Building on the insights generated through these national analyses, the research consortium developed a comparative report that examines the five key concepts across the different national contexts, identifying convergences, contrasts, and shared challenges within European long-term care systems.

1. Definitions and History

One could say there is some dissonance between the empirical evidence available and the perceived relevance of inequalities in Long-Term Care (LTC) in Portugal. Although empirical evidence is not collected for the specific purpose of measuring inequalities, it can easily be extrapolated from available data that the Portuguese LTC system is marked by several types of inequality. However, the topic has had a very shy presence in political debates and has not ranked high in the list of topics addressed by interviewed stakeholders. It is in the academic debate and in published scientific papers that we can find some systematic discussions about inequality in LTC, but also there in limited doses.

There are two aspects that explain why **inequality as a subject has still not gained significant attention** in both political debates and scientific discussions about LTC.

On the one hand, LTC in Portugal has grown from social assistance, so it has an historical bias towards the persons in worse-off socioeconomic situation and walks very much hand in hand with tackling social vulnerabilities. Need for formal care is often conceptualised as a socioeconomic vulnerability since it means the person has not enough support and/or material resources of their own to tackle their needs (family, support network and financial capacity). In a way, it is taken for granted that formal LTC bears an intrinsic pro-poor approach, so it is correcting inequalities rather than generating of replicating them. Adding to this, in its social care component, the Portuguese LTC is not embedded in any notions of rights, which deviates attentions from discussions about topics such as equitable access to LTC.

On the other hand, LTC in Portugal is still very much focused on expanding coverage to deal with the insufficiency of social care responses. In that sense, debates are still very dominated by aspects of quantity. Inequalities have to do with a second layer of worries that are not seen as a priority for now. If anything pops out with some relevance is the territorial dimension of inequality as it more clearly intersects with aspects of coverage.

In terms of the **dimensions of inequality that pop out** in the literature and in the interviews, we find, by order of frequency, the following:

1. **Territorial inequalities in coverage** of formal care services – there is a general problem of coverage in the country, but discourses and the literature tend to highlight the differences across territories. This relates to inequality in access due to shortage of services and unequal distribution of services in the territory. Public funding programs to support expansion of coverage often incorporate in eligibility and evaluation criteria the location of the service, in view of favouring regions with very low coverage.

2. **Socioeconomic inequalities in access** to care and good quality of care – in a context of insufficient coverage there is room for the expansion of private commercial care services, that are costly and seen as accessible to those who have the means to afford them. There are two distinct views on this topic: on the one hand, lack of services has led to the expansion of illegal institutional care facilities, operating without a license and seen as expensive and of low quality, but the only available alternative to middle class groups that cannot secure a place in the non-profit sector; on the other hand, there is a private commercial sector, properly licensed and seen as offering high quality care, but very expensive and only accessible to high income groups.

3. **Gender inequalities** are not so frequently addressed but they started gaining additional attention after the approval of the Informal Care Act. Discussions on the policy arena started

mirroring discussions that were already well established in the literature about the gender gradient in informal care provision and the impacts of becoming an informal carer seen as disproportionally affecting women. The discussion is purely conceptual though and has not had any relevant consequence in terms of policy development.

Conceptually, the framework of the socioeconomic determinants of health and illness is present in the framing of policy discussions and programmes. Since care has developed from social assistance, there has always been an understanding that those in a situation of socioeconomic vulnerability are also more vulnerable in terms of their health, their limitations and their need for care and support. It is a conceptual principle that one can consider incorporated by default in the way the system is designed but that is not explicitly addressed *per se*.

We are a network, we are a poor network, we have the answers that are for the poorest population. We have a large universe, but we reach the most deprived population, (...) They knock on the door and don't stay at the door. Well, perhaps because of this paradigm of poverty, the state doesn't look at us with the same pomp and circumstance that it looks at other sectors.

Interviewee code: ORN_2410

There is some discussion in the literature, and growing recognition in the policy arena, that there might be inequalities in access to care services and cash benefits due the complexity of the bureaucratic process of applying to the benefits. This relates to the issue of uptake that is not known objectively for lack of data, but still perceived as a source of inequalities due to differentials in access to information and e-literacy.

Not least because people are in very fragile economic and social situations and therefore don't know what kind of support they have or can get. So the status of informal carer is not publicised. People have heard about it on television, but sometimes they don't identify themselves as carers, they don't know that it also concerns them. People with dependency don't know about the dependency supplements, they don't know about the IRS deductions, the technical aids. So there's a lot of ignorance on the part of people who are socially vulnerable about the support they can get and where they can turn and ask for it.

Interviewee code: PIN_2709

One aspect related to the way the system works that is discussed in the literature concerns the management of admissions. Determination of eligibility, including assessment of needs, and decision about admission is entirely controlled by the non-profits providing the services. There are anecdotal reports of this allowing for excessive discretionary power, leading to inequalities based on social capital and access to social networks of influence.

Then I can't understand how the social care sector is demonstrably prioritising the elderly on higher incomes over those on lower incomes, which is completely unnatural. I don't understand how there are still reports of non-profit institutions demanding 10, 15, 20 thousand euros from the elderly (...) It's not to donate to the institution, it's to buy the right of admission. With an aggravating factor. When they buy the right of admission, they are bypassing others who have been on the waiting list for longer, but who don't have the same resources and who see others bypassing them. And there's something else, too: even for subsidised beds, they're giving preference to elderly people with higher pensions. This is also unnatural. That's not what

the IPSS and Misericórdias were born for. I often say, you'd have to prove it, but I think it's easily proven. I often say that there are many elderly people in the misericórdias and IPSS who should probably be in the for-profit private sector, and vice versa. We have a lot of elderly people whose families have enormous difficulty paying the monthly fees and who perhaps, given their resources, would naturally be in an IPSS or a Misericórdia

Interviewee code: DRN_1209

2. Boundaries, Differentiation and Interrelations

Inequalities and LTC intersect from two main angles. The first angle, dominant in both the literature and in discourses of stakeholders, places LTC on the side of the dependent variable. In other words, LTC indicators mirror inequalities that are related to broader socioeconomic dynamics. The second angle, much less expressive, and largely confined to expert-based debates, looks at how the LTC system, both due to design and to operational aspects, generates, reproduces and even strengthens inequalities.

Socioeconomic vulnerability and poverty are discussed as risk factors for lower healthy life expectancy and for higher risk of health problems leading to limitations in ADLs and IADLs. They are also approached as a factor that limits the capacity of individuals and families to tackle their needs and therefore putting additional financial pressure on demand for formal care. Discussions of stakeholders tend to emphasise that the demand for LTC comes mostly from persons that are in a very vulnerable socioeconomic situation and therefore with limited capacity to have a significant participation in co-payments for care provision.

It's certainly a determining factor. It's been well studied and proven that this big difference we have in relation to European countries that have a life expectancy very similar to ours, but that we, in fact, have the last years of life that are much more worrying and painful, and even costly. It has a lot to do with this economic determinant. Being able to eat fish or chorizo makes all the difference.

Interviewee code: DPL_1309

Territorial differences, both in terms of geographic characteristics and in terms of local and regional socioeconomic dynamics, are seen as a relevant constraint on how LTC operates, leading to inequalities in coverage, accessibility and affordability. The topic though is mostly discussed from the perspective of the difficulties that territorial aspects create for operators and not so much from the perspective of how that impacts the respective populations. Sociocultural aspects are briefly mentioned, highlighting the urban/rural divide. But on this, views are mostly recognising the existence of a difference and not so much valuing it as fair or unfair.

Looking at the territory, it's clear that the south, and often the central part too, has a harder time because of, let's say, exactly that, the possibility of people moving to these areas. They have far fewer people and they also have much poorer support in the area of health in general, unlike the North.

ORN2_2410

Because there is indeed a different behaviour inland in rural areas and in the big urban centres. There's much more supply of homes [in large urban centres]

MPN_0310

Regarding the second angle, the model of LTC provision seen as generator of risks of inequalities, aspects that are highlighted included considerations about the quasi-public (non-profit) vs private commercial divide in provision associated to inequalities in access and in access to good quality care, and about the funding model and how it generates distortions that end up generating inequalities in access.

A last angle that can be identified concerns LTC workers. However, on this specific case, the topic of inequalities is not explicitly addressed but rather extrapolated from discussions on working conditions and on rewards. There are two instances to identify: on the one hand discussions and research on the hardship associated with LTC that puts workers in the sector in a position of disadvantage in the labour market, since their work is not valued and their salaries are low; on the other hand, the discussions about inequalities among LTC workers, namely the differences between social care and healthcare workers.

I believe that there is no proper appreciation of this type of profession, in other words, they are poorly paid professions, they are professions that basically require a lot of responsibility, we are basically looking after others and they are not well classified. Then there also needs to be work on dignifying the workers who work in these areas as carers.

Interviewee code: DTN_1111

3. Resources, Infrastructure and Regulation

Inequalities *per se* are not monitored in Portugal. There are no regular reports on inequalities in LTC and no clear mandates to any specific stakeholder to take stock of the issue. There are no observatories focusing on LTC. The availability of data reflects this institutional context. There is no shortage of data to run analyses on inequalities in LTC. The data is not produced for that purpose and because of that may not be available in the best formats and with the desired disaggregation levels.

Typically, most indicators available to analyse LTC in Portugal will be disaggregated at some territorial level. If referring to individuals, they will typically be disaggregated by gender, age, sometimes by income group and by schooling level.

There is one important divide in data availability that stems from the fundamental divide in Portugal regarding social care and healthcare. Indicators for social care are more difficult to get and less transparent. Healthcare, under the RNCCI, offers a public platform with up-to-date information about several indicators of performance of the LTC network.

Table 1. Estimates of inequalities in needs based on available indicators of dependency and need for help rates

Dependency rates[1] indicators	National data
16-24	12,1
25-34	16,3
35-44	20,7
45-54	30,1
55-64	42,2
65-74	44,7
75-84	54,7
85+	67,8
Males	30,2
Females	39,0
1st income quintile (low)	44,5
3rd income quintile (medium)	34,2
5th income quintile (high)	26,2
Lower secondary or less	47,4
Upper secondary and post-secondary non-tertiary	22,1
Tertiary	20,2
Need for help rates[2] of persons 65+	**National data**
Males	6,2
Females	11,7
Lower secondary or less	10,7
Upper secondary and post-secondary non-tertiary	1,0
Tertiary	2,2
Males	18,7
Females	41,1
Lower secondary or less	35,0
Upper secondary and post-secondary non-tertiary	11,3
Tertiary	12,1

Source: EU-SILC-2021 and EIHS-2019 (authors' computation)

(1) Dependency rates are computed as percentage of the population that self-report limitations in usual activities due to health problems. Data concerning year 2021 and collected with the EU Statistics on Income and Living Conditions survey (EU-SILC-2021).

(2) Need for help rates are computed as percentage of the population that self-report severe limitations in daily activities. Data concerning year 2019 and collected in the European Health Interview Survey (EHIS-2019)

Not surprisingly, the evidence supports the classic socioeconomic gradient in needs for LTC. The feminisation of needs is particularly expressive in the Portuguese case.

Table 2. Estimates of inequalities in LTC provision based on available indicators of service usage

LTC service provision indicators	National data
Rate of severe limitations of users of home-care services, by gender	
Males	64,1
Females	78,8
Rate of severe limitations of users of home-care services, by age	
55-64	40,1
65-74	50,4
75-84	88,9
Percentage of 65+ who used home-care services, by gender (2019)(1)	
Males	5,1
Females	7,3
Share of households in need of LTC not using professional homecare services (2016)	
For financial reasons	30,8
Because services not available	7,4
Household out-of-pocket payment as % of GDP (2018)	
LTC Health	0,2
LTC Social	0,3

(1) Data from LTC Report 2021, collected for 2018. https://data.europa.eu/doi/10.2767/183997

Service usage mirrors the gradients identified for needs, which in itself is a positive indication that the system is overall matching the distribution of needs. The evidence also suggests, on a negative note, persisting inequalities in access to needed LTC due to financial barriers, more than due to underservicing.

Table 3. Estimates of inequalities in LTC provision based on available indicators of workforce and caregivers' engagement and working conditions

LTC workforce indicators	PT
Percentage of the population providing informal care, by gender (2016)(1)	
Males	9,6
Females	14,6
Share of informal carers providing more than 20 hours care per week (2016)(1)	
Males	23,6
Females	34,7
% of employment in the HeSCare sector by age group (2021)(2)	
15-24	4,0
25-49	63,0
50+	33,0
Average hourly wages of LTC workers as % of the economy-wide gross average hourly wage(3)	
LTC workers in residential care	69
LTC workers in non-residential care	78
Workers in healthcare	119
Workers in education	162
HeSCare sector workers by working situation (2021)(2)	
% of total with precarious employment conditions	6,0
% of workers holding multiple jobs	12,0
% workers experiencing low payments for achievements	72,0
% workers reporting a not good worklife balance	25,0
% workers reporting that their health or safety is at risk because of work	52,0

Sources:
(1) European Commission: Directorate-General for Employment, Social Affairs and Inclusion, Long-term care report – Trends, challenges and opportunities in an ageing society. Volume II, Country profiles, Publications Office, 2021, https://data.europa.eu/doi/10.2767/183997
(2) EU-OSHA (2024), OSH in figures in the health and social care sector report, Publications Office of the European Union, Luxembourg, doi:10.2802/0384857
(3) OECD (2023), Beyond Applause? Improving Working Conditions in Long-Term Care, OECD Publishing, Paris, https://doi.org/10.1787/27d33ab3-en

4. Stakeholders, Governance

The introductory words of several pieces of legislation, policy programmes and other similar guidance documents include some reference to the need to make sure that equity is a guiding principle in aspects of policy formulation. In practice this is mostly in reference to a targeted approach that is justified as the means to secure that the ones in vulnerable situations are the primary beneficiaries of policies.

The argumentation is not framed by a rights-based approach (which is not a reference in LTC in Portugal) but rather by a social assistance principle.

Recently there were debates in the Parliament regarding the passing of a bill with a Charter of Rights of Older Persons, which was rejected by the centre-right and right-wing political forces. The proposals included an explicit reference to access to LTC as a fundamental right. This was rejected.

There are territorial differences, that translate into inequalities, in aspects of access, usage, coverage, labour force availability, quality of services and technology use.

The current debate is very much dominated by the need to expand coverage which leads to the emphasis on territorial inequalities in coverage that require correction.