Què funciona en cures de llarga durada?

Report

What works in long-term care?

Conceptualisation, context and presentation of the project

ivàlua
Institut Català d'Avaluació de Polítiques Públiques

Taula d'entitats del Tercer Sector Social de Catalunya

Diputació Barcelona

laconfederació

Què funciona en cures de llarga durada?

What works in long-term care?

Conceptualisation, context and presentation of the project

Final Report:
October 2024

Thematic area:
Social issues and inequality

Project funded by:
Diputació de Barcelona (Barcelona Provincial Council)

With the support of:
Taula del Tercer Sector and La Confederació

Synthesis carried out by:
David Palomera

Coordination:
Ivàlua

Què funciona en cures de llarga durada?

A project to compile, analyse, and transfer information in order to improve public long-term care policies.

A project participated in by:

ivàlua Institut Català d'Avaluació de Polítiques Públiques

Diputació Barcelona

Taula d'entitats del Tercer Sector Social de Catalunya

laconfederació

Què funciona?

Index

1. Introduction

Caregiving is an essential part of all our lives. In order to find enjoyment in life, perform tasks, or relate to society, we must first have an adequate environment to live in and have our basic needs met, both physiological or emotional. In other words, as social beings, our well-being depends largely on participating in and being included in society and on being able to live in spaces that meet our aesthetic and ethical standards, according to the desires and preferences of each person. Thus, **at all stages of our lives, the provision of care is a central element that structures and organises societies**, and the ability to satisfy care needs makes a society more or less prosperous. Likewise, **how this provision is distributed and who has responsibility for it entails a key democratic problem**, since this creates societies that are more equal or less equal, especially in terms of gender, ethnicity and social class.

Currently, due to our aging population, one of the main challenges faced by societies such as ours is long-term care (hereafter LTC). In 2021, life expectancy at birth in Catalonia was 84.[1] Together with a declining birth rate, an increasingly aging population is projected, with a dependency rate[2] that will increase from 54.2% in 2022 to 62.9% in 2035.[3] This aging population might well increase the percentage of people who need LTC. At the EU level, it has been estimated that the current 11.6% of the population over 50 with LTC needs could rise to 14.1% in 2070.[4] Despite the social challenges this presents, **the increase in life expectancy and an aging population could be considered a social success.** The new demographic paradigm contributes to us having more time for the activities we enjoy and to providing knowledge to new generations about the social and economic problems we must face. Likewise, in societies like the one in Catalonia, there are social and technological resources available, as well as the time necessary, to guarantee all people with LTC needs a dignified life.

Unfortunately, the economic systems and welfare states in Europe, including Catalonia, often fail to guarantee the necessary care for everyone and **we are experiencing what has been called a crisis in care.**[5] Currently, there is a lack of quality care —based on the person-centred care model— to meet existing demand. In addition, participating in the care sector, whether as a provider or recipient, involves material, physical and psychological risks. Furthermore, a characteristic of the care crisis is that its consequences are distributed

[1] Data taken from IDESCAT, 2024.
[2] Coefficient, as a percentage, between the population under 16 or over 64 years of age and the population from 16 to 64 years of age.
[3] Martínez-Buján et al., 2022: 38.
[4] Belmonte et al., 2023.
[5] Tronto, 2013; Fraser, 2016.

unevenly among different social sectors depending on determinants such as disability, gender, economic situation, country of origin or age. In the case of Catalonia, which has a model based on the provision of LTC within the family, the care crisis is hitting particularly hard. The aging population and, specifically, the rising numbers of elderly people with disabilities or dependency is usually conceived as a problem, generating feelings of contempt and a relegation of responsibilities that translate into ageist and ableist attitudes.[6] In this context, "public discourses on old age offer **paternalistic views and protectionist measures that homogenise** old age and consider older people as vulnerable and passive subjects, something that has kept hidden the many different situations and needs of older people and also their own initiatives [...]".[7] We could also extend this conclusion to the dominant discourses and practices in the care of people with disabilities.

We are thus faced with the challenge of building a society that is capable of providing quality care for everyone who needs it, and with a social organisation that does not generate inequalities. Far from considering population aging and disability as an economic problem that must be solved case by case, **the social organisation of care must become a central and cross-cutting issue in the public debate, and the structural conditions of the provision of care must be improved,** for the people providing the care, the people who receive care and the sector in general. For all this to happen, it is crucial to foster the agency, autonomy and voice of all these people.[8] It is also necessary for the administration to foster an interdepartmental perspective, including a vision that is social, educational and health-based. Likewise, it is key to move towards a more holistic vision of care, which takes into account the needs and desires of each individual in order to build a more supportive society.[9]

However, **in order to transform the public policies on LTC, it is first necessary to understand the limitations of the current policies and to understand what the viable alternatives might be.** In short, it is necessary to know *what works* to improve the quality of life of people with disabilities and in a situation of dependency, to improve the working conditions of the professionals that care for them and the conditions in which care is provided in the family or in the non-professional sphere, as well as to redistribute the burdens of care. The *What works in long-term care?* project seeks to provide this information. By identifying, filtering and putting the rigorous evidence that exists on LTC policies and services into an accessible format, it seeks to help public policy decision-makers make informed decisions. Furthermore, given the marginal nature of LTC in the

[6] Comas-d'Argemir and Bofill-Poch, 2022: 21.
[7] Comas-d'Argemir and Bofill-Poch, 2022: 20 citing Walsh et al., 2021.
[8] Tronto, 2024: 28.
[9] Tronto, 2024: 27.

institutional space —despite its social relevance in both the productive and reproductive spheres— the project serves to give it greater visibility.

The goals of this first issue that presents the project are threefold. In the second and third sections, a conceptual and diagnostic overview is offered on what LTC is and how it is currently organised in Catalonia. The fourth section seeks to understand the main public policies that configure the public efforts in this sector, including its cross-cutting features and the people to whom these policies should be addressed. Throughout the document, the aim is to establish structuring elements to analyse evidence that allows improvements to be made to LTC. The aim is to ensure that sufficient places are made available and that the service is good quality, sustainable –both for the people who provide it and for society as a whole– and fair –both for the recipients and the caregivers, so that the services avoid reproducing existing social inequalities. The fifth and final section explains the *What works in long-term care?* project, including the methodology and objectives that underpin the following issues.

2. What is long-term care and how should it be approached conceptually?

2.1. What are LTC facilities?

Care can be defined as all activities carried out by living beings towards the environment or other living beings in order to guarantee decent living conditions and people's full participation in society.

Care can be defined as all activities carried out by living beings regarding the environment or other living beings in order to guarantee decent living conditions and people's full participation in society. People need care at all stages of their lives, something which highlights how interdependent we are. Within the framework of care services, **LTC is care aimed at people who, for reasons involving health or disability, cannot meet their most basic needs by themselves, both physiological ones and also all those that contribute to giving them independent and community-based lives, guaranteeing their participation in society and in an adequate environment.**[10] For these people, care needs are essential and if they are not met, this can lead to serious situations of deterioration, and even put their

[10] Fields, 2024: 22.

lives at risk. This type of work thus becomes essential for building just and supportive societies, turning care into an area that structures social institutions.

The concept of social care

Long-term care can be analysed under the concept of social care.[11] Social care is a multidimensional concept that refers to care as work that is an obligation and responsibility, and as an activity that involves an expense, both financial and emotional. The work dimension allows us to take care out of its social organisation and study it with respect to other occupations, defining variables such as the types of care work that are paid and those that are not. The obligation and responsibility dimension allows us to give it a normative character, and avoid considering care as only a work activity, since it is provided under social and/or family relationships and responsibilities. Finally, the expense dimension allows us to analyse how the costs are distributed among the different social actors.

Within the framework of LTC, a large part of the care work focuses on **basic daily activities,** such as physiological ones, personal hygiene, proper nutrition, taking medication and prevention work to maintain or improve the recipients' health and well-being. Besides basic daily needs, work that guarantees **personal autonomy** is also important so that people can continue to live in their own homes and participate in public and community life. This includes travel —something that can be challenging in the case of reduced mobility— adapting and cleaning homes, emotional support, listening, accompaniment, support for participation in social events, access to information and communication channels, political participation, measures to alleviate loneliness, etc. Finally, a key task in LTC that is not usually given enough consideration is **coordination** with the social environment of the person being cared for (their care ecosystem), including the relationship between paid and unpaid caregivers and between essential personal services, such as health and social services.

2.2. Which institutional actors are involved in the provision of LTC?

When we talk about the facets of responsibility, obligation and expenditure in the provision of LTC, four institutional actors can be underlined: **the family, the community, the public administration and the market.** Traditionally, since the end of the 19th century the construction of welfare states has been based on and has reproduced the model of the male bread-winner, with social policies being concentrated on protecting men's incomes

[11] Daly and Lewis, 2000.

and jobs, including their pensions. This meant not acknowledging the poverty generated for women who spent time in care activities, both for adults and for children.[12] This historical fact has produced **low state participation in the sphere of social care,** with shortfalls in the construction of state programmes dedicated to reducing the burden of care imposed on women, and unpaid care work bearing a disproportionate responsibility in meeting the needs of the population. It is precisely this lack of remuneration and of recognition of care activities that allows the productive system not to invest sufficiently in work linked to social reproduction, thus increasing the profitability of the productive sphere and of capital.[13] The economic impact of this work cannot be underestimated. Unpaid care work represents somewhere between 20% and 40% of global GDP.[14] One key problem within the framework of societies such as ours that reward production is that LTC services have a low productive value; i.e. the future returns on the expenditure made in them cannot be forecasted. Investment in LTC is perceived as an expense which has no productive value and, therefore, as a burden. This translates into the people who need care being discriminated against socially and the the labour rights of those that provide care being neglected, as well as a lack of willingness or capacity on the part of social actors to invest resources in these services.

Within the scope of public administration and the market, the LTC sector offers a variety of job profiles, in a system of division of labour where training and experience are important to distinguish the specific role of each person. The key job profiles in LTC services in Catalonia are that of nursing assistant, gerontologist, family worker, home assistant or personal assistant, depending on the type of service. **In this report we will refer to all these people as *care workers*. They are the ones that carry out most of the tasks helping the elderly residents with their daily activities and personal autonomy.** The training required is more or less demanding and wide-reaching depending on the country and the administration that regulates the sector. Another service that is closely linked to LTC services is health, in particular, nursing; regulations and training mean that nurses have the capacity to implement treatments that care workers are not allowed to perform. In addition to these professional profiles, a wide diversity of other profiles are key to guaranteeing quality personalised care services, including reablement personnel (occupational therapists, speech therapists, physiotherapists), and administrative staff, among others.

Given the precarious conditions of direct care labour markets in LTC —including low pay, part-time positions, the psychological and physical burden, etc.— when more people are in vulnerable situations the fluctuating demand for work in the sector increases. This demand is higher when there is higher unemployment and economic crises and lower in situations where better opportunities exist in other sectors. In addition, the sector suffers from high

[12] Daly, 2023: 149.
[13] Duffy, 2005.
[14] International Labour Organisation, 2018.

rates of employment in the shadow economy, something especially true of home care. It is estimated that in Catalonia in 2023, around 35% of domestic and care work was informal.[15] Similarly, in terms of demand for services, in Catalonia, where the public LTC sector has traditionally fulfilled an institutionalised care function, the people who turn to public services are those who lack private resources. In addition, it must be taken into account that dependency or disability constitutes an economic disadvantage in itself. People with disabilities suffer an additional economic burden that ranges, on average, between 17,700 and 41,200 euros per year.[16] Therefore, **it is common for both demand and supply in the public or community care sector to involve people who have financial difficulties.** The Law for the Promotion of Personal Autonomy and Care for People in Situations of Dependency (hereafter LAPAD) was approved in 2006, and has helped the system move towards becoming more universal by making LTC a right enshrined in law. However, as explained in the following section, lack of funding and the design of the law itself have posed limitations to meeting the existing demand.

2.3. Current inequalities in responsibilities for providing care

As already mentioned, the LTC sector and the provision of social care in general are highly feminised. According to EPA data, in 2019, 95.5% of nursing assistants, home carers and domestic workers were women.[17] Furthermore, if in 2014 10.8% of households in Spain required LTC, in 81.8% of the cases, most of this care was carried out by someone in the family and in 64.7% of these cases it was carried out by a woman.[18] According to an OECD report (2022), Spain, together with Italy, is one of the countries with the highest percentage of caregivers who are relatives or acquaintances of the person being cared for: approximately 15.3% of the population. According to the same study, Spain is also one of the countries where the provision of care is most intensive in terms of hours, with the majority of non-professional caregivers dedicating over 20 hours a week to care tasks. Therefore, the role of the family in the provision of care in Spain is crucial.[19]

One of the main causes of the feminisation of social care is gender inequality in the social organisation of care and the differentiation made by patriarchal societies between production and reproduction. **A central element here is how the figure of women is subordinated to and dependent on the institution of the family and the predominance of**

[15] Work Observatory and Productive Model, 2022.
[16] Ajuntament de Barcelona (City Council) 2019.
[17] Martínez-Buján et al. 2022: 78.
[18] Martínez-Buján et al. 2022: 48.
[19] Quintana et al. 2024

family-centred cultural models that dominate the division of labour and state institutions.[20]

Gender inequalities in the demand and supply of care
Social norms construct femininity based on private responsibility for care, whether for children, the elderly or people with disabilities. This has two consequences. First, within the household, women are more likely to be responsible for providing care, both for children and for relatives who need support due to illness, disability or old age. This makes it more difficult for them to participate in the productive sphere and, therefore, to train and gain experience within the labour market. Second, gender inequalities are also present in the labour market, where the wage gap, segmentation of labour markets and gender discrimination penalise women's participation in the public sphere and put them at a disadvantage in negotiating the distribution of care tasks within their households. Furthermore, in welfare states that determine social rights based on labour participation, the lack of contributions from work hinders the right to social benefits in old age, including access to social care services. For example, the average retirement pension for women in Catalonia in 2022 was 886 euros for women and 1,426 for men.[21] Thus, from the demand side, women are also more disadvantaged when it comes to accessing LTC services. This is especially important if we take into account that the demand for services for people over 65 is also feminised: in 2024 in Catalonia 61% of people aged between 65 and 79 years old who were entitled to a dependency benefit were women, a figure that increases to 75% for people aged 80 or over.[22]

When analysing care, it is crucial to take into account an intersectional perspective in order to understand how there are other social factors besides gender that create inequalities, discrimination and differentiated identities within the sector.

It must be taken into consideration that gender is only one of the social determinants that conditions the unequal social composition of the LTC sector. Country of origin, social class and age are also key factors. When analysing these aspects, it is necessary to use an **intersectional perspective to understand how other social factors besides gender create inequalities, discriminations and differentiated identities within the sector.**[23] Taking these intersections into account will help give a voice to people on the margins of institutions so

[20] O'Connor, 1993; Harding, 1996; Moreno et al., 2014; Pfau-Effinger 2017.
[21] Quotidiana, 2022.
[22] Data taken from IMSERSO, 2024.
[23] Crenshaw, 1991.

that they can participate in public policies, leading to programmes designed and adapted to the complexity of inequalities according to identity, experience and access to resources.[24]

In Catalonia, two key profiles can be highlighted that have key responsibilities in the provision of care. Firstly, **middle-aged migrant women who are from the middle or lower social classes in their countries of origin.** According to EPA data, in 2019, 51.6% of nursing assistants, home caregivers and domestic workers were migrants.[25] Many of them have had to leave their countries, families and communities for political or economic reasons or to escape violence. Global care chains thus reproduce neo-colonial relationships, with a global care labour market that operates between economically unequal countries.[26] On the one hand, when people emigrate from certain countries, they find it difficult to validate their qualifications and previous work experience; on the other hand, their irregular administrative situation means that the work offered to newly arrived women are in social care. Many of these jobs are not stable. They are performed in the shadow economy and are poorly paid, placing workers in highly vulnerable and unequal positions.[27] In addition, since these workers are women, socially their roles involve having care responsibilities in their own homes, and the barriers to "externalising" them hinder their professional and social development.

Secondly, **another major profile, especially among unpaid caregivers, is that of older women who are approaching retirement age or have passed it.** For example, in 2023, 78% of unpaid caregivers were over 50 and 34% over 67.[28] Thus, we find that older women care for people, especially other women who are older than them, and/or care for their disabled children. This situation is precisely due to the inequalities they have accumulated throughout life due to their gender, class, and other factors. The age and physical condition of caregivers and the number of years they perform this role are relevant to public policies, as they determine the quality of care that can be provided in the non-professional space, the health risks posed for caregivers, and the types of support in terms of services and benefits that may be required.

Finally, it should be remembered that LTC services take care of people who, due to their disabilities, suffer from significant physical and social barriers in accessing the labour market and generating income. In addition, these people incur numerous extra expenses, both for direct care services and for residential and adaptation resources. Therefore, people who need LTC care have a greater risk of falling into poverty. Likewise, **sexual orientation, gender expression and gender identity** are also important factors that can condition

[24] Daly, 2023: 156.
[25] Martínez-Buján, 2023: 78.
[26] Hochschild, 2014.
[27] Canada, 2021.
[28] Data taken from IMSERSO, 2024.

access to care resources, especially when social norms lead to discrimination and expulsion from both state and family institutions.

3. The role of the public administration in the LTC sector in Catalonia: advances and deficits in the creation of a model that aspires to universal coverage

Although most care in Catalonia continues to be provided by the family, with the public administration applying policies that tend towards targeted welfare, in the last two decades **progress has been made towards a model that aspires to universal coverage,** especially after the approval of the LAPAD in 2006, and the Catalonia Social Services Law in 2007.

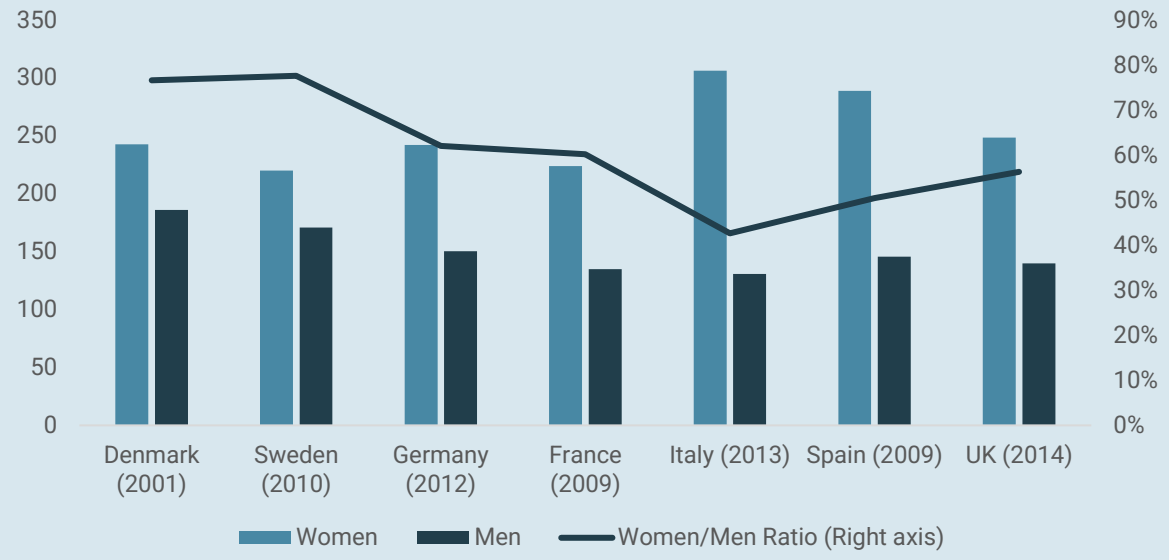
3.1. The LTC system before the LAPAD was passed

In terms of multi-level governance, there were two main actors in Catalonia in the financing and provision of services from the development of the welfare state in the 1980s to the LAPAD being passed in 2006. On the one hand there was the Generalitat, responsible for developing most of the specialised institutional services, such as nursing homes and day centres. On the other were local authority bodies, which through their social services networks provide basic social services, such as home care services, telecare, as well as other complementary services, especially for people in situations of social exclusion. In addition to the administration, social or community sector organisations, including those made up of self-managed workers and families, as well as entities from what has been called the third sector, have also played a relevant role as service providers and in the governance of the system.

LTC provision models

In the academic literature, an effort has been made to distinguish between different welfare state regimes in order to understand the different institutional configurations that LTC provision can take: the continental model, the Mediterranean model, the Nordic model[29] and the liberal model.[30] In the continental (e.g. Germany) and Mediterranean (e.g. Spain) models, the family, and especially women, play a central role in the provision of LTC. Although some changes have taken place over time, the State still has a minority role in the direct provision of services and is mainly concerned with implementing welfare policies for those at risk of social exclusion. However, apart from this, the continental model, which has high labour participation and productivity, has built a well-funded and extensive social system for the social classes that are well integrated into the labour market. If we look at the time-use statistics in Figure 1, at the beginning of the 2010s, women devoted more time to unpaid tasks in Spain than in Germany, both in absolute terms and relative terms compared to men.[31]

Graph 1. Average number of minutes per day dedicated to unpaid work



Source: own elaboration with data from OECD Data Explorer

[29] Typical of countries such as Denmark or Sweden. These countries have been characterised by a faster entry of women into the labour market and greater State responsibility for care, including a universal coverage perspective and direct management of services at the local level.

[30] Characteristic of countries with an Anglo-Saxon tradition such as the United Kingdom. In these countries, the participation of the State is minor and decentralised, but the entry of women into the labour market has generated vastly expanded LTC provision markets which are financed under welfare programmes set up by social actors and charities.

[31] Unfortunately, these time-use surveys, standardised at the European level, are not carried out frequently. In the case of Spain and Catalonia, data collected in 2023 and 2024 are expected to be published soon.

Since the 1990s, the demand for public LTC resources has increased progressively, a trend caused by the aging population and a crisis in the family provision model, caused by the entry of women en masse into the labour market and cultural changes regarding the responsibility of providing care. Faced with a lack of public coverage and sufficient home support services, as well as a paradigm of the institutions mainly serving people in situations of social exclusion, **there has been a proliferation in the LTC system of private residential and home services** (including ones in the shadow economy). The Generalitat (regional government) and local entities have prioritised the outsourcing of services through public procurement, while at the same time, their management and **services have been standardised.** In the process of the LTC sector growing, there has been a tendency to scale up the services (nursing homes, tenders made of lots, etc.), especially in the most populated urban areas, to take advantage of economies of scale and reduce spending.

This type of LTC provision model has been based on low labour costs and **the arrival and work of migrant women,** mostly from Latin America, but also from Eastern Europe. These workers have often been pushed into the shadow economy due to immigration regulations that make it difficult to obtain work permits.[32] Furthermore, together with the high level of informal jobs in the sector, its labour market has had low levels of unionisation and a lack of formal professional development. In this sense, **one of the major barriers to professionalisation in Spain —including in Catalonia— has been the social acceptance of the informal nature of care work.**[33]

A lack of public coverage and home support services, as well as a paradigm of the institutions mainly serving of people in situations of social exclusion has led to the proliferation of private residential and home services in the LTC system.

3.2. Approval of the LAPAD and its subsequent deployment

When the LAPAD was approved in 2006, care for elderly dependent people **became a right enshrined in law.** In Catalonia, the 2007 Social Services Law established that administrations must guarantee universal access to basic social services and must aim for them to be free, taking into account that users may have to contribute to paying for a part of telecare and home care services, in accordance with the provisions of this law. In accordance with the Social Services Portfolio, they must also guarantee universal access to guaranteed service benefits and the financing of the social module of these benefits. The Social Services Portfolio was established under this law, and sets out the benefits that are enforceable as a guaranteed right. In accordance with the provisions of the Social Services

[32] León, 2010.
[33] Moreno et al., 2014.

Portfolio, people who are in need have the right to receive these benefits and the Administration has the obligation to provide them, regardless of budgetary availability.

The framework of the LAPAD gave the central government a more predominant role in the coordination of the LTC sector and its financing, and the System of Autonomy and Dependency Care (SAAD in its Catalan acronym) was created.[34] An important innovation of the LAPAD was the inclusion of **direct monetary transfers,** including benefits linked to services and financial aid to caregivers who are family members. Thus, the development of LTC services has followed the same decentralisation process as other areas of the welfare state, following a quasi- federal logic:[35] the central government has a significant role in their financing and regulation, but powers for LTC services fall mainly to the autonomous communities, which, in turn, delegate a large part of home care services to the municipalities. The new regulation establishes that the right to a public benefit and its intensity depend on the degree of dependency that has been accredited by health authorities: Grade 1, Grade 2 and Grade 3. **A new circuit has been created to distribute these benefits:** after the degree of dependency has been determined, the basic social services centres and the authorised authorities develop an individualised care plan (PIA in its Catalan acronym) with the help of a specialised social worker, together with the person in a situation of dependency and their family.

The new LAPAD system has serious design flaws and practical limitations in terms of universalising benefits, defamiliarising care and improving quality of services and working conditions.

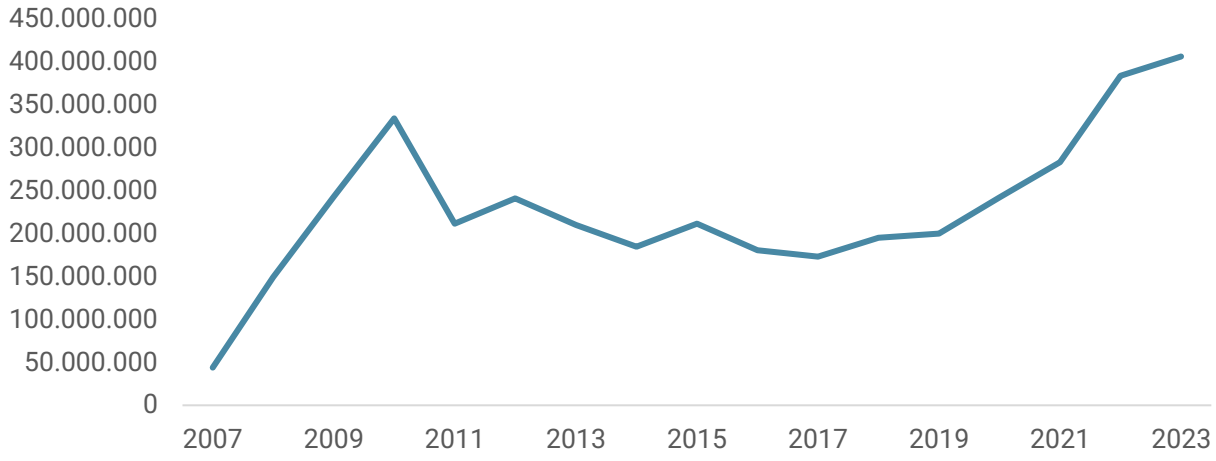
The LAPAD created high expectations about the system's ability to adequately finance services, improve working conditions and professionalise the sector. And it is true that the new system has been effective in expanding the social services network, public coverage and employment in the LTC sector.[36] However, the system **has serious design flaws and practical limitations** in terms of universalising benefits, defamiliarising care and improving the quality of services and working conditions. In practical terms, the 2008 economic crisis and subsequent austerity policies led to significant cuts in funding and benefits, including the suspension of funding that had been agreed and the freezing of the public price of

[34] Specifically, two components were created: a minimum funding from the General State Administration (GSA) and the autonomous communities (ACs) based on the people accredited as dependents in each territory and their degree of dependency, and funding agreed on by the GSA depending on the agreements reached in the Territorial Council of Social Services and the System for Autonomy and Care for Dependency, created under the new System for Autonomy and Care for Dependency (SAAD in its Catalan acronym). Finally, the additional contribution made by the ACs was maintained. The concept of co-payment based on economic capacity was also created, established at a maximum of one third of the cost. Likewise, under the SACD, the autonomous communities, including Catalonia, deployed regulated service portfolios.
[35] Gallego, 2016.
[36] Cabrero and Gallego, 2013.

services in the social services portfolio. Although by law co-payment cannot exceed a third of the total funding of the system, in the worst years of the crisis the average reached was 50%, with differences observed between autonomous communities.[37] As can be seen in Graph 2, overall the period from 2011 to 2021 was a lost decade in terms of funding for the LAPAD. Thus, it was not until 2019 that the funding that had been agreed upon began to recover. In fact, in Catalonia, the first updates of public prices and benefits since 2008 were made in in 2021.

Today, the average time that elapses from a degree of dependency being decided to the equivalent benefit being granted has been reduced considerably, and has gone from 340 days in January 2020 to 106 days in May 2024.[38] In comparison, the average in all of Spain was 158 days in 2020 and 112 days in 2024. In this way, **Catalonia has gone from being the autonomous community with the longest waiting time to being in the middle of the range.** As a result, in Catalonia the figures have gone from 69,904 beneficiaries who have to wait over six months without receiving benefits to 39,615, a figure that is still very high.

Graph 2. State administration financing in Catalonia through the agreed minimum financing under the SAAD



Source: own elaboration with data from IMSERSO

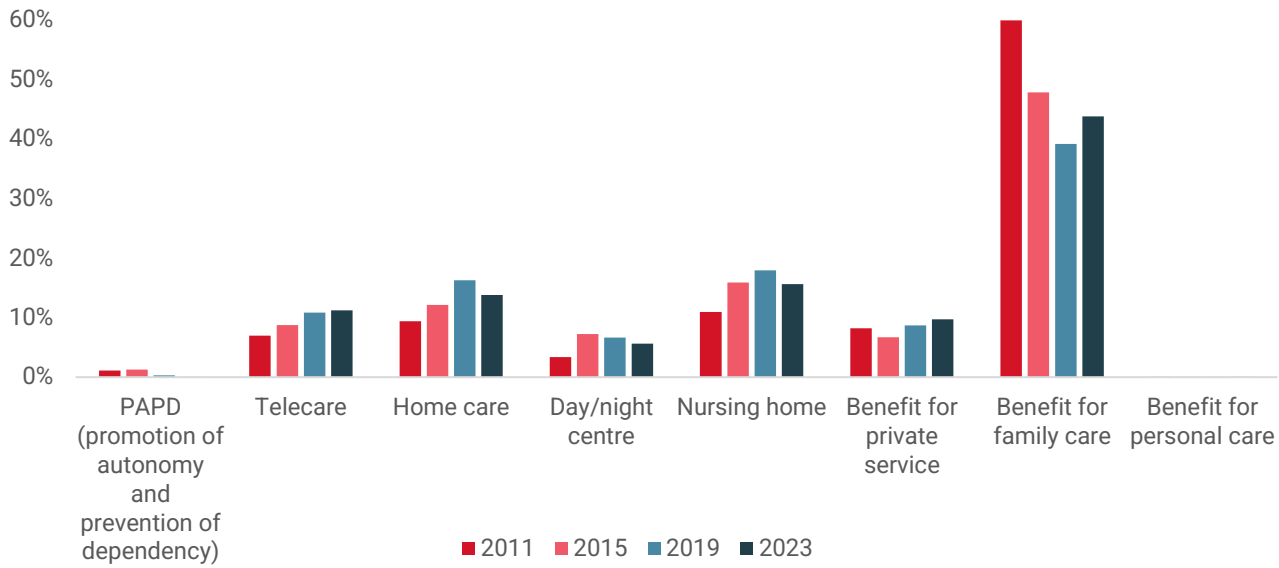
However, in terms of funding, Spain still falls far behind other countries. It is estimated that in 2019 Germany dedicated around 1.8% of GDP to LTC services, while in Spain the figure was 0.7%. Thus, it is estimated that, for example, if in Germany the public system covers (on average) 80% of the cost of home care services, in Spain this is only around 40%.[39]

In terms of design, **the system has relied heavily on monetary benefit payments.** As can be seen in Figure 3, the majority of benefits under the SAAD correspond to benefit payments

[37] Pozo-Rubio et al., 2017.
[38] Data taken from IMSERSO, 2024.
[39] European Commission, 2021.

for care in the family. The prevalence of benefits paid to non-professional caregivers goes against the goals of the LAPAD, which are to lessen the involvement of families and to promote professional care at home.[40] In line with what has already been noted in previous sections, it should be taken into account that 65% of non-professional caregivers are women, 34% are children of the recipients of care, 32% their partners, and 20% their mothers.[41] Likewise, along with the remuneration of caregivers in the family, in the last decade, under a paradigm of aging at home, driven in part by activism and by associations that represent people with physical and organic disabilities, an **expansion and strengthening of home services** is taking place in Spain**,** approaching the mix of services available in other European countries (see Graph 4).

Graph 3. Evolution of the proportion of benefits granted under the SAAD over total benefits in Catalonia, 2011 to 2023



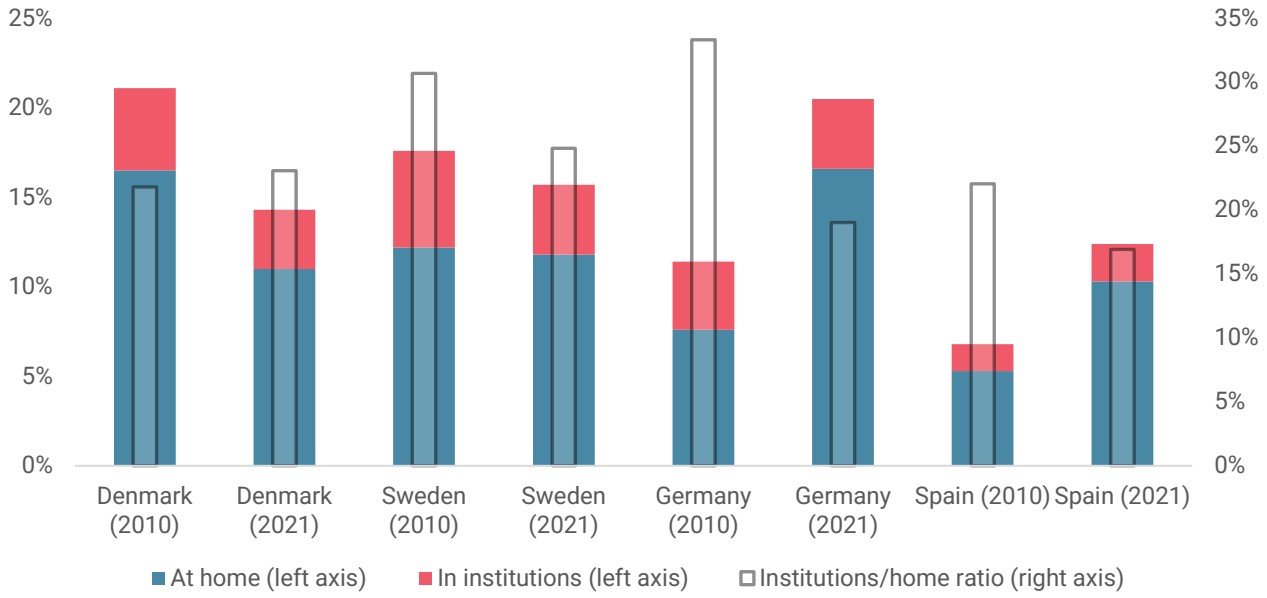
Source: authors, with data from IMSERSO.

Furthermore, the system has maintained a significantly **externalised provision,** something that has been **motivated and structured by reducing costs rather than by trying to improve quality and choice.** This fact has made it difficult to move towards high quality models that redistribute the burden of care between the different actors involved in providing it. It should be mentioned that there is also a general trend in Catalonia (and in Europe as a whole) of the **commercialisation and financialisation** of LTC services, with large multi-service multinationals or specialised companies entering the sector.[42] Although the presence of for-profit actors has been common in many regions for decades, including in

[40] Martínez-Buján et al., 2023: 59.
[41] Data drawn from IMSERSO, 2024.
[42] Palomera and León, 2023.

Catalonia,[43] the current feature that differentiates Catalonia is the potential increase there in market concentration around large multinational companies and investment funds, with the management of outsourced services being a central activity of the business model. And although services are still in the hands of several providers, with many small and medium-sized social entities managing modest-sized services, the market concentration in terms of the new services, including residential ones, should not be underestimated, along with the financial pressure that can be posed to social entities when they have to compete with management models that are based on generating large economies of scale.[44]

Graph 4. Proportion of the population over 65 receiving care in institutions and at home, 2010 and 2021



Source: own elaboration with data from OECD Data Explorer

[43] According to the Map of Social Services of Catalonia, in the case of residential services, in 2000 there were 37,281 residential places in Catalonia; 17% of them were publicly owned, 14% privately owned under agreements or in collaboration with the Generalitat, and 69% privately owned without any agreement or collaboration in place. After an accelerated growth process, in 2014 this number had reached a total of 58,294 places. Subsequently, the trend has been one of much slower growth, reaching 61,322 places in 2022. The increase in residential places has mainly been through more places being offered through agreements and collaborations, which in 2022 represented 35% of places, 21 percentage points more than in 2000, while publicly owned places continue to represent 17% of the total. Likewise, there has been a slight increase in the proportion of for-profit companies, which went from managing 65% of the places in 2000 to 72% in 2022. In addition, it must be taken into account that a majority of publicly owned places are under delegated management, although historical data on this is more difficult to access. In the case of Barcelona, which has a large nursing home market, since 2000, under 10% of public nursing homes have been under direct management; in 2018, for-profit companies managed around 50% of the places, compared to 40% managed by non-profit bodies.

[44] Palomera and León, 2023.

One of the concerns voiced by several administrations, both in Catalonia and in the rest of Europe, is the **shortage of (skilled) labour that exists in the LTC sector.**[45] In this regard, the sector continues to suffer from significant deficiencies that negatively affect the living conditions of workers, as well as making professionalisation and the retention of talent more difficult. In Spain, in 2020, 36.9% of nursing assistants and 32.5% of home carers had temporary contracts.[46] In 2009, the turnover of direct care workers in nursing homes was 23%. This dropped to 17% in 2014 –in the midst of the economic crisis and a downturn in labour markets in general– and then rose again in 2019 to 23%.[47] These figures contrast with the turnover of management and administrative staff, which in the same years was around 7%. It is also necessary to take into account the wage gap that exists in the social sector compared to the health sector, with people in the same professional category being paid lower wages simply for the simple fact of working, for example, in a nursing home rather than a health centre.

Furthermore, even though the LAPAD has been passed, the system has not moved towards the creation of a more integrated and coordinated system, besides greater regulation and the increased importance of the LTC sector in social services. **The problem of fragmentation became especially evident during the COVID-19 pandemic crisis,** with the institutions displaying little capacity to regulate and apply preventative measures in private nursing homes.[48] It could also be added that one of the main problems of the LTC system in Catalonia, apart from the lack of public control and the delay in benefits reaching the beneficiaries, is a **lack of information, transparency and data generation,** which make it impossible for families to obtain sufficient information to be able to choose from the available services and for administrations to have data on the results of the benefits granted, in order to be able to assess their suitability.

4. LTC policies in Catalonia

As already explained, the current model of LTC in Catalonia suffers from several shortcomings in both its objectives and its strategy. It **prioritises reducing costs** through processes of outsourcing to the family, the market and community institutions. In line with an egalitarian vision that aims to moves towards universal coverage, there is a need to **socialise social care so that individuals are not left to find their own solutions** and so that it ceases to be structured in a way that its negative effects affect specific sectors of the population. These sectors especially involve women, in particular migrant women with scarce resources and older women in the recipient of care's family environment. The

[45] Eurofound, 2020.
[46] National Institute of Statistics, 2020.
[47] IDESCAT Economic Survey of Social Services, 2024.
[48] León et al., 2021.

responsibility of the public administration in terms of organising LTC needs to be increased, in line with the LAPAD; strategies for aging at home need to be reinforced, and the right of people with disabilities to lead an independent life in the community while they receive quality and participatory services needs to be respected. Likewise, a major challenge is the care of complex cases, including people with multiple disabilities and autism; here there is a need to adapt the services offered, including better carer-recipient ratios and training for professionals.

In this sense, **a model that is now widespread in Catalonia is that of Comprehensive Person-Centred Care** (hereinafter CPCC). CPCC is a widely used concept that can currently have varying interpretations. CPCC can be defined as care that "aims to achieve improvements in all areas of the quality of life and well-being of the person, based on full respect for their dignity and rights, their interests and preferences and taking into account their effective participation".[49] In terms of LTC care, the CPCC philosophy also defends the right of people with disabilities to live independently and in the community, the right of people to choose where they age, the deinstitutionalisation of the system and the creation of support systems so that all this can be carried out (personal assistance, more independent living units both in nursing homes and in new co-housing designs, etc.). In terms of a person's right to live independently, one key element is the protection of their autonomy and avoiding paternalistic approaches. In this way, CPCC aims to ensure that the organisational and professional elements of care do not take precedence over the people cared for exercising their choices. The CPCC model is a model of care that seeks to be applied to the whole range of LTC services and policies, both home services and nursing homes.

The responsibility of the public administration in terms of organising LTC needs to be extended, in line with the LAPAD; strategies for aging at home need to be reinforced, and the right of people with disabilities to lead an independent life in the community while they receive quality and participatory services needs to be respected.

The inclusion of a CPCC vision to the services has certainly been influential. In parallel, and somewhat related to it, recent public policies in the LTC sector have been showing a growing interest in **community-based deinstitutionalisation methods and practices,** which question individual-level models of intervention.[50] Under concepts such as the creation of caring cities, caring neighbourhoods, caring municipalism, the democratisation of care, etc., used by supramunicipal organisations such as the Diputació (Barcelona Provincial Council) or the Spanish Federation of Municipalities and Provinces (FEMP), as well as various local

[49] Rodríguez, 2010.
[50] Comas-d'Argemir and Martínez-Buján, 2022: 431; Espai Zero Vuit, 2023.

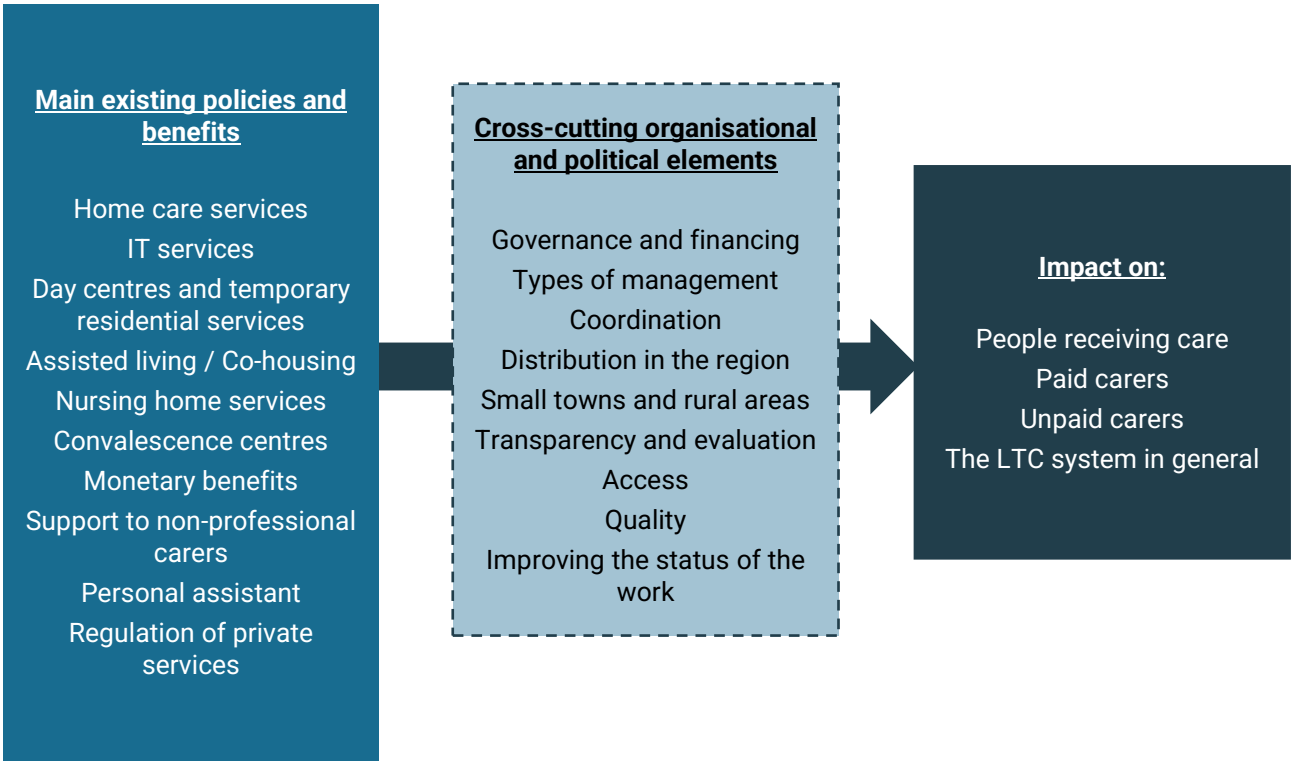
councils and other local entities, is the idea of **creating local provision systems that are capable of distributing and organising care work using democratic principles.**[51] Likewise, the recent deinstitutionalisation strategy of the Ministry of Social Rights includes the goals of promoting personal assistance, offering a support service for independent living or the creation of living units within nursing homes to better organise care.[52] With these systems, the public administration seeks to simplify services and better adapt to the needs of people involved in direct care, including the people cared for and their carers, both paid and unpaid. It also seeks to promote ways in which these people can participate in the changes made and steer them, increasing their decision-making and self-management capacity. Finally, the administrations seek to improve the coordination between public and private services (or their integration).

To advance these objectives, **public administrations are using various tools,** including implementing more LTC services with community perspectives all over the region, improving workers' conditions, fostering the participation of users and workers in the organisation of services throughout the entire process, from the initial identification of needs, to the design, implementation, monitoring, evaluation and continuous improvement of services. In addition, social infrastructures to strengthen the community are being reinforced, new forms of urban planning and housing are being contemplated, and new ways of organising care are being promoted, including fostering mutual support and the greater involvement of society as a whole in care, including men.[53]

In order to examine the different elements that can help us understand the current LTC system and where improvements can be made to it, firstly, a review is made of the main services in place. The results aimed for by these services are then explained. Finally, there is a discussion of the cross-cutting issues to consider when organising LTC services.

[51] Ezquerra and Mansilla, 2018; Valdivia, 2018; Dowling, 2021; Martínez-Buján, 2020; Kussy et al., 2023.
[52] It can be consulted here (in Spanish).
[53] Ezquerra and Mansilla, 2018; Comas d'Argemir and Martínez-Buján, 2022: 442; Kussy et al., 2023.

Figure 1. Conceptualisation of the elements underpinning the LTC system



Source: own elaboration

4.1. Main existing policies and benefits

The LTC system is based on a catalogue of services that are regulated by the LAPAD and developed in the social services portfolios of each Autonomous Community. However, each Autonomous Community's laws and portfolios may offer additional services. When addressing the instruments for LTC care here, the services in the Generalitat de Catalunya's social services portfolio are those that are taken as a reference. However, using this reference does not mean that this is the correct categorisation that a LTC system should have in order to move towards an effective CPCC model.

Home care services

These are social care services provided in the environment of the person being cared for, which should include both their home and the public spaces and infrastructures around their homes. The objective of home care services is to allow people in situations of dependency to maintain an adequate standard of living in their homes. In this service, care workers provide direct care so that the recipient can carry out basic daily activities and participate in society. But home assistants are also an essential tool to further this goal; they are responsible for making sure the home is kept in an appropriate state to guarantee the well-being of the person, including its correct hygiene. In general, the satisfaction

expressed by the people cared for regarding the services is usually high, due to the needs they have, although these services also present some shortcomings that are explained below:

→ **inadequate intensity** of services compared to people's real needs;[54]

→ **high turnover** of domestic workers caused by substitutions;

→ **workers' pay eroded** in the face of the increase in the cost of living in cities;

→ lack of **emotional and logistical support and training** for workers;

→ deficiencies in **coordination processes and the possibility to self-manage** work, including inflexible tasks, managing substitutes, and the ability to adapt schedules to the people helped;

→ **lack of flexibility** in schedules, including lack of coverage on weekends;

→ and the need for a systemic vision of services to **avoid fragmentation** with other services.

IT services

It is crucial to look into the opportunities that **technological innovation can offer for continued care, better monitoring and the provision of new services for people receiving care in terms of support for self-care and empowerment.** Technological innovations can take various forms and can be used in multiple ways. At home, improving the telecare system and prevention tools is key. The inclusion of robots or other systems that can help improve health indicators and monitor medical guidelines, including activating alarms in case of need, can offer important ways of allowing people to age at home and relieve caregivers of care tasks. New technological supports based on sensory inputs allow for care to be personalised and promote autonomy (for example, controlling lights or raising or lowering beds automatically, etc.). Similarly, artificial intelligence can be an important aid for the early detection of mental illnesses, such as dementia, among others. The Internet of Things can also help personalise care based on behavioural patterns. Both at a person's home and in nursing homes, technologies can also help increase autonomy and lighten the physical burdens borne by caregivers. These include robots and other support products that facilitate mobility and the performance of basic tasks. Along these lines, technological innovation must serve to promote physical and sensory accessibility for all people, in order

[54] According to data from IMSERSO for 2024, the average number of hours provided for a Grade 1 dependent person is 3.2 per day for five days, 5 hours for Grade 2 and 6 hours for Grade 3.

to guarantee the application of the regulations set out in the Accessibility Code (Decree 209/2023).

However, **the incorporation of these innovations must be carried out as a complement to the essential social care provided by workers, and not a replacement for it.** Technology cannot be used to replace human interaction and social relationships, as this could increase people's feelings of loneliness further. Nor should using more technology create greater complexity in the LTC system, barriers to access to care or a heavier workload for workers. It is important to highlight that a digital divide affects the elderly and many people with disabilities; this means that support must be provided for them in using technologies and their choice to use of this type of service or not must be respected. To include people with disabilities, the provision must take into account their specific needs, and for this reason their participation in designing IT tools, as well as in their monitoring and control, is necessary. It is also necessary to foresee the energy expenditure of these systems, since this must not represent an additional cost for communities that already suffer from poverty in general, including energy poverty.

Day centres and limited time accommodation

Day centres and accommodation centres with time limitations care for people who are in a situation of dependency during the day or at night, covering their basic needs and providing recreational and social services. These services are complementary to the support that these people receive in their own homes, with an aim to allow them to remain there. In some cases, the services can also function during the weekend or throughout the day, especially in the cases of people with intellectual disabilities. Often, nursing homes have a day centre in their buildings, optimising the use of resources, such as staff.

Unlike nursing homes, which can have an occupancy rate of around 90%, the occupancy rate in day centres managed by for-profit companies is around 50%,[55] indicating a lower preference for these centres. In addition, subsidised day centres without residential places find it difficult to be profitable because the demand for them and their level of occupancy is insufficient compared to the cost of their operations (in general, day centres, night centres and subsidised nursing homes need to have full occupancy to be economically sustainable, especially given the low public prices). Being able to use a day centre does not eliminate the cost of support at home, which is why going into a nursing home may be a preferable option in economic terms and in terms of time. While the public price of a day centre is around €900 for seven days a week, that of a nursing home is around €1,900. The difference in price is lower if the co-payment is low. Thus, **the greatest challenge for day centres is to become an attractive and affordable option for families.** This would involve

[55] IDESCAT, 2023.

extending public support and including complementary services in their financing, including adapted transport. Another barrier is lack of information available about the existence and scope of these centres, both for professionals and for society in general. In addition, to improve these centres, **support could be given so that they become public interdisciplinary infrastructures that serve the community**. They should also support care work and training, and should be open to the participation of interdisciplinary teams and voluntary activities, incorporating initiatives to combat the loneliness and isolation felt by people with dependencies.

Assisted living / Co-housing

On the one hand, assisted living is infrastructure designed to guarantee autonomy for people in a situation of dependency, providing them with the support of social care services to meet their basic needs. On the other hand, co-housing schemes promote new shared housing models and facilitate social participation and mutual support between residents. Although these types of resources are not part of the SAAD, **they have gained prominence over the last decade** under the paradigm of aging at home and CPCC, and assisted living is included in the framework of the social services law of Catalonia. However, there are several differences in their management models that can determine their outcomes. It is necessary to distinguish between forms of living and cooperative ownership under self-management logics (co-housing) as opposed to forms of public ownership that work under a social rental regime, and require the support of social workers (housing with support offered).

The main barriers to this type of housing are **building and financing it.** These are significant barriers faced by municipalities that may have scarce public land and/or low spending capacity, and also by groups that would like to set up housing cooperatives. Public-community collaboration is usually a tool for promoting these kinds of projects, and can work both by facilitating financing in the form of subsidies, direct credit or guarantees, and by freeing up land for housing projects under transfer-of-use contracts. When deploying these resources, however, it is necessary to include universal access criteria, in order to guarantee social benefits for the people who will live there. It is also necessary to promote projects that free up existing private housing. **Another major challenge for this new type of housing is to become a real alternative to institutionalisation for people who have high degrees of dependency.** To achieve this, key actions could be the inclusion of specialised support, promoting services such as personal assistance and home care services, as well as designs that generate common areas for shared care.

Nursing home services

Nursing home services are infrastructures dedicated to the care of people in a situation of dependency that work round the clock and offer all the services necessary to respond to their physiological needs, in terms of personal hygiene and accommodation, food and cleaning, as well as emotional support needs and social needs, such as social and cultural activities. Additionally, nursing homes also offer complementary services, such as physiotherapy, podiatry, and hairdressing, among others.

In Catalonia, a predominant model is currently in place of increasingly larger,[56] privately managed nursing homes (including in publicly owned centres). These suffer from the following problems:

→ a hierarchical organisation pushed by a **quest for efficiency** and reducing spending, with a growing trend towards for-profit nursing homes with high profit margins;

→ **low-quality care** practices (that can even violate the principle of dignified care, such as physical, mechanical, chemical or pharmacological restraints);

→ low salaries and lack of staff, with the LAPAD establishing **low staff ratios and prices;**

→ an **overload** of work for the carers who work in them, leading to low job satisfaction and a high incidence of absenteeism;

→ a **widespread lack of resources,** which includes a lack of coordination with other services, such as social services and health services (limiting the ability to react to situations such as COVID-19);[57] [58]

→ a growth in complex cases (multiple disabilities, behavioural disorders, etc.) that current services do not have the expertise, ratios, or professional profiles to handle.

However, despite nursing homes being the last option for more than 90% of families and people with care needs, places in them are still in demand due to their cost and their wide coverage of needs, as well as the lack of effective alternatives for aging at home in situations of high care needs. Elsewhere, the current trend is to create new care models

[56] According to the Register of Social Entities, Services and Establishments of the Generalitat de Catalunya's Department of Social Rights, the average size of the nursing homes registered increased from 60 places in 2000 to 90 places in 2022. However, the average number of places in the nursing homes in Catalonia is still lower than in other autonomous communities. According to data from IMSERSO (2020), the average size of nursing homes in Catalonia was around 70, while in Madrid it was 120.
[57] Comas-d'Argemir et al., 2022: 302.
[58] León et al., 2021.

and architectural designs based on the **creation of more independent living units and more adequate staffing and resources,** as well as a greater democratisation of the management and use of services. This is a process that was already carried out in Nordic countries such as Denmark in the 1980s and 1990s and which is also spreading to countries such as Germany.

In the rest of Spain there are also some interesting cases to examine, including the Basque Country. In the 2019-2023 legislature, the central government approved a new model that established a maximum number of residents in each nursing home, increased staff ratios, and required the creation of living units for a maximum of 15 people, with a minimum of 65% single rooms that were public.[59] Among the greatest challenges faced by the deployment of this law will be higher funding, improved working conditions, improved transparency, greater coordination with community health services and social services and the limits placed on profits. A cultural change related to independent and community living models is also needed (training for professionals, support for the community where the centre is located, etc.), as well as guaranteeing a CPCC model that includes the participation of users in the planning, management and evaluation of the services offered.

Despite being the last option for more than 90% of families and people with care needs, nursing home places are still in demand due to their cost and their wide coverage of needs, as well as the lack of effective alternatives for aging at home in situations of high care needs.

Convalescent health services

The convalescent health service is a service under the **jurisdiction of the Department of Health but which works in coordination with the Department of Social Rights.** In Spain, it is a service that exists only in Catalonia and is mainly financed by the Department of Health, as well as by a deferred and lump-sum co-payment that only affects long-stay services. Convalescent health care includes care intended for people with illnesses that are generally chronic, as well as care for people with disabilities who, due to their special characteristics, can benefit from the simultaneous action of health and social services to enhance their autonomy, alleviate their limitations or suffering and facilitate their social reintegration. It is also intended for people with dementia, people with neurological diseases that might result in disability, the elderly, people with advanced terminal illnesses and people who require palliative care. The aim is to provide comprehensive, interdisciplinary and geriatric care in

[59] The new criteria can be consulted in the "Resolution of July 28, 2022, of the Secretariat of State of Social Rights, by which the Agreement of the Territorial Council of Social Services and the System for Autonomy and Attention to Dependency is published, on the common criteria for accrediting and upholding the quality of the centres and services in the System for Autonomy and Attention to Dependency" (in Spanish).

centres that have both health teams and social workers, who also seek to promote people's autonomy so that they can age at home. Some of the key services they offer are inpatient services in the form of social and health care, both medium and long-term, and home care support services, such as day hospitalisation and home care programme/support (PADES in its Catalan acronym), deployed in interdisciplinary teams that provide support in advanced illnesses or in end-of-life situations.

Unlike other services, which have been growing to a greater or lesser extent, in the case of convalescent health services **the number of places has dropped over the last decade,** going from a maximum of 5,865 places in 2009 to nearly 30% fewer places available in 2020. This is a service that also has high rates of outsourcing to private management. Among the main problems of this type of service are:

→ the **lack of funding** granted by the LAPAD, which does not include additional funding for the Autonomous Communities that provide greater health and social health benefits to their populations;

→ the **lack** of a greater **community and public perspective** ;

→ **overcrowding** due to the lack of available residential spaces;

→ the inclusion of **co-payment.**

Monetary transfers linked to services

As seen in previous sections, the current SAAD highlights the economic benefits linked to services, both at home and in residential settings. There are various types of benefits, which are configured differently, including the maximum amount disbursed. Ideally, giving people the possibility to choose the services that best suit their preferences can be very positive. In this sense, instead of transfers linked to services, the implementation of measures such as **self-directed support** could be further developed. This provides families with their own budgets for organising care, giving people greater flexibility to adapt to their particular needs. One proposed measure is the creation of **personal budgets,** understood as a system that allows each person to decide which services they wish to receive and how they would like to receive them, according to a personal budget that is assigned to them to spend how they wish.[60]

A system based on transfers involves complementing them with public policies to ensure:

[60] For example, you can consult the request for a personal budget and its configuration in this manifesto (in Catalan).

→ **a commitment** made by the **administrations** to provide quality care, and not seek to save on the public cost of providing services by replacing it with benefits;

→ support and **guidance** for people who have less information when making choices;

→ **systems for coordinating** and simplifying the system, in an attempt to make the most efficient use possible of public and private resources.

Models based on economic transfers work best if they are **high enough** and if there is **public control and leadership,** including the inclusion of a list of providers supervised by the administration or local bodies; the providers must follow social and ethical criteria, including the protection of working conditions. In Catalonia there is currently an accreditation system in place to be able to open a centre and sign a contract with the public administration and receive benefits linked to services; however, better evaluation and monitoring of the quality and social contribution of the services is needed.

In Catalonia, the lack of transparency regarding the LTC sector and the scarce value given to it has not yet generated an ideal context for this type of benefit to be successful. **Monetary transfers have been used by administrations more as a last resort in the event of a lack of public services, and compared to direct provision, represent an economic saving for public coffers.** For example, in the case of the economic benefit linked to nursing home services, from 2013 to 2022 in Catalonia the maximum payment was frozen at 715 euros per month. Over that period, the public price of a nursing home place for a person with accredited Grade 3 dependency was 1,850 euros, meaning that at least 1,135 euros (61% of the cost of the place) had to be paid in the form of a co-payment. In 2023 the maximum amount of the benefit was updated to 1,238 euros, which did suppose a significant increase. However, the public price of a nursing home place for a person with accredited Grade 3 dependency also increased, to 2,002.56 euros. In this way, the co-payment was at least 764 euros (38% of the cost of the place). In addition, it must be considered that this co-payment is usually higher, since private residential places tend to have higher prices than those established for public places, especially for single rooms. According to the LAPAD, co-payments can in no case represent more than one third of the financing of the system, so despite the increase in the benefit in 2023, it is still insufficient to comply with this legal mandate. Moreover, besides the question of whether the law is being upheld or not, it is questionable that the public system forces people without financial resources who cannot access a public place to pay a co-payment.

Support for non-professional caregivers

This type of resource is essential in a context like the one in Catalonia, where the family continues to play a central role in providing care. As previously seen, the LAPAD created a **monetary benefit for non-professional caregivers.** This benefit is widespread but

contradicts the goal of the public administrations being far more involved in care. Due to the lack of control over the impact of these benefits and their uses, some families use the benefits to pay a private caregiver who is hired without a contract, promoting an underground sector and preventing its professionalisation.[61] Furthermore, **the benefits granted are very low.** In December 2023, non-professional caregivers caring for a person with Grade 1 dependency status received an average of 174 euros per month, while those caring for a person with Grade 2 status received an average of 283 euros per month and carers of people with Grade 3 status received 384 euros. These amounts are very low indeed, especially if we take into account the waiting lists to access public services and the opportunity cost that the provision of care has on the ability to participate in the labour market. Logically, the support that is most lacking in order to care for people in a situation of dependency is economic support (43.7% of households.)[62]

Besides economic benefits, public services and infrastructures have also been deployed to support non-professional caregivers. Particularly noteworthy are **temporary nursing home and respite services,** which care for people in a situation of dependency for a short time to give their caregivers a break; municipal and community services dedicated to offering social and cultural activities to caregivers; and training, emotional support and mutual support for non-professional caregivers so that they can provide care in a sustainable way. However, these services should be developed, expanded and incorporated into the new Social Services Portfolio in different ways. The greatest challenge is **to expand these services and make them more widely available, not only for people with low incomes and in situations of social exclusion.** In this sense, the recognition of the figure of the family therapist would be a support for all these non-professional caregivers; this person would be able to accompany all families, specifically those with family members who are aging.

Personal assistance

As has been seen, **personal assistance has barely been implemented in Catalonia and the rest of Spain** (with the exception of the Basque Country, where this benefit is of key importance, reaching 7.3% of the benefits under the dependency system in 2023, and where it has also been developed with the aim of helping the elderly). This help is designed above all for people with disabilities and is linked to this group's demands to move towards exercising their rights to live independently and in the community, from a position of autonomy and social inclusion. And indeed, besides the needs of personal care, personal assistance offers the support necessary for a person to be able to live as they wish, a decision made independently and within the community. This means that personal assistance should provide support in all areas of a person's life, with the assistant's

[61] Martínez-Buján, 2011.
[62] Martínez-Buján et al., 2022: 53.

functions being established by the recipient of the help based on each person's wishes and needs. In other words, this help should allow them to participate in the community on equal terms with the rest of the citizenry.

Some of the problems with the current configuration of this type of benefit are that:

→ the **amount granted is too low** for the service to be affordable without a significant contribution made by the person or their family;

→ there is a **lack of regulation** and specific type of work contract for the professional figure of personal assistant, as well as discrepancies in the training required;

→ the adoption of this service possibly is **incompatible with a high level of other services received** within the LAPAD, including the home help service.

Regulation of private services

Finally, besides the benefits regulated by the State, it is important to take into account the public policies that regulate the provision of social care carried out in the private sector. As mentioned before, improving working conditions and the quality of services in the private sector implies elevating the value of care. This can also generate a virtuous circle regarding the facilities since they are recognised in the public sphere. The **creation of indicators and assessments** of the type of contractual regimes of domestic workers and of companies that provide services fosters a move towards higher levels of information and more empowerment both for the people cared for and for care workers. **Policies to support the organisation of workers through mutual support networks** are also important, as is the regularisation of people who have migrated without legal documentation and the formation of work cooperatives based on the promotion of good practices and innovation in work organisation. Responsible public procurement and the formation of mixed cooperatives are also solutions for developing more locally-based quality suppliers that work with social and ethical criteria.

4.2. Policy objectives

LTC policies have a direct impact on recipients of care and on paid and unpaid carers. They also have more systemic effects, and to understand what works, the overall use of resources and their distribution must be considered. A brief overview follows of the impact that these policies or services can have on each group involved.

Person receiving care

In the case of people receiving care, at least three dimensions must be taken into account: physical health, emotional and social well-being, and the person's participation, preferences and decision-making (i.e. their autonomy). The table below lists the main indicators that should be considered in order to assess the effect of policies on these three dimensions.

Dimensions	Examples of indicators
Physical well-being	→ Health indicators (e.g. healthcare, nutrition or daily life activities). → Evolution of functional capacity (e.g. autonomy in carrying out daily activities or capacity for communication). → Indicators of material well-being (e.g. housing quality, savings or accessibility).
Emotional and social well-being	→ Satisfaction and general well-being (e.g. feeling safe, lack of anxiety or stress). → Interpersonal relationships (e.g. social relationships, family relationships or sexuality). → Service quality measures (e.g. satisfaction with services or having support). → Indicators regarding rights and inclusion (e.g. feeling like a valued member of society or being considered the same as other people).
The person's participation, preferences and decisions	→ Indicators of autonomy (e.g. personal goals and preferences or decisions). → Implementation of tools for transparency and participation in services (e.g. existence of communication plans, user and worker participation in decision-making spaces or preparation of surveys). → User satisfaction with services, including the correspondence between service preferences and their final choice.

Paid caregivers

In the field of professional or formal care work, besides the overall satisfaction of workers, the following categories can be considered: working conditions, possibilities for training and professional growth, and participation and autonomy.

Dimensions	Examples of indicators
Working conditions	→ Contractual conditions measured in absolute terms or relative to other sectors (salary, length of contract, hours worked, flexibility). → Staff turnover and absenteeism. → Workers' satisfaction with their jobs.
Training and professional growth	→ Type and proportion of professional categories in the sector, hours of training, qualifications required. → Job progression and evolution of contractual conditions. → Satisfaction and expectations of remaining in the sector.

Dimensions	Examples of indicators
Participation and decision-making capacity	→ Legal status of the provider and type of service management. → Degree of unionisation of the sector. → Adaptation of working hours to care needs. → Participation in service design.

Unpaid caregivers

For non-professional caregivers, the most relevant aspects of LTC services involve being able to exercise choice in the provision of care, including reducing overload, being able to organise their schedule, and training and support provided by institutional actors.

Dimensions	Examples of indicators
Ability to choose	→ Uses of time and establishing the care overload threshold according to variables of gender, class, age, etc. → Feeling of overload in caregiving tasks (based on surveys). → Ability to access public and private services or resources to support non-professional caregivers (waiting lists and costs).
Possibility to organise own schedule	→ Satisfaction with existing services. → Ease of organising schedule (surveys).
Training and support	→ Number of attendees and number of training courses, activities and/or meetings with care providers. → Surveys assessing the type of support received by the different actors in the system.

Impacts on the system

Besides the direct results affecting the people involved in LTC, it is important to know how the instruments and services and their features make an impact on different indicators of quality, efficiency and sustainability of the system as a whole. This includes understanding the cost-effectiveness measures of the instruments implemented, the coverage and frequency of the services provided, the waiting lists for attending the people served, or the economic results of the providers. In terms of this point regarding the impacts made on the system, the situation and evolution of the organisations that participate in LTC services can also be taken into account, including bodies from the third sector as well as worker and user cooperatives. In this way, a broader vision of the role of the organisations and the logic governing the provision can be included.

4.3. Organisational elements and cross-cutting policies

Finally, it is also necessary to consider that a LTC system has varying results based on improving a series of characteristics that are transversal to the policies and that can be analysed by the system as a whole. Here is a compilation of the main features that the LTC system needs to have.

Governance and financing

The financing systems in place **must be adequate** for creating universal services and meeting the objectives of the LAPAD. For example, the aging of the population and providing sufficient benefits mean significantly expanding public spending on LTC to bring Catalonia closer to the spending in other European countries. In addition, as mentioned above, the Catalan system currently suffers from a multilevel organisation with a significant imbalance. On the one hand, **local authorities are under increasing pressure** to expand home care and local support services, but on the other hand, they are highly dependent on the decisions and financing criteria of higher authorities, namely the Generalitat (regional government) and the Spanish government. This leads to significant territorial inequalities depending on the spending capacity and social needs of each municipality. When it comes to financing, it is also necessary to consider the effects caused by the introduction of **co-payment** within the framework of the SAAD. Although this co-payment is configured based on income, it can be very high in relation to a family's possibilities of paying, especially if we consider the economic benefits recognised by the LAPAD.

It should be added that in LTC in Catalonia, a **system based on services** has been predominant. This is very different from the private insurance models in place in continental contexts such as the Dutch one, and approaches Nordic-type models. A system that aims to be universal and is based on services can be **more efficient** than one based on private provision, both in terms of total public spending and in the consumption of resources, due to a smaller number of providers, the coordination capacity of public administrations, a lack of the costs that derive from competition, and the greater availability of prevention services which are accessible to the entire population, and that help avoid some future health problems. However, in the LTC sector, unlike the health sector, there is a significant lack of available services and, as has been seen, **the provision is currently mostly private.** In this context, cash transfers can be used as a resource to facilitate greater autonomy for users and their families, but various aspects must be taken into account to guarantee equity, good quality services and efficiency. In this sense, the forms of management used are important, including the participation of users, groups of self-managed workers and the third sector.

In the LTC sector, unlike the health sector, there is a significant lack of available services and, as has been seen, the provision is currently mostly private.

Management types

In conceptual terms and to simplify matters, the types of management can be divided into three ideal categories, although there is usually a mix of these in place: "traditional" public management, public-private management and public-community management. Each model is explained below, with its main benefits and drawbacks set out in the table that then follows.[63]

→ **"Traditional" public management** is where the entire process of organisation, financing and provision is carried out by public institutions, either directly through the administration itself or through a public company which has majority public participation. An example would be a publicly owned and managed nursing home.

→ **Public-private management** is based on the implementation of public contracts, agreements or other collaboration regimes in which the public administration participates in the organisation and financing of the service, but delegates the actual management to a private company. In the example of a nursing home, its management would be carried out by a private company.

→ In **public-community management,** under a logic of the commons, a long-term concession is granted to social entities (including self-managed organisations and third sector bodies) to manage an asset, under democratic and social criteria. In the example of a nursing home, this would be managed by a board or an assembly with decision-making capacity, participated in by the actors involved in the area.

Management type	Advantages	Disadvantages
"Traditional" public	→ Protection of public goods and working conditions. → Equal access to quality services. → Continuity and coordination, with all services controlled together.	→ Difficulties in adapting to needs. → Hierarchical, with limited participation. → Budget limitations.
Public-private	→ Accountability and expense controls. → Competition between suppliers. → Professionalised management.	→ Fragmented system and lack of transparency and control. → Market concentration of for-profit companies.

[63] A more detailed and complementary explanation can be found in Espai Zero Vuit, 2023.

		→ Lack of worker autonomy and participation.
Public-community	→ Possibly better alignment of providers' missions with the needs of the users and families. → Fosters relationships of trust and mutual support. → Integration into the social fabric that allows community resources to be maximised.	→ Requires a pre-existing community fabric. → Does not guarantee universal coverage. → Limits to scaling the model up.

Coordination and integration

The Catalan LTC model is one that rests on familialism and where public participation is mostly outsourced to private entities; it is marked by a high degree of fragmentation that can cause significant barriers to communication and effective coordination between different services, providers and administrations in the provision of the services. We can differentiate two types of fragmentation, horizontal and vertical.

→ **Vertical fragmentation** can occur in hierarchical decision-making structures, from management positions and public policy design to direct provision. Outsourcing and contracting pose a significant challenge, creating greater degrees of complexity in areas such as communication and information channels and the administrations' capacity for control. This also encourages the provider companies to look out for their own interests.

→ **Horizontal fragmentation** can occur between the different administrations and service providers that attend a person with LTC needs. One example is the division between health services and home care services, which are managed by different departments and involve different professions and providers. Similarly, coordination between municipal services and nursing homes and day centres depends primarily on regulations and coordination between the Generalitat (regional government) and municipal entities.

Some of the challenges for better integration between the services are the **social and administrative boundaries that delimit the actions of each professional field,** as well as their social status. Other challenges are lack of time and sufficient material and human resources in the sector to make effective collaboration feasible, especially in contexts of even greater pressures on time and resources. Thus, policies that seek to favour greater integration, both vertical and horizontal, will have to take care to provide the necessary resources to make it possible.

Territorialisation

These types of services can be organised in a more or less territorialised way. In the past, there has been a tendency to increase the size of services and centralise their management to take advantage of economies of scale. However, faced with the limitations of large bureaucratised structures, fragmentation, and the lack of self-management of workers, recent local innovations have shown the effectiveness of **teams of self-managed workers who work in their local areas.**[64] Under names such as Buurtzorg (in the Netherlands) or social superblocks (in Barcelona and El Prat de Llobregat), these models aim to ensure that the decisions that affect the quality of services and working conditions involve the people affected, thus allowing the services to be better adapted to their needs. In addition, greater territorialisation allows social problems to be observed more closely, and with more knowledge of the assets available to respond to them, be they community-based, public, or private. Finally, territorialisation and teamwork allow for increased interactions between people, facilitating better organisation, transfer of information, and the establishment of trusting relationships. Also, ensuring this territorial perspective should help prevent the fact of living in a nursing home causing a separation from the family unit. In this sense, it seems important to create professional **case managers and key community figures,** who will be capable of coordinating services and establishing links between administrations.[65] It is important to point out that territorialisation must take care to integrate and coordinate management between neighbourhoods and municipalities, to avoid increasing the already high fragmentation present.

Small municipalities and rural areas

LTC policies must take into account the realities of municipalities with low population densities.[66] In these municipalities, it can become more difficult to manage services due to a possible lack of human or technical resource capacity. However, provision by a regional entity can lead to a distancing from direct management and care. For this reason, a possible solution is the **pooling of services,** which allows smaller municipalities to contract services from neighbouring municipalities by implementing good practices. Another added problem may be **territorial dispersion,** which makes care services more expensive due to the cost of travel and the need for adapted transport. Currently, there is no efficient and harmonised adapted transport model in Catalonia. Funding for these municipalities should be adapted to the reality on the ground there, and not only take into account people in a situation of dependency, but also the problems encountered by a dispersed population. It is also necessary to consider the lack of workers in the sector as well as the lack of quality

[64] Torrens, 2020; Moreno-Colom, 2021; Kussy et al., 2023.
[65] Comas-d'Argemir and Martínez-Buján, 2022: 429.
[66] Espai Zero Vuit, 2023.

professional providers. At this point, **training and attracting workers** can solve this problem while fighting depopulation.

Transparency and evaluation

To guarantee the universalisation of good quality services, including good working conditions, an **ecosystem of quality providers is needed,** as well as the possibility of obtaining **appropriate information** and maintaining **public and community control** of the quality of existing services. In the field of public procurement, special attention must be paid to the types of contracts through which services are outsourced. The establishment of alternative contracts or agreements or responsible contracting which includes social clauses must foster long-term collaborations with trusted providers. In this sense, clauses that ensure the periodic measurement of quality during the execution of the contract, based on the well-being of the people cared for and that of the unpaid carers and the workers, can be explored and innovated. Signing contracts with specialised public companies can also be promoted, as well as an improving working conditions through labour agreements. Within public procurement, it is necessary to strengthen penalty and incentive systems, including an extension of the prohibition on signing new contracts with companies that have been sanctioned for reasons related to the service conditions.

In addition to improving quality, better evaluation systems need to be put in place regarding the implementation and results of LTC services and benefits. This would allow for more rigorous information to be put together on how they work and for whom, and to be able to suggest improvements. To achieve these objectives, in addition to the public administrations carrying out the corresponding studies, greater collaboration is needed with private management companies, in terms of collecting and communicating data about their services (while ensuring the protection of personal data).

Access

Under the current LTC system in Catalonia, which aims to offer universal coverage, the main criterion for being entitled to public benefits at certain levels of intensity is the level of **dependency that one has been accredited** by the health authorities, including authorised third-party entities. One of the greatest difficulties that people encounter in this process is being able to guarantee that this accreditation can be adequately and rapidly adapted to their needs. Changes in health status and dependency can occur quickly, but the processes for updating the degree of dependency and the intensity of services granted are often slow, especially in the areas that are most overloaded. Once a degree of dependency has been accredited, the **availability of services** in the geographical area of care for the person is key. The universalist spirit of the LAPAD has been hampered by a lack of services on offer and insufficient monetary transfers. The **intensity** of services is another key aspect. Here, it

must be taken into account that in the context of a deinstitutionalisation process, a home care service is usually insufficient for people's care needs, and needs to be complemented with private and/or family and community services. For this reason, it is also necessary to develop a more coordinated system run by case managers that allows access to services based on the person's life stage and changing needs. In this sense, access to and use of services is strongly **conditioned by the resources available,** in terms of both monetary benefits to finance private services and help from the family and community environment.

Besides public benefits, the familialist frame of our LTC system means that **a large proportion of LTC spending is privately financed.** Given the lack of public provision of benefits, public pensions, savings and accumulated wealth become a key determinant in inequality in access to private LTC services. Likewise, again, the availability of human resources, including unpaid caregivers, for the person that needs care, is a determinant when it comes to accessing quality services, although this is often at the expense of the health and well-being of the caregiver. Thus, in a context of a shortage of public benefits, public policies to support private incomes and the pooling of community resources become essential for guaranteeing equality in access to quality care.

Quality

When defining quality in LTC services, it is first of all necessary to take into account the intensity of hours offered by each service (including direct care and complementary services). Currently in Catalonia, the intensity of services can be limited. It is also necessary to take into account that care is a service that has **a high intangible and subjective content** because people's care needs, although universal, can be covered in different ways. Furthermore, in the field of social care, **quality must be understood as part of a wider care process, to which trust and knowledge are central.** Here, the standardisation processes of benefits, as well as excessive bureaucratic control rules, can go against the principles of the CPCC model which promotes greater flexibility in adapting care to the well-being of the person receiving it. Additionally, in opposition to a hierarchical service model, in CPCC the voice of caregivers can be fundamental, since they are the ones that know about the interests and preferences of the people they care for, especially when the latter cannot express their wishes. In this sense, **the quality of work and the well-being and conditions of both paid and unpaid caregivers are key for moving towards CPCC.** Precarious working conditions deter talented people from staying in the sector and increase turnover and absenteeism at work, which means a deterioration in quality, with workers changing often and lacking the ability to understand needs and adapt the services. Similarly, in the case of unpaid workers, overload and psychological distress can mean difficulties in guaranteeing care at home.

Besides CPCC, another element of service quality that has gained acceptance is the incorporation of a **reablement** vision. The objective of reablement is to help people regain and maintain functional skills and autonomy, in this case for the elderly. Reablement is a holistic, person-centred approach that seeks to improve a person's physical and/or other functions, increase or maintain their independence in performing meaningful daily activities in their place of residence and reduce the need for LTC.[67] It is a risk minimisation strategy that helps older people and people in situations of premature aging (due to disability or illness) to adapt to age-related changes and help them prevent certain dependencies.[68] Reablement processes ideally require a diagnosis and a work plan developed with an interdisciplinary team composed of care workers, nurses, occupational therapists, speech therapists and physiotherapists who work together with the person being cared for in the home and in community infrastructures to achieve objectives which include both physical mobility and social participation.[69] In Catalonia this type of support is mainly provided by the health services. However, there are currently barriers in place to expanding these programmes effectively, including long waiting lists and lack of staff, high cost of materials, a lack of effective coordination between services, and the fact that LTC services suffer from a lack of autonomy to guarantee these services. These barriers are especially problematic if they do not allow for early detection and thus cause delays in prevention measures.

Respect and adequate conditions for care work

The labour market of the LTC sector has been growing continuously in recent decades. The percentage of people registered as working in nursing homes and social service activities without accommodation, of the total number of registered workers in Spain, has increased from 3% in 2010 to 3.8% in 2020.[70] Of these people, in 2020, 83% were employed in the private sector and 15.1% in the public sector, indicating once again the importance of regulation and public policies focused on improving working conditions in the private sector, especially considering the high level of outsourcing in publicly owned services.

The **professionalisation of care work** is an idea at the centre of the debate regarding the goal of the LTC sector: to strive towards a quality care system which offers good working conditions. Care work contrasts with the nursing or teaching professions, which are seen as pillars of the welfare state, and professionalising care work should make it as valued as those jobs, along with improving its working conditions. In this sense, as previously mentioned, it is important to reduce the wage gap between people in the same professional categories who work in different sectors, such as between the health and social sectors.

[67] Metzelthin et al., 2020: 11.
[68] Rostgaard et al., 2023: 3.
[69] Rostgaard et al., 2023: 6.
[70] Martínez-Buján, 2023: 74.

Within this professionalisation, it would be necessary to work towards a diversification of profiles in order to properly recognise the skills and knowledge of workers. It is especially important that the figure of personal assistant becomes a reality and that a diversification takes place of the care worker profile, including community-based workers, carers who are specialised in cognitive impairment, etc.

However, a series of considerations must be made regarding the limits of professionalising the sector and the need to implement complementary measures to make this an effective policy:

→ **The paradigm of aging at home that is prevalent in current public policies can generate two barriers to professionalisation.**[71] On the one hand, under this paradigm, care work can be understood as a relationship of love and affection developed within the family, which makes it natural –more for women than for men – for family members to have the skills and competencies related to care, and generates distrust towards complementary social services. On the other hand, maintening care in the private and domestic sphere and the high prevalence of hiring domestic workers creates a barrier to the professionalisation of care work, generating a strong stratification according to social class, gender and ethnic origin.[72]

→ In this sense, one of the greatest barriers to improving the conditions of care workers is **the high rate of workers providing home care who are employed in the shadow economy.** Certain workers' movements have even demanded the abolition of caregivers living with those who receive care. Therefore, with or without professionalisation, public and collective policies that reduce unlicensed employment in the sector and increase regulation, collective action and financing may generate an improvement in working conditions, both for the people directly affected and for all other workers in the LTC sector.

→ However, it cannot be ignored that from an CPCC and community perspective, the aim is to ensure that the family and community environment can participate in social care, without barriers being put up with other institutional actors. Thus, **it is necessary to value, recognise and redistribute the social care work carried out by all people, also when they provide unpaid care,** giving them access to the resources and support necessary so that their situation does not lead to a deterioration in their living conditions.[73]

[71] Martínez-Buján et al., 2022: 51.
[72] Martínez-Buján et al., 2022: 52.
[73] Comas d'Argemir and Martínez-Buján, 2022: 436.

The professionalisation of care work is an idea at the centre of the debate regarding the goal of the LTC sector: to strive towards a quality care system which offers good working conditions.

5. The *What Works in Long-Term Care* Project

Despite the importance of social care in our societies, the recognition and centrality of LTC services in the field of public policies is still limited. The lack of public leadership in the deployment of services and benefits has resulted in a highly externalised, commercialised and fragmented sector, with low levels of public control and where priorities given to cost reduction have produced negative effects on quality, working conditions and the autonomy and decision-making capacity of the people involved. Additionally, the responsibility for how to deploy and articulate services is delegated to local authorities which do not have the financial capacity to respond to the challenges of the aging population.

In this context, the *What works in long-term care* project, promoted by Ivàlua, the Diputació de Barcelona (Provincial Council), the Taula del Tercer Sector and la Confederació, aims **to contribute to improving the design and implementation of long-term care policies and services,** by gathering together, filtering, organising and presenting the scientific evidence available, all in an accessible format. This is a task that is led by the four aforementioned institutions but that involves researchers who are specialized in specific areas of intervention. Additionally, the project is supported by an Expert Committee —made up of 12 experts in long-term care, drawn from academia, local administrations, professional associations and the third sector— which ensures the that the documents generated will be useful on the ground.

In methodological terms, the project aligns with the standards of other "What Works" initiatives underway in Catalonia and elsewhere in Europe. In order to draw conclusions about the effectiveness of different interventions (policies, services, leave, regulations, etc.), a **systematic review of academic studies is carried out to provide rigorous data and causal evidence,** as far as possible, **regarding the capacity of these interventions to achieve their objectives.** In other words, the "What Works" approach prioritises evidence that is generated from impact evaluations that employ robust experimental and quasi-experimental methods. More specifically, it prioritises evidence that has been collected in systematic reviews; something that, on the one hand, converts the products generated within the framework of the project into "reviews of reviews", and on the other, means —given the scarce tradition of evaluation in our country— that much of the evidence considered has been generated in other contexts. However, prioritising these sources of information does not mean that they are the only ones considered. Researchers

complement this information with analyses of specific policies (primary studies), as well as analyses carried out by using other types of methods, when they consider it necessary.

Another important feature of the “What Works” initiatives is that they do not limit themselves to pointing out which interventions work best, but also seek **to identify for whom they are most effective and in what circumstances.** In the case of *What Works in Long-Term Care* this translates into the fact that all the reviews—regardless of whether they focus on one of the policies listed in section 4.1 or on a feature of the LTC system (mentioned in section 4.3)—consider the effects that an intervention would have on both recipients of care and on paid and unpaid caregivers, as well as the impacts on the system itself (section 4.2).

However, to inform evidence-based care policies, it is not enough to simply synthesise the existing evidence. It is necessary, first, **to ground it in the context of Catalonia,** a task in which the project's Expert Committee plays a fundamental role. Second, it is key to extract specific conclusions and recommendations. And third, these conclusions and recommendations need to be delivered to the people who make decisions about the design and implementation of care policies. In this sense, it is important to bear in mind that the project is committed to a local perspective, and therefore focuses on the capacity of local administrations to influence the configuration of the long-term care system in Catalonia.

The *What Works in Long-Term Care* project aims to contribute to improving the design and implementation of long-term care policies and services, by gathering, filtering, organising and presenting the available scientific evidence, all in an accessible format.

6. Glossary

→ ***Comprehensive Person-Centred Care***: long-term care focused on achieving improvements in all areas of the person's quality of life and well-being, based on full respect for their dignity and rights, their interests and preferences and taking into account their effective participation.

→ ***Targeted Welfare****:* a form of public provision of services and transfers focused on people at risk of social exclusion and with fewer resources. This type of approach usually requires bureaucratic control systems that determine who is entitled to receive public assistance.

→ ***Care*****:** all the activities carried out by living beings towards the environment or other living beings to guarantee decent living conditions and full participation in society.

→ ***Social Care****:* a multidimensional concept that refers to care as work, as an obligation and responsibility, and as an activity that involves a cost, both financial and emotional.

→ ***Long-Term Care***: care aimed at people who, because of poor health or disability, cannot cover their most basic needs by themselves. These include physiological needs, but also everything that they need to live independently and as a part of the community, ensuring them a decent environment and participation in society.

→ ***Welfare State***: the set of public policies deployed by the public administration and the social organisation that are necessary to achieve social objectives, including the protection of social rights and action to minimise the social risks that the population may face (such as health problems, lack of income, educational needs, etc.), as well as the pre-distribution and redistribution of resources to reduce social inequalities.

→ ***Public-Community Management****:* a model of service management where, under a logic of the commons, the public administration concedes the management of a long-term asset to social entities based on democratic and social criteria.

→ ***Professionalisation***: creation of social and state norms that grant workers greater training and labour specialisation within the social organisation of their work. This specialisation, due to the current division of labour, should mean that their work is more by respected administrations, care providers and care seekers and that they gain greater control over their work, including a greater capacity for self-organisation.

→ ***System for Autonomy and Dependency Care (SAAD in its Catalan acronym)*****:** set of services and economic benefits framed in Law 39/2006 and intended to promote

personal autonomy, care and protection for people in situations of dependency, through public and private services.

→ ***Universalism***: a modality of public provision of services and transfers focused on the entire population or on all people who demonstrate the need for assistance, regardless of income level or economic resources.

7. References

Ajuntament de Barcelona (2019). *El greuge econòmic de les persones amb discapacitat de la ciutat de Barcelona*. Available (in Catalan) at: https://ajuntament.barcelona.cat/dretssocials/sites/default/files/arxius-documents/greuge-economic-persones-discapacitat-barcelona-ca.pdf

Belmonte, Martina, Sara Grubanov-Boskovic, Fabrizio Natale, Alessandra Conte, Alain Belanger and Patrick Sabourin (2023). *Demographic microsimulation of long-term care needs in the European Union*. Luxembourg: Publications Office of the European Union.

Camps, Victoria (2024). El cuidado, un derecho y un deber universales. In *La necesidad de cuidado: un reto político, social e institucional,* pp. 13-24. Barcelona: Fundació Víctor Grífols i Lucas

Comas-d'Argermir, Dolors and Sílvia Bofill-Poch (2022) Cuidar a mayores y dependientes durante la pandemia. In Comas-d'Argermir, Dolors and Sílvia Bofill-Poch (eds), *Cuidar a mayores y dependientes. En tiempos de la covid-19*, pp. 17-36. Tirant Humanidades: València

Comas-d'Argemir, Dolors, Metxalen Lagarreta-Iza and Cristina García-Sainz (2022). Las residencias, en el epicentro de la crisis sanitaria. In Comas-d'Argermir, Dolors and Sílvia Bofill-Poch (eds), *Cuidar a mayores y dependientes. En tiempos de la covid-19*, pp. 257-312. València: Tirant Humanidades.

Comas-d'Argemir, Dolors and Raquel Martínez-Buján (2022). Hacia un modelo alternativo de cuidados. In Comas-d'Argermir, Dolors and Sílvia Bofill-Poch (eds), *Cuidar a mayores y dependientes. En tiempos de la covid-19*, pp. 423-450. València: Tirant Humanidades

Comissió Europea (2021). *Long-term care report. Trends, challenges and opportunities in an ageing society*. Luxemburg: Publications Office of the European Union.

Crenshaw, Kimberle (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, 43(6), 1241-1299.

Daly, Mary (2023). *Theorizing the Relationship between Family, Gender, and the Welfare State.* In Daly, Mary, Pfau-Effinger, Birgit, Gilbert, Neil and Besharov, Douglas (eds): *The Oxford Handbook of Family Policy Over the Life Course,* pp.143-159. New York: Oxford University Press.

Daly, Mary and Jane Lewis (2000). The concept of social care and the analysis of contemporary welfare states. *The British Journal of Sociology,* 51(2), 281-298.

De Quintana, Júlia, Cristina Ferrer, Marta Mirambell, Sandra Ezquerra, Christel Keller (2024). *Avaluació de necessitats. Les cures a Catalunya. Identificació, dimensionament i anàlisi de la seva provisió des de l'esfera familiar i dels principals serveis públics.* Barcelona: IVÀLUA.

Dowling, Emma. (2021). *The care crisis: What caused it and how can we end it?* New York: Verso Books.

Duffy, Mignon. (2005). Reproducing labor inequalities: Challenges for feminists conceptualizing care at the intersections of gender, race, and class. *Gender & Society*, *19*(1), 66-82.

Espai Zero Vuit (2023). Cap a un model públic-comunitari per la provisió de serveis públics. El cas dels serveis de cura a Catalunya. Available (in Catalan) at: https://www.espaizerovuit.com/2023/05/14/cap-a-un-model-public-comunitari-per-la-provisio-de-serveis-publics/

Eurofound (2020). *Long-term care workforce: Employment and working conditions.* Luxemburg: Publications Office of the European Union.

Ezquerra, Sandra and Elba Mansilla (2018). *Economia de les cures i política municipal: cap a una democratització de la cura a la ciutat de Barcelona*. Barcelona: Ajuntament de Barcelona, Universitat de Vic, La Ciutat Invisible Coop. Available (in Catalan) at: https://www.barcelona.cat/ciutatcuidadora/sites/default/files/economia_i_politica_13.pdf

Fraser, Nancy (2016). Capitalism's crisis of care. *Dissent,* 63(4): 30-37.

Gallego, Raquel (2016). Conclusiones. Ideología, financiación territorial y (des) igualdad: que margen hay para la autonomía política?. In Gallego, R. (ed.): *Descentralización y desigualdad en el estado autonómico,* pp. 386-404. València: Tirant lo Blanch.

Harding, Lorraine (1996). *Family, State and Social Policy.* New York: Palgrave MacMillan.

Kussy, Angelina, David Palomera and Daniel Silver (2023). The caring city? A critical reflection on Barcelona's municipal experiments in care and the commons. *Urban Studies,* 60(11), 2036-2053.

León, Margarita (2010). Migration and care work in Spain: The domestic sector revisited, *Social Policy and* Society 9(3), pp. 409-418.

León, Margarita, Marco Arlotti, David Palomera, Costanzo Ranci (2021). Trapped in a Blind Spot: The COVID-19 crisis in nursing homes in Italy and Spain. *Social Policy and Society*, 1 – 20.

Lewis, Jane (1992). Gender and the development of welfare regimes. *Journal of European social policy,* 2(3), 159-173.

Meltzelthin, Silke, Tine Rostgaard, Matthew Parsons, Elissa Burton (2020). Development of an internationally accepted definition of reablement: a Delphi study, *Ageing and Society*, 42(3), 703-718.

Martínez-Buján, Raquel (2011). La reorganización de los cuidados familiares en un conctexto de migración internacional. *Cuadernos de Relaciones Laborales*, 29(1), 93-123.

Martínez-Buján, Raquel (2020). El paradigma de los comunes y la protección social publica como claves hacia el bienestar. *Cuadernos de relaciones laborales,* 38(2), 289-304.

Martínez-Buján, Raquel, Marcela Jabbaz and Montserrat Soronellas (2022). Envejecimiento y organización social del cuidado en España ¿en qué contexto irrumpe la covid?. In Comas-d'Argermir, Dolors and Sílvia Bofill-Poch (eds.), *Cuidar a mayores y dependientes. En tiempos de la covid-19*, pp. 37-91. Tirant Humanidades: València

Monsterrat, Júlia (2019). Sostenibilidad del sistema de atención a la dependència. *Papeles de Economía Española*, 161, pp. 164-185.

Moreno, Sara, Carolina Recio, Vicenç Borras and Teresa Torns (2014). Los límites de la profesionalización del trabajo de cuidado. In *Crisis y cambio: propuestas desde la Sociología*: *Actas del XI Congreso Español de Sociología, Facultad de Ciencias Políticas y Sociología Universidad Complutense de Madrid 10-12 de julio de 2013 (pp. 835-845).* Madrid: Universidad Complutense de Madrid.

Moreno-Colom, Sara (2021). Construyendo comunidad desde lo público: el caso de las Superilles Socials. *Revista Española De Sociología*, *30*(2), a27.

O'Connor, Julia *(1993).* Gender, class and citizenship in the comparative analysis of welfare state regimes: theoretical and methodological issues. *British Journal of Sociology, 501-518.*

Observatori del Treball i Model Productiu (2023). Model productiu. El treball de la llar i les cures a Catalunya. Available (in Catalan) at: https://observatoritreball.gencat.cat/web/.content/generic/documents/treball/treball_llar_cures/arxius/Treball-de-la-llar-i-les-cures_2023.pdf

Organització Internacional del Treball (2018). *Care Work and Care Jobs for the Future of Decent Work.* Ginebra: International Labour Office.

Palomera, David and Margarita León (2023). The Growth and Consequences of Quasimarkets bin Long-term care. In M. Daly, N. Gilbert, B. Pfau-Effinger and D. Besharov, D. (eds.), *International Handbook of Family Policy: A Life-Course Perspective*, pp. 961-978. New York: Oxford University Press.

Pfau-Effinger, Birgit (2017*).* Cash and Care. The historical introduction of capitalist logic into family life*. DaWS Working Paper Series,* WP 2017 – 6.

Pozo-Rubio, Raúl, Isabel Pardo-García and Francisco Escribano-Sotos (2017). El copago de dependencia en España a partir de la reforma estructural de 2012. *Gaceta Sanitaria*, 31(1), 23-29.

Quotidiana (2022). *Desigualtats de gènere a la vida quotidiana.* Available at: https://quotidiana.coop/quot_dada/desigualtats-en-lestat-del-benestar/

Rodríguez, Pilar (2010). La atención integral centrada en la persona. Principios y criterios que fundamentan un modelo de intervención en discapacidad, envejecimiento y dependència. In *Serie: Informes Portal Mayores, nº 106*. Madrid: IMSERSO/CSIC

Rodríguez-Cabrero, Gregorio and Vicente Marbán-Gallego (2013). Long-Term Care in Spain: Between Family Care Tradition and the Public Recognition of Social Risk. In Ranci, C. and Emmanuelle Pavolini (eds). *Reforms in Long-Term Care Policies in Europe. Investigating Institutional Change and Social Impacts*, pp. 201-219. New York: Springer.

Rodríguez-Cabrero, Gregorio, Julia Montserrat-Codorniu, Ana Arriba-González, Vicente Marbán-Gallego, Francisco Javier Moreno-Fuentes (2018). *ESPM thematic report on challenges in long-term care, European Social Policy Network.* Brussel·les: Comissió Europea

Rostgaard, Tine, Hanne Tuntland and John Parsons (2023). Introduction: The concept, rationale, andimplications of reablement. In Rostgaard, T, Tuntland, H. and Parsons, J. (eds), *Reablement in Long-Term Care for Older People*, pp. 3-20. Bristol: Bristol University Press.

Torrens, Lluís (2020). Barcelona para las personas mayores. Las supermanzanas sociales. *Revista Barcelona Societat. Revista de Investigación y Análisis Social*, 25.

Tronto, Joan (2013). *Caring Democracy. Markets, Equality, and Justice*. New York and London: New York University Press.

Tronto, Joan (2024). Cuidar a las personas mayores democráticamente y contando con ellas. In *La necesidad de cuidado: un reto político, social e institucional,* pp. 25 – 45. Barcelona: Fundació Víctor Grífols and Lucas.

Valdivia, Blanca (2018). Del urbanismo androcéntrico a la ciudad cuidadora. *Hábitat y sociedad*, 11.

Walsh, Kieran, Thomas Scharf, Sofie Van Regenmortel and Anna Wanka (2021). The intersection of ageing and social exclusión. In Walsh, Kieran, Thomas Scharf, Sofie Van Regenmortel and Anna Wanka. (eds.), *Social exclusion in later life. Interdisciplinary and policy perspectives*, pp. 3-21. New York: Springer.

Què funciona
en cures de llarga
durada?

Què funciona
en cures de llarga
durada?

A project to compile, analyse, and transfer information in order to improve public long-term care policies.

A project participated in by:

ivàlua
Institut Català d'Avaluació de Polítiques Públiques

Diputació Barcelona

Taula d'entitats del Tercer Sector Social de Catalunya

laconfederació

Què funciona?