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

The meanings of long-term care sustainability in Portugal

National report

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Executive summary

It was possible to identify a shared understanding of sustainability when revising the literature and when interviewing key stakeholders, although a narrow one: sustainability equates financial sustainability. The word “sustainability” as such is only used in association with financial aspects, both by interviewees, in research papers and in policy documents. Aspects of what one would consider social sustainability are not addressed as such.

Discussions on sustainability seem to always circle back to financial aspects. During the interviews the stakeholders mentioned several aspects of how LTC operates in Portugal that they see as sources of pressure that may ultimately put the system at risk. Shortage of workers and low qualifications are generally acknowledged as one of the most straining problems in the LTC sector.

Available data seems to support the concerns expressed by both interviewed stakeholders and read in the academic literature about the insufficient amount of LTC provision in the country and about underfunding of LTC.

Because the LTC system is very centralised in the government regarding issues of funding and overall regulation, and because the system relies heavily on provision of services by the non-profit sector, the truly influential stakeholders in debates about sustainability are government officials and representatives of non-profits.

The territorial dimension intersects discussions about sustainability on aspects of additional pressure on the financials associated to provision of services in certain regions of the country, although it is not a topic *per se*, neither in the literature nor in stakeholder’s discourses.

The narrow understanding of sustainability as financial sustainability has led to a one-dimension debate that revolves around the topic of funding (or underfunding to be more exact). Interestingly, there is hardly any debate about funding models, apart some discussions of a purely academic nature. The debate seems confined to a perception of care provision being a constant struggle between providers requesting more funds and the central government resisting expanding social expenditure based on budgetary constraints.

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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

To fully understand debates about the sustainability of LTC in Portugal one must consider how LTC is organised in the country. Two features of the system must be highlighted. The first concerns division of responsibilities for funding and provision of LTC between public and private providers, The second concerns the split between social care and healthcare.

Portugal, as thoroughly discussed in the literature about welfare state models, shows a mix of Beveridgean and Bismarckian elements in how social protection is designed. Following the democratic revolution of 1974, the country has created a National Health System (*SNS – Serviço Nacional de Saúde*), based on the recognition of the universal right to healthcare of all residents, and based on direct public provision of healthcare services, free of costs for the end-users. Regarding social care, a different pathway was followed. It does not rest on any universal right to social care, and it does not rest on direct public provision of services. There is a division of responsibilities between the State, that acts as funder and regulator, and private providers of services, typically non-profits. The State licenses providers and signs with them cooperation agreements that secure the transfer of a fixed-rate amount of money from the State to the service providers. Access to services involves co-payments from users and their families defined following a means-testing approach. The system is designed, as far as the principles are concerned, to secure equitable access and to favour those that need it the most.

Focusing now of LTC, Portugal has a dual system that mirrors the classic splits between healthcare and social care. Traditionally LTC in Portugal has developed from social assistance and therefore the concept in use more commonly is “social care”. This system covers all areas of social care, organised along a menu of services that target two main groups of the population (persons with disabilities and older persons) and that include homecare, residential care, day-care, teleassistance, occupational centres, autonomous residences, among others. For a detailed list of what social care provision involves in Portugal see report on meanings of care. More recently, in 2006, it was created a new parallel system, the National Network of Integrated and 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 that would focus on securing continuous, long-duration and focused on rehabilitation and reablement care, as well as on palliative care. This new system merges healthcare and social care, but the healthcare component is dominant in both the design and in the operational aspects of care services (see more on this in the report of meanings of care and quality of care). This merge also includes funding arrangements: the healthcare component is secured by the Ministry of Health and does not involve any costs for the end-user; the social care component may be supported by the Ministry of Labour, Solidarity and Social Security on a means-testing basis, or may be shouldered by the end user. The system is a national system, with a high degree of centralisation of regulatory and funding aspects in the central government. Municipalities have a very limited role in the care provision system. Care providers negotiate directly with the central government. Regulations and rules of financing apply to the entire country in a unified manner.

It was possible to identify a shared understanding of sustainability when revising the literature and when interviewing key stakeholders, although a narrow one: sustainability equates financial sustainability. The word “sustainability” as such is only used in association with financial aspects, both by interviewees, in research papers and in policy documents. Aspects of what one would consider social sustainability are not addressed as such and it is not just a question of terminology. They are identified as challenges that need to be addressed but failure to address them is not put in

terms of non-sustainability but rather associated to low quality (e.g. lack of workers, reliance on informal care, lack of choice) and to underservicing of those in need.

Research mainly explores the problems of financial sustainability due to the impact of demographic imbalances (high rates of old-age dependency) leading to pressures on the demand side of LTC. Some authors point to a public discourse marked by negative representations that older people are a burden on society, based on arguments that the increase in the share of older persons in the population implies a burden on public spending (pensions, health costs, social care), jeopardising the financial situation of national economies and that of future societies (Figueiredo et al, 2014; Capucha, 2014).

Santana et al (2015) also pick up the demographic element (growth in the number of older persons in the population) which they claim has led to concerns about the increase in the number of cases of dementia. This in turn leads to an approach to financial sustainability (although implicit, since the term is not used in the text). According to the authors, the high direct and indirect costs of morbidity associated with the chronicity of dementia conditions place a burden on national systems as well as on families' savings. The authors further offer some national estimates of the financial burden of dementia-specific medication, specifying the burden on the state and the burden on the patient.

Some studies, mostly from health economists, address funding models associated to sustainability. There are also some discussions on aspects of the overall design of LTC in Portugal and how some features of the system raise concerns in terms of financial and social sustainability (e.g. monopoly of non-profits in service provision; funding model directly from the central government to providers with no participation of users; orientation of the system to the poorest) (Lopes, 2016; Barros, 2017). These are, however, a handful of papers and hardly constitute a strong line of academic debate.

In regards understandings of financial sustainability by stakeholders, discourses are very narrow in scope. In the interviews, financial sustainability was systematically discussed in association to the idea of underfunding of care provision by the State, which puts a lot of pressure on service providers. Underfunding is approached from two angles, depending on whether the focus is on the RNCCI or on the social care sector.

Services provided under the RNCCI are mostly funded by the Ministry of Health. There is a price list for each specific act and service providers are paid accordingly. The main issue that is discussed as leading to unsustainability problems is the lack of regular revision of the price list to keep up with the rising costs of operations. The shared view is that there is a big mismatch between the real costs of service provision and the values defined in the price lists, which has already led to some closures of services for reasons of financial collapse.

In the last three years, 307 long-term care beds have been closed. They went bankrupt. Units closed because they were insolvent... because they couldn't cope with the deficit from the existing underfunding. And there are many units at the moment, in fact there have been for a long time, but at the moment there are many units in these circumstances, on the verge of closing because of underfunding.

Interviewee code: DRN_1009

In other words, what the system pays for, and the system here is a whole. It's the public system, it's people's co-payment. And the price, let's put it this way, whether or not the price accommodates what the costs are. This is sustainability, anywhere. The return I get covers what I've spent.

Interviewee code: DPL_1309

Services provided under the social care sector involve a fixed amount of money that is transferred from the Ministry of Labour, Solidarity and Social Security to service providers, defined per user and per type of service. The view shared by stakeholders is that the growing complexity of needs of older persons requires more differentiated care that tends to be costly and impossible to cover with the current payment rates. One topic that is highlighted concerns the need to employ more workers than what the ratios staff to users stipulate in applicable regulations. This increases the costs of service provision and is seen as putting many service providers under financial stress.

If we look at the legislation on the long-term care network, and it's one of the causes of underfunding, I'm fed up talking to the government, in the health committee and in the media, I'm always talking about this, which is the human resources framework. If you look at the legislation... a series of human resources that are not in the legislation are essential for a unit to function. And governments, I think, have made calculations based on this human resources framework. For example, there are no cleaners. A unit can't function without cleaning staff. There's no kitchen staff. A unit can't function without a kitchen. There's no laundry staff. There are no receptionists or administrative staff who have to deal with invoicing, a whole series of documents and receive visitors to see the patients. They're not there either. And there isn't a pharmacist, something that Infarmed requires, but which the network doesn't, but you have to have and it's a cost. What's more, the ratios of nurses and medical assistants are much higher than the legislation states. This means that expenditure on human resources is much higher than what is recommended by the network.

Interviewee code: DRN_1009

Often there is no provision for a psychologist in the home help service, there is no provision for one in the ERPI or in funding. There are institutions that do, but because they manage it differently, in other words, they take from here and put it elsewhere. But that's not the system, I think we should think about it. So it's not obligatory by law and it's not included in the staffing plan. And it would make sense to have a psychologist, a physiotherapist, other therapists, occupational therapists that other countries have on their staff in these centres.

Interviewee code: PIN_2709

Further to this, some stakeholders view the financial strain on care providers as a trigger of some distortions in admissions. In principle those individuals that have lower income would be prioritised in terms of admission into social care units managed by non-profits with State funding. This, however, means they may end up not being eligible for co-payments or that the co-payment rate will be very low, since it is determined by using an algorithm that is officially defined in applicable regulations. For service providers it is more attractive to admit persons with higher income so that they can shoulder the co-payments and contribute to the financial sustainability of operations. Some stakeholders describe this as a sort of spontaneous redistribution mechanism that non-profit providers need to use to compensate with some better-off users the financial burden of admission of poorer ones, but that ultimately constitutes a deviation from what the principles of care provision stipulate.

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

Despite the very explicit criticisms of stakeholders about public funding of LTC, in both the healthcare and the social care components, never was the funding model discussed or questioned as a funding model. Criticisms are almost exclusively targeting the amounts invested but not the overall design of the funding model.

One additional line of discussion about sustainability of LTC concerns the specific case of informal care and informal carers. The literature highlights the costs of engaging in informal care for the carers and how that leads to situations of unsustainability that are discussed at the individual and family level: health problems, loss of income and increased risk of poverty, social isolation, depression. These issues are discussed as the negative impacts of becoming an informal carer and seen as elements of an arrangement that risks becoming unsustainable for individuals and families. This line of reasoning is used as an argument to advocate for support policies targeting informal carers to guarantee the long-term sustainability of informal care provision (Pego & Nunes, 2018; Pires et al, 2020; Alves et al, 2020). This view is shared by academicians and stakeholders alike.

there is a lack of answers, especially at home, both in terms of health care and social care, both for people, because when it comes to ageing, we feel that the answers are not being prepared and thought out and, therefore, there is a great burden on carers (...) And just this week, a study was published in the media in which the families of Alzheimer's patients are spending more than a thousand euros a month on carers. So you can see here that this amount is hardly... and this amount doesn't take into account the carer's loss of income, because then the person doesn't make any deductions for their contributory career, even though the law allows access to voluntary social insurance, but it's the carer who has to deduct this amount, it's an amount that most carers can't afford. So there's always a financial loss for the carer. And on the other hand, there is no psychological support, no support from health teams.

Interviewee code: PIN_2709

in the Statute for Informal Carers. It was clearly designed for people with limited resources. This support, the Statute, is given so that the person receiving it, the person who makes themselves available to look after a family member, because they can't afford to leave their family member in the care of an institution that provides home care or ERPI services, chooses to be the carer themselves. The support is just over €500. This is unacceptable.

Interviewee code: MPN_0310

2. Boundaries, Differentiation and Interrelations

Sustainability is framed primarily and almost exclusively as **financial sustainability**. The main aspects of current understandings of financial sustainability are:

1. Current **price lists for care provision** are considered inadequate to meet real costs of service provision by non-profit service providers. There is a general perception that some service providers are already facing financial non-sustainability and deemed to close in the near future. This has already happened with providers of the National Network of Continuous Care (*RNCCI*).
2. **Changes in needs**, especially with growing needs for healthcare, in a system traditionally focused on support with ADL is seen as a source of additional pressure on the financials of service providers, requiring additional financial support from the government (as well as revision of some regulations concerning staff lists and ratios).
3. There is an emerging discussion about **private commercial providers** and the need to secure they can operate a profitable business to guarantee the continuation of their activities and expansion of private investment.

Discussions on sustainability seem to always circle back to financial aspects. During the interviews the stakeholders mentioned several aspects of how LTC operates in Portugal that they see as sources of pressure that may ultimately put the system at risk.

Shortage of workers and low qualifications are generally acknowledged as one of the most straining problems in the LTC sector. Although it is acknowledged that this stems from deeper problems, namely labour market dynamics and traditional lack of recognition of care professions, stakeholders tend to see this problem as fixable if the financials of the organisations providing care are strengthened. In the specific case of non-profits, they consider they cannot compete for workers given the low salaries they can afford to pay. Some even mention the competition with private commercial providers and, in the case of the RNCCI, with public providers. Private commercial providers are seen as targeting a market that has higher purchasing capacity and therefore able to generate more revenue to service providers that compete in the market on the basis of the quality of the services they offer and therefore have more aggressive HR strategies. Public providers operate in healthcare and their workers are public servants, with all the benefits that condition entails. It is therefore more attractive for healthcare workers, especially nurses, to work in a public healthcare facility than in a health unit of the RNCCI run by a non-profit.

> On the other side, of the differentiated professions, we have another problem. Another problem, essentially, is that if we don't have a career path, I'm talking about nursing and other technicians who are also differentiated, they also run away. This all has to be balanced. What is the biggest difficulty in the long-term care network? It's the flight to the hospital network. Because at the moment there's a shortage and so if they come with some training in long-term care, it's good for their CV and therefore for absorption at hospital level. We have to improve conditions. There's no other way, it's to improve conditions and public funding has to increase
>
> **Interviewee code: DPN_0212**

However, of course sometimes it happens, we end up doing fieldwork and we end up with a private operator and we didn't even know it was private. And what we sometimes see when we talk about these workers is that they are much more motivated to work, precisely because they are valued. Because it's not the quality, but the hiring requirements that are completely different for these operators. Precisely because they have the conditions, but not because they have the conditions, because they have a policy of valuing their own workers, don't they?

Interviewee code: STN_1410

The same line of argumentation was identified on discussions about quality of care. Lowering quality standards is described as a reaction of service providers to financial pressures and once more something solvable by improving the financial situation of these organisations.

A last issue that is also discussed in relation to sustainability concerns coverage rates of LTC in the country. These are considered low, especially in comparison to other EU countries. However, there is a shared scepticism about the actual capacity to expand coverage considering the current financial arrangements of the system.

These are organisations that don't aim to make a profit, but they do aim to create, they have to aim for surpluses, to create surpluses so that there can be reinvestment. Otherwise, how can it grow? Not at all. Not profit, and in that respect this message is getting through more and more, and indeed it is. But the institutions' costs per user per month are higher than the Social Security contribution and the participation of the users themselves. (...) So there really is a great deal of decalage here, and a difficulty.

Interviewee code: ORN_2410

I think there needs to be greater state investment. The question of 0.5 per cent of GDP in the European framework (...) We have to go up. This is also a matter of political choices, what we want. If we don't do that, we won't succeed.

Interviewee code: DPN_0212

For example, Sweden has 11 people working in long-term care for every thousand people over the age of 65. Now we have, from a numbers point of view, not even one per thousand people.

Interviewee code: DPN_1211

There was no mention to sustainability of care provision in cash (Cash for care or Carer's allowance), both in interviews and in research papers. This is most likely explained by the very low amounts involved in cash-benefits, that somehow make them less likely to be considered as a source of strain on the system.

A broader discussion about what sustainability entails beyond the financial sustainability is found in some literature. Pereira (2014) explores the unsustainability factors of the formal network and the informal network of care. Regarding informal care he highlights demographic ageing (there are more and more older persons to look after, for longer) coupled with the decrease in available informal carers (due to the smaller size of families, the predominance of the nuclear family and the increasingly advanced age of the carer). This author also addressed the specificities of gerontological care (care required is 'increasingly sophisticated and prolonged') and territorial imbalances (different levels of economic development across regions seen as the root of the

demographic ageing). Regarding the formal network of care, factors of unsustainability highlighted include the cost of care (high cost of institutionalised gerontological care), demand side pressures due to demographic ageing and the crisis of the welfare state (as a combined consequence of weak socioeconomic development, insufficient and ill-adjusted public policies and demographic ageing).

Discussions about sustainability in the literature also explore, although in a relatively shy manner, aspects that favour sustainability of care arrangements. This is particularly the case of discussions about informal care. National cultural patterns 'characterised by the intensity of intergenerational exchanges between family members and strong bonds of mutual help between friends and neighbours', but with a tendency to disappear; the adoption of sustainable development policies in more disadvantaged regions in the rural inland regions are pointed as promising pathways to the resilience of informal care solutions (Pereira, 2014). Regarding formal LTC, topics such as the gains in knowledge and technical skills associated to the consolidation of new professions such as gerontologists and geriatricians, and the development of private care markets, are mentioned as factors that may facilitate sustainability of formal LTC in the country (idem, ibidem).

3. Resources, Infrastructure and Regulation

LTC in Portugal is funded by the State Government and operates based on national legislation applicable to the entire country in the same manner. The only exception concerns the autonomous regions of Azores and Madeira, the two archipelagos that are part of Portugal and that have regional governments. The dispositions on healthcare, however, are universal so they apply in the same manner. Dispositions on social care may have some regional variations but residual in terms of the fundamental architecture of the system. Where there is a substantial difference is in data availability. While for Portugal mainland there is public access to data platforms, such sources are not available for the islands.

This section of the report offers evidence to support discussions on three topics that are related to the sustainability of LTC arrangements in the country. Firstly, we resume data on needs, provision and usage to discuss the sustainability of current arrangements in terms of their capacity to tackle needs. Secondly, we will look at funding and financial arrangements in the sector to discuss financial sustainability. Thirdly, and finally, we will look at cash-for-care and other related cash benefits, as well as to informal care provision, to discuss sustainability of informal care.

3.1. Provision and usage of care services

Although there is no specific monitoring of data for the purpose of monitoring the sustainability of the LTC system, it is possible to pool some data that is regularly monitored to extrapolate conclusions about sustainability concerns.

Census data collects information about functional impairments and allows to estimate some statistics about care needs. We have taken a very conservative approach to avoid any overestimation and looked at the number of persons that have declared they are totally unable to bathe or dress/undress without the help of a third party. This figure amounts to 135,839 persons in the 65+ group. This corresponds to an incidence rate of 5,6% in that age group. If we add to the data those who have

declared they experience a lot of difficulty performing this same task (a total of 107,267 persons in the 65+ age group), then the incidence rate doubles to a bit over 10%[1]. It is fair to say that individuals with this type and degree of difficulty bathing and dressing/undressing are likely to need some form of support.

The data from the last wave of the National Health Survey, in 2019, points to an estimated 112,718 persons over 65 declaring severe difficulty in getting in an out of bed or chair. 116,873 declared severe difficulty with dressing/undressing, 58,692 have severe difficulty using the toilet and 157,195 declare severe difficulty bathing/showering (Source: INE, 2019, available at www.ine.pt). Census data and survey data seem consistent and point to a total figure of around 120,000 individuals living in the community and requiring support with basic personal care activities. It should be noted that survey data does not include those individuals living in institutions, which means that the actual number of persons requiring support is likely higher. However, one can also consider that those living in institutional care facilities have their needs already met. The ones in the community are the ones more likely experiencing unmet needs.

When we now look at service capacity, currently the country has a capacity for 115,323 users in homecare services. This corresponds to a coverage rate for the 65+ population of 4,8%. Considering the very conservative estimates of care needs incidence around 10%, the homecare services sector does not meet at least half of the needs.

If we turn our attention to service provision under the RNCCI, data on referrals points to a total of 33,419 referrals to some in-patient care service during 2024. This does not mean that there were 33,419 referrals since some of these referrals can involve the same person being referred across different services (e.g. admission to a convalescence unit leading to a referral to a medium duration and rehabilitation unit). The admission rate for the same year, however, was only around 56%. Some of those not admitted died in the meantime (around 10%) or had the referral cancelled (29%). Still, almost 9% of those referred were pending clinical evaluation or already waiting for a place (Source: *SNS Transparência*, available at https://tranparencia.sns.gov.pt). This can be considered the waiting list for admission, suggesting some strain on the supply side to accommodate the demand. Some additional data of interest comes from the Barometer of Social Hospitalisation, a term that designates in Portugal the unnecessary hospital stays of patients that can be clinically discharged but that are in a situation of socioeconomic vulnerability, therefore cannot be sent home and there is no available place for them in the social care sector. According to that data source, between March 2023 and March 2024 there was a daily total of 2164 hospital beds taken by patients that do not need acute hospital care. The average length of stay in the hospital after the date of clinical discharge was 175 days. According to the estimates of hospital administrators this phenomenon costed over 260 million euros to hospitals during that period of time. The main causes for this undue hospital stays involves the insufficient response from the RNCCI, especially in the South of the country, and the lack of available places in residential care facilities for older persons in the social care sector, especially in the region of Lisbon and in the North of the country (Source: *Associação Portuguesa de Administradores Hospitalares*, available at https://apah.pt/).

Finally, and as far as informal care is concerned, data from the 2019 National health Survey suggested that a total of 898,650 adult persons were engaged in informal care activities caring for relatives. Among these, a bit over half were also employed. This corresponds to a bit over 10% of the total employed population (Source: INE, 2019, available at www.ine.pt).

All in all, the data seems to support the concerns expressed by both interviewed stakeholders and read in the academic literature about the insufficient amount of LTC provision in the country. Whether

[1] Census data available for consultation at www.ine.pt. For computation of coverage rates we have used the total number of residents aged 65+ also from census data.

this is phrased using the specific term of sustainability or not, seems to be of less relevance than acknowledging that there is a supply problem in LCT in Portugal. On this diagnostic the consensus is high.

3.2. The financials of LTC

LTC in Portugal is secured primarily by non-profits. In both the social care system and in the RNCCI they account for around 80% of the service provision. The system is regulated centrally by State authorities (Ministry of Labour, Solidarity and Social Security for the social care system; Ministry of Health and Ministry of Labour, Soldarity and Social Security for the RNCCI). The regulatory role involves licensing operations, establishing rules of operations and supervising activities. The central government also takes up the responsibility for funding care provision.

The **social care system** involves a model of partial funding from the State complemented by out-of-pocket co-payments by the users. Public funding is transferred directly from the central State to the care providers. Amounts to be transferred are defined nationally at a fixed rate per user and by type of service. Co-payments by the users are computed following an algorithm that is also defined by State authorities in specific regulations. This algorithm adjusts co-payments to the income level of the users. Co-payments can be as high as the difference between the full cost of care provision and the amount covered by the State, and as low as zero in case of low income. For definition of total cost of care provision, cap values are defined in applicable regulations. The main argument of stakeholders involved in social care provision is that the reference values are outdated and do not keep up with changes in needs, that are becoming more complex and requiring more staff and more differentiated staff. The funding model is hardly questioned beyond some discussions in academic for a.

For illustration purposes let us look at the values for two main social care services: homecare service for older persons and residential care service for older persons. Dispositions concerning financial aspects are hard to describe due to the relatively high level of discretion that the applicable legislation leaves for the providers. We describe here what can be understood as the core rationale of the system.

For homecare services, the central state, in 2024, would transfer 350,23 euros per user, per month, to non-profits providing that service. The co-payment by the user is determined following the computation of the individual income for the specific purpose of determination of co-payments. This follows an algorithm that is centrally defined by State authorities. Care providers then define, as percentage of individual income, the amount to be paid for the service provision by the user and as co-payment. This is where care providers have some discretionary power. Each provider defines, in its internal regulations, the percentage of individual income to be paid by service provided. There is a ceiling for that co-payment that cannot exceed the value of the real cost of provision as published annually by the care provider in its annual balance sheets, that must be publicly available in the organisation's website. There is no database that gathers information about all care providers. Some keep up-to-date information on their websites, but still, one would need to visit thousands of websites to be able to collect the information. Just to illustrate the process, we take two examples of two service providers.

One non-profit institution in the North of the country defines a co-payment rate of 40% of the individual income of the user if the homecare service includes food delivery and laundry service and is delivered on weekdays. If the same service is also delivered on both days of the weekend, the co-payment increases to 50% of the individual income. If, for example, the service includes food delivery, laundry service, cleaning of the house and personal care (hygiene), the percentage for

determining co-payments is 55% if only on weekdays and 65% if also on both days of the weekend (Source: http://www.scmviana.pt/wp-content/uploads/2021/07/Regulamento-Interno-SAD.pdf).

One other example, this time from a non-profit that operates in the outskirts of the capital, Lisbon, offers a more detailed description of components of service provision for the purpose of determination of co-payments. Once more, the co-payment is expressed as percentage of individual income: delivery of lunch only involves a co-payment of 25%, but if food delivery includes lunch and dinner, the percentage rises to 35%. If the user also needs help with the feeding, an additional 5% is added to the co-payment. Personal care once a day (bathing and dressing) involves a co-payment of 20% if done once a day, 25% if done twice a day. This institution sets a ceiling of 60% of the individual income as the limit for co-payments irrespective of the menu of services that are agreed (Source: https://misericordia-oeiras.pt/wp-content/uploads/2022/03/Regulamento_ApoioDomicilia%CC%81rio.pdf).

For residential care, the central state will transfer 573,53 euros per user, per month. Co-payments can go as high as close to 1,000 euros per person for a user that is at the highest level of co-payment. It is unclear whether the amounts are adequate or not to cover operational costs. All non-profit care providers are obliged, by law, to publish their annual reports of activities with the demonstration of financial results. There is no integrated database with these data, but *ad hoc* consultation of public records shows some variation, with some institutions presenting positive results in both types of services, while others show negative balance sheets.

Considering the evidence, it is not clear whether claims of financial strain by non-profit providers are grounded or whether they are the reflex of some problems of organisation and management in a sector that still struggles with some difficulties in terms of professional management.

In the **RNCCI**, funding arrangements involve a mix of rules proceeding from the healthcare system and from the social care system. The healthcare component of the RNCCI is funded by the Ministry of Health in full. Citizens do not have to pay anything. The social care component of the RNCCI is paid by the user but he/she can request support from the Social Security after means-testing assessment. The lion share of the funding of the RNCCI involves payments for healthcare. These are defined in price lists that are quite detailed and that are transferred to care providers based on typologies of service and users.

The main source of discontent among care providers that operate in the RNCCI is the mismatch between the values defined in prices lists and what they consider the real costs of care provision. The National Association of Continuous Care Providers partnered with the School of Economics of the University of Porto to do an evaluation of the real costs of care provision. The results were publicly presented in September 2024. The assessment involved analysis of data from a sample of care providers. According to the estimates presented by the authors, the difference between the amount paid by the state for the healthcare service provided and the real costs of provision ranges from -4.35€ per day/per user in the UC, -6.67€ in the UMDR up to -10.79€ in the ULMD. The results ground the claim that the state is underfunding long-term care institutions, with a greater impact on the ULMD. For this type of institution, the study estimates a yearly underfunding of around 122,000 euros per institution running an average of 31 beds[2]. According to the contents of the study, the most influential cost item in the unit cost (cost per user/per day) is Costs with Personnel, namely due to the increases in the national minimum wage and the need for more professionals than what recommended by Ordinance 174/2014 that defines the composition of professional teams to operate

[2] Funding of the healthcare component in the RNCCI involves the following pricelist: for Convalescence Units (UC), the State pays 115.27€ per user/per day; for Medium Duration stay and Rehabilitation Units (UMDR), the payment is 77.50€ per user/per day; for Long Duration and Maintenance Units, the payment amounts to 37.5€ per user/per day (Source: Pricelist of the RNCCI as defined in Ordinance no.74/2024)

services. Furthermore, the study continues, some institutions face additional costs, equivalent to 15 months salaries per year, to cover replacements during holidays (FEP, 2024). The underfunding of service provision is seen as jeopardising the quality of care provided and the financial sustainability of institutions, causing budget shortfalls, infrastructure degradation and equipment shortages, as well as demotivation among professionals and difficulties in investing in innovation and continuous training.'(idem, ibidem: 23).

The funding model is not questioned in its principles. The claims from the providers' side revolve around the need to update price lists on a regular basis to keep up with rising costs.

And so this has been the history since 2015. […] there's legislation from an ordinance from 2007, so the decree is from 2006, there's an ordinance from 2007, which says, among other things, that prices have to be updated, reviewed every 5 years. They never have been, to this day. And that, at least, to give a guarantee to those who invest in long-term care, at least that prices are updated based on the previous year's inflation. (...) Just now, we had brutal inflation in 2022 and 2023, namely in 2022 it was 7.8 per cent, and the government didn't update prices. In 2024, in the middle of the election campaign and after a lot of media pressure, including many public interventions on my part, the government updated the prices of long-term care for 2022 by 2.4 per cent, in other words, a third of the inflation rate. And on the 7 of December, former Prime Minister António Costa, who even held a public ceremony with the sector's representatives, signed an agreement called the 'Social Sector Commitment', in which the Prime Minister says, and swears an oath of love, if you'll excuse the expression, that 'this is the time, I'm really going to deliver'. It's just a reaffirmation. And it was the Prime Minister who signed the document. Normally it's the ministers from the various sectors who sign the document. 'This time it's going to happen!'. And it didn't. They sign these increases in writing and then don't fulfil them.

Interviewee code: DRN_1009

3.3. Cash-benefits and informal care

The Portuguese LTC system also includes **cash benefits**. There are two cash benefits of the same type but targeting different groups of the population. The first is the **Subsidy for Supporting a Third Party** (*Subsídio por Assistência a 3ª Pessoa*), paid to the parents of persons with disabilities (children and youth) that are entitled to the family allowance and that are in a condition of dependence from a third party for activities of daily living. The amount of money paid monthly to those eligible is 122.90 euros. In September 2024 there were 12,438 persons collecting this cash-benefit (Source: *Boletim Estatístico, MTSSS*, September 2024).

The second cash benefit targets specifically older persons that are dependent of a third party for activities of daily living. The benefit is known as the **Dependency Complement** (*Complemento por Dependência*). This benefit is paid to the older person to help him/her to organise for the needed support. It splits into two levels, to account for the severity of the dependence of the older person: 1st level dependence involves situations of dependence on activities of daily living; 2nd level is for those that are bedridden or with dementia. The benefit also splits into two branches depending on the situation of the older person as a pensioner: if the person is an old age pensioner, the value is slightly higher than the one paid to an older person that is not eligible for an old age pension. For first level dependence, the values are 122.90 euros and 110.61 per month. For second level dependence, the values are 221.21 euros and 208.92 euros per month. Last figure available concerns 2023, with a record of 201,525 old age pensioners receiving this cash-benefit (INE, 2024, https://ine.pt, last access on the 31st of January 2024).

One feature of these cash benefits is their obvious extremely low value. But one other unique feature is that a person is entitled to receiving this cash benefits even if also receiving in-kind care from some formal social care service (homecare, daycentre or residential care). It is an idiosyncrasy of the cash-based LTC provision in Portugal that seems to be more oriented to improving the available income of persons with dependence to facilitate co-payments in social care services than to increase their purchasing capacity to meet their needs on their own.

Regarding **informal care**, in September 2024 there was a total of 15,263 persons formally recognised by the public authorities as informal carers. Of these, 62% were recognised as primary carers, meaning they were potentially eligible for the **informal carer's allowance**. At the same date, 5,401 primary carers were in fact receiving that cash-benefit, which represents around 57% of primary carers. The average value of the carer's allowance paid, per month, amounted to 351.94 euros (Source: *Boletim Estatístico, MTSSS*, September 2024). It should be noted that the carer's allowance can vary in value following a means-tested assessment, that considers household income as the reference and not individual income. For comparison purposes, the minimum wage in Portugal, in 2024, was set at 820 euros per month. It should also be added that old age pensioners are not eligible to be awarded the carer's allowance, even if recognised as primary informal carers.

The evidence seems to support the main claims of non-governmental organisations that advocate for the rights of informal carers regarding the risks of failure of traditional forms of informal support if current arrangements to support, financially, informal carers are not revised. The literature offers discussions on the risks of impoverishment of informal carers and how this may act as a negative trigger in decisions about becoming an informal carer (Gil, 2023).

4. Stakeholders and Governance

Because the LTC system is very centralised in the government regarding issues of funding and overall regulation, and because the system relies heavily on provision of services by the non-profit sector, the truly influential stakeholders in debates about sustainability are government officials and representatives of non-profits. The relationship between the two parties is simultaneously of collaboration and of tension. Public discourses, especially in the media, generally pass the idea of collaboration and alignment. Statements by higher-rank policy makers (Prime-ministers, Ministers of Social Security and Secretaries of State) are always positive and highlight the importance of the non-profit sector in provision of LTC. Representatives of the main sectorial bodies of representation of the sector align in this overall positive discourse.

It is mostly when issues of funding are negotiated that positions tend to antagonise, with the representatives of the non-profit sector demanding more significant updates in funding and government representatives acknowledging the merits of the demand but refusing it on the grounds of budgetary discipline. The bi-annual negotiations of cooperation agreements between the central government and the non-profit sector that establish how much the central government will pay per user to service providers seem to follow an almost performative script that marks the position of each party but has never led to any sign of rupture. Overall, it seems that the two main stakeholders are in agreement regarding the funding model, so debates about its sustainability are absent. It is just about the actual amounts involved that there is disagreement.

The topic of the sustainability (and desirability) of the funding model in place is one that has been seeing some developments over the last decade, although still outside the spotlight. It is largely an academic debate that some scholars from the disciplines of health economics and social policy have been feeding. Arguments presented highlight the limitations of a funding model that transfers payments for services directly from the State to the care providers without any participation of end-users as one that limits choice on the users' side, and that fosters quasi-monopolies in care provision (Lopes, 2016; Pita Barros, 2017). Another issue that is also discussed concerns the standardised approach to funding of service provision, based on types of services and not on actual needs of service users (Lopes, 2016). This is something that also resonates among stakeholders involved in care provision that see the benefits of more flexible algorithms to determine costs of care provision to bring them closer to the needs of users that are not only different across users but also dynamic along time.

In Spain, for example, the care responses are categorised by degree of dependency, in other words, they have responses for the most autonomous, the most dependent and the moderate degree, and the funding is different according to these typologies. I think this is very necessary in our country, because then, for example, the funding is always the same, there is no rigorous characterisation and knowledge of the people who are in ERPI [residential care facility for older persons]*, that is, when I say ERPI, I also mean home support services, because if we realise that an ERPI, for example, is for 20 users, there are 12 who have dementia, there are 5 who are bedridden and there are x who are autonomous, well, here there had to be a differentiation in funding, because there is a prior characterisation of the users, so that there is a different allocated ratio of nursing hours, in this case of formal carers. What's more, I think […] rehabilitation and non-pharmacological therapies, is undervalued, because most of these services, even at home, don't have rehabilitation therapies available. My institution's home support service has psychomotricity, they have weekly psychomotricity sessions, but it's not usual.*

Interviewee code: PIN_2709

Another recent trend concerns the emergence of some tensions within the non-profit sector regarding representation of interests. Traditionally, the only voices heard by the central government in negotiations with the non-profit sector would be the three main players representing the Holy Houses of Mercy – UMP, by far the most powerful and influential –, the private institutions of solidarity – CNIS – and the social care provision cooperatives – FENARCERCI. More recently, other representation bodies have been created with an agenda that in some respects deviates from the traditional approach of sectorial representatives. They are smaller in number of affiliates, but are very active in voicing their claims, with communication strategies that tend to be effective in putting them under the spotlight. These new instances of sectorial representation come embedded in a view (and a language) that is closer to managerial currents of care provision, emphasising aspects of professionalisation, quality of care and competitive management of staff. They often criticise institutions such as CNIS or UMP for their backwards approach to the management of service provision, that they see as influenced by the Christian Catholic framework, very much based on notions of charitable work that represents care work as a sort of mission rooted in a sort of moral obligation. They emphasise, for example, the advantages of creating good market opportunities for the expansion of LTC, that they see as one aspect of a pathway to the sustainability of LTC in the country.

Other complementary topics that could be identified are primarily addressed by the academic literature. Some authors discuss financial sustainability of LTC in a context of population ageing and in the specific context of the financial crisis that followed the crisis of sovereign debt in the second decade of the millennium following the crash of the banking system in 2008 (Barbosa & Matos, 2014, Capucha, 2014). Capucha (2014) highlights the influence of a particular stakeholder, the

supranational institutions (known as the Troika – International Monetary Fund, European Central Bank and the European Commission), in the design of policy measures with implications for the economic security and well-being of the older population, such as the reduction in the value of pensions, including the lowest ones, the cut in cash benefits targeting the poor and the interruption of funding programmes supporting the expansion of care facilities. Others highlight the increase in the rates of use of health services and subsequent decrease in quality and timely service provision (Barbosa & Matos, 2014). The context of the financial crisis is seen as having exacerbated the problems of the LTC system in general, leading to the implementation of policies focussed on budgetary containment, with not only cuts in care provision and cash-benefits but also an explicit call for families to contribute even more, both in terms of care provision and in financial terms (Capucha, 2014).

5. Territorial Differentiation

The territorial dimension intersects discussions about sustainability on aspects of additional pressure on the financials associated to provision of services in certain regions of the country, although it is not a topic *per se*, neither in the literature nor in stakeholder's discourses. There are no clear divides concerning territories when discussing issues of sustainability (e.g. urban/rural, seaside/inland). The territory is seen as having specificities that generate additional concerns about sustainability and that clash with the very standardized, one-size-fits-all model of funding in place. Aspects of territorial differentiation that are highlighted are topography and density/dispersion of the population.

Some regions of the country have an occupation of the territory that is scattered, with small and very small villages with low population density. Provision of services in these regions, namely home-based care, involves covering a wide geographic area, with costs of transportation rising and not duly translated into the payments centrally defined by the government. Service provision in these regions is seen as more costly due to operational costs. This is more common in the South of the country.

That's why I argue that there should be an increase in the payments that are made to those organisations that are located in the so-called low-density territories. This was finally done, after many years, and has now been done, just a few months ago, for home care services. Finally. But it was the only area in which this was done. I hope that in the future it can be extended to others, particularly long-term care.

Interviewee code: DRN_1009

In Alentejo it is capable of travelling many kilometres to provide home care. It's capable of travelling 40, 50 kilometres to go to one person, then going to another point.

Interviewee code: DPN_0212

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. […] The South has fewer people, everything is more expensive, the distances are much greater, people are much more isolated and this limits a homogenised response at national level. (...) So what's different has to be dealt with in a different way, in a different way.

Interviewee code: ORN2_2410

The big urban centres are seen as more costly due to the price of real estate and construction in general, leading to difficulties in investing to expand service coverage. They are also seen as the regions with higher numbers of persons requiring care so where shortages in coverage leave more people with unmet needs (Lisbon, Porto and Setúbal are identified as the critical regions in terms of coverage). Recently, some stakeholders have been warning that there is a high likelihood that investments to expand the coverage of the RNCCI, namely those supported by EU funds under the RRP, may not happen due to the very high costs of construction in big urban centres.

The big problem of inequality in access to long-term care is Lisbon, Porto and Setúbal, where it's most difficult. And why is that? And now we have the advent of the PRR. What's the difficulty? Because these places, Lisbon and the Tagus Valley, Porto, Setúbal, Braga, are the most expensive to build. And therefore where there are fewer applications from institutions.

Interviewee code: DPN_1211

Rural regions are sometimes mentioned as struggling with comparatively bigger difficulties in hiring staff given the general shortage of labour that affects the country, but more so rural inland regions.

For many years now, I have been advocating that both in long-term care and in the social sector in general, there should be an increase in payments for units located in low-density territories. Why? Because these are organisations that have much higher costs than those on the coast and near the big cities, don't they? The cost of goods and services is much higher. Labour is also more expensive, because... I'll give you an example. (…) in a low-density área (…).It's one of those that's been due to close for some time, but it hasn't yet because the [municipality] has been injecting hundreds of thousands of euros into the institution every year so that it doesn't close. Because it makes brutal losses with the LTC Unit (…) it drags the institution into a very complicated situation. And they don't have a single nurse on staff. Zero. None. They use nurses who work in hospitals, in clinics, in other places and they go there to do so-called extra shifts and are paid on a green slip. And they get paid a lot, they get paid very well, so they get paid very well. Why is that? This also happens inland and in various regions. There are nurses who travel 100, 200 kilometres or more to work a shift. And that has to be reflected in the price, of course. It's the shift itself, it's the travelling.

Interviewee code: DRN_1009

6. Debates and Strategies

The narrow understanding of sustainability as financial sustainability has led to a one-dimension debate that revolves around the topic of funding (or underfunding to be more exact). Interestingly, there is hardly any debate about funding models, apart some discussions of a purely academic nature. The debate seems confined to a perception of care provision being a constant struggle between providers requesting more funds and the central government resisting expanding social expenditure based on budgetary constraints.

There is hardly any discussion about cash benefits and the concept of cash-for-care is not common in political debates or in academic readings. More recently, the debate has turned to the situation of informal carers and the need to secure the personal financial sustainability of those engaging in care provision to prevent poverty and social exclusion. Current carer's allowance is seen as very low and insufficient to achieve that goal. Grass-root social movements of informal carers have been gaining some visibility in the public arena and pushing forward the agenda of rights of informal carers.

There is no explicit refusal from the State representatives of the merit of all the claims voiced by care providers representatives and by informal carers. In that sense, one can say there is consensus around the reality of the country being characterised by underfunding and insufficient support to social agents involved in care provision. What is also voiced is a belief that the country does not have the financial robustness to shoulder significant increases in LTC funding at the risk of hurting the financial balance of public spending.

Regarding the social sustainability of the LTC model, the debate is shy and largely confined to expert-based discussions. The reality of the policy decision in recent years seems to be at odds with recommendations from international instances, namely the OECD and the EU regarding the expansion of home-based solutions to secure fast expansion of LTC coverage. In Portugal and looking for example at the use of RRP funds, they are being allocated mostly to expand institutional care coverage. Announcements about projects approved suggest that there will be an increase of almost 30% in the number of beds in residential care facilities over the next couple of years. In this respect, sustainability of care provision seems to continue to rest a lot on institutional care provision.

There are debates about the need to innovate, especially to maximize the potential of technologies, but in practice there is no clear strategy or programme that supports such innovation. Some specific initiatives launched by private foundations have allowed some providers to implement new approaches, but they are done in a limited time and once the funding is finished, they struggle to continue operations and most of them are discontinued.

It is in the academic literature that one can identify some streams of debate that point to other aspects of sustainability and to concrete proposals to strengthen the LTC sector. Some look at the topic from a broader perspective and discuss systemic aspects. According to Capucha (2014), the services provided to older persons and other dependent citizens (children, persons with disabilities or long-standing ill persons) create jobs and boost the economy. The problem of sustainability, for this author, arises because the pension and health systems were designed for a different society and economy that no longer exist today. For him, sustainability of care arrangements requires a substantial reform of the entire social protection model, including on aspects of funding.

For Pereira (2014), the provision of services of high quality for older persons requires a minimum number of users to be viable from a social, economic and technical point of view. The argument here relates to productivity gains associated to scaling up operations, which the author sees as necessary. He further adds that services do not need to be available in every town and village. The author

advocates organising the provision of services according to a logic of functional proximity: 'it should follow the principle of subsidiarity (i.e. it should provide the service to the entity that is closest and most qualified to do so), thus creating a social support network that secures a good distribution of and access to services' (idem, ibidem: 203).

Discussions about alternative funding models, namely regarding the creation of an LTC-specific contribution was not identified in the literature or in discourses of interviewees.

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