



Spain

FINANCING OF CARE SERVICES FOR PERSONS WITH DISABILITIES

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Executive Summary

The Constitution establishes the same rights for persons residing in any part of the territory of the State. Spain has general rules for the State and also provides part of the funds used to provide social services, but the seventeen Autonomous Regions have legal competency in the field of social services, and they have their particular rules in order to provide the services and to finance them, so the Spanish regulation of care services is highly complex.

The Public System of Social Services is financed mainly from the budgets of the Autonomous Regions, contributions of the general budgets of the State. They may also be financed by user contributions who have to pay for the service, depending of the type of the service and/or their economic capacity: this is called co-payment.

All Regions have similar models and systems based on the same basic national legislation, although there are important differences in terms of budgets and coverage. This factsheet explores the model of Valencia Region as an example.

The main funding model of care services is public-private collaboration. Since 2016, there has been a significant trend of regional legislative changes aimed at redefining the provision of social services, in particular due to the publication of the new Public Procurement Directives, and most of them sign social partnership agreements with service providers. This system provides greater stability to both the service providers and users; however it coexists with other funding systems, including grants and private procurement, although these are less used than the Social Partnership Agreements.

Service providers must be registered and must also prove compliance with basic requirements and evaluation criteria, including seniority in the provision of services. Currently, these agreements are signed for a year and are extended for another year, but the aim is to evolve to a four-year social partnership agreement to give more stability to entities, staff and users, avoiding unnecessary bureaucracy.

The care sector is attracting more and more profit-oriented companies. Initially common in residential services, this practice has expanded to day care centres. Some regions have penalized more than one such company for not meeting their commitments to ratios and quality of services.

Since the financial crisis of 2007-2008, most of long-term care services have undergone several adjustments, making access more complicated and resulting in large waiting lists where persons need to wait years to access the service they need.

The wages earned by care services support staff are set according to the collective agreement of the sector, depending to the type of service they provide and their professional category. While the salaries are generally better than those of staff working in residencies for the elderly, they are worse in private providers than in public ones. However, there has been an increase in the number of staff working in care services hired with social security: in December 2006 there were 220,050 workers hired on social services and in August 2020 the number was 442,529.

The ownership and management of most **Day Care** enters in Spain belongs to private non-profit entities. The places are public and the administration decides who will occupy the places. Service users do not have to pay for this service. Meanwhile, most of the services provided for independent and supported living have associated co-payments, that is, the user pays according to their economic capacity.

Co-payment greatly affects service users, some of whom have to pay so much for the places in which they reside, sheltered houses and residences that they prefer to look for private places that are economically more favourable to them.

Regarding residential services, waiting lists are very long. In the Valencia Region, often, the only way to get a place is to request a civil incapacitation of the person and the determination of the administration as legal guardian, which is a violation of the UNCRPD.

In Respite Care, only non-profit entities can participate as providers. Workers can be volunteers, differing from services such as day care centres, sheltered houses and residences, which are completely professionalized.

Main Findings

- ★ Social Services are financed mainly from the budgets of the Autonomous Regions, contributions of the general budgets of the State and also they may be financed by user contributions.
- ★ The main model of care is public-private collaboration.
- ★ New Public Procurement Directives contribute to create new social partnership agreements with service providers. The new system provides greater stability to the service providers, workers and users.
- ★ Management of most Day Care enters in Spain belongs to private non-profit entities.
- ★ The waiting lists of residences for PWDs are very long.
- ★ In Respite Care only non-profit entities can participate as providers.

Introduction

The Spanish national regulation of care services explored in this factsheet is highly complex. This is due to the great decentralization in many of the powers of the administration, in its seventeen Autonomous Regions (Comunidades Autónomas).

The State has general rules which affect all citizens according to their support needs, and at the same time all the seventeen regions have their particular rules in order to provide the services and to finance them.

The Spanish State pays benefits to persons with disabilities or reduced ability to work and, through the public institution IMSERSO¹, takes care of a great share of the cost of social services that are paid to service providers by the Autonomous Regions. Service providers must comply with the legislation of the region they are located in, each with their own rules, and then with the different models implemented by each Autonomous Region to control the services and their financing.

Public policies, benefits and services aimed at persons with disabilities in Spain affecting access to social services have continuously extended the protection and benefits for persons with disabilities, especially since the adoption of the first sectoral legislation in 1982. However, major social policies and long-term care provision suffered significant cuts during the financial crisis of 2007-2008. This crisis generated significant waiting lists, as well as co-payment² of services. Nonetheless, despite the continued existence of these issues in 2020, more and more people are being served, and Spain continues to extend the quality and quantity of services. A figure that reflects this growth is the affiliation of social service professionals to social security. From 2006 to 2020, the number of professionals with social security has doubled. While impossible to disaggregate how many of them work specifically for PWDs, in social services in general, in December 2006 there were 220,050 workers hired and in August 2020 they were 442,529³. Thus, despite many issues that still need to be resolved like waiting lists⁴, social services and protection for their workers are constantly growing.

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- 1 IMSERSO is the "Institute for the Elderly and Social Services". It is one of the management entities of the Social Security of Spain responsible for the management of the complementary social services of the Social Security System benefits, of inability to work and retirement pensions, in its non-contributory modalities, as well as the exercise of the powers of the General State Administration in matters of the elderly and in matters of dependency.
 - 2 In some public services, users have to pay for part of the services they receive, depending on the type of service, the economic capacity of the user, and on the region they live in. The same public service could be completely free or not, depending on different personal parameters.
 - 3 Data extracted from IMSERSO statistics from system for autonomy and attention to dependency https://www.imserso.es/InterPresent2/groups/imserso/documents/binario/estsisaad_compl20200831.pdf
 - 4 In August 2020 the waiting list for care of dependency in the Valencian Region, in the set of different services of attention to the support of independent life was 27,573 persons. <http://www.inclusio.gva.es/documents/610460/171127247/4+Estad%C3%ADstica+Dependencia+Lista+Espera/c1a025e5-9828-4d37-8cc1-53321131b116>

This study, which cannot cover, by its extent, all the legislation and forms of financing of the seventeen autonomous regions, analyses the situation of the Comunitat Valenciana (hereinafter called Valencian Region) by way of example. All the regions have similar models as they stem from the same basic national legislation, although there are differences in terms of budgets and coverage.

Main Policies on Governance, Management and Funding for PWDs

The Spanish Constitution⁵ establishes the same rights for persons residing in any part of the territory of the State, but confers legal competency in the field of social services to the autonomous regions. At the same time, there are different state-level laws that regulate aspects of social services and which must also serve as a guide for the regional legislator.

Law 13/1982, of April 7, on the social integration of the disabled, the first general Spanish law on disability, defined the different services for the care of persons with disabilities.⁶ Subsequently, Law 39/2006 on the Promotion of Personal Autonomy and Care of Dependent Persons⁷ (known as the Dependency Law) collected and standardized throughout the State a system of long-term care, homogenizing the dispersed rules establishing the right of access of the citizen to a basic level of protection by request of the beneficiary or his family.

This national Dependency Law (Ley 39/2006) establishes a range of monetary compensations or services (home aid services, tele-help, residences, day care centers or occupational centers) managed by regional governments. Access to these services and benefits depends on the results of an assessment of the degree of dependency. It is the different regional governments that, on a scale applicable to each person, recognize and evaluate both the degree of disability and the degree of dependence. On the basis of such an assessment, the regional governments generate an Individual Care Program facilitating the right to a number of different services and benefits.

The current General Law on the Rights of Persons with Disabilities and their Social Inclusion of 2013⁸, with a different scope of action to that of the Dependency Law, recognizes that the person with disabilities is entitled to a number of rights and that it is the Government who is responsible for protecting these rights. Spain also has a centralised so-called Spanish Disability Strategy 2012-2020⁹.

With direct reference to the financing of social services, it is necessary to take in account the Law 38/2003 of November 17, General Grants¹⁰, which aims to respond, with financial support measures, to social and economic demands of people, public and private entities. Finally, the annual call for grants¹¹ made by the Spanish State to carry out activities of general interest considered of social interest, is financed by personal income tax.

5 Constitución Española. Spanish constitution <https://www.boe.es/buscar/act.php?id=BOE-A-1978-31229>

6 Ley 13/1982, de 7 de abril, de integración social de los minusválidos. *Law 13/1982, of April 7, on the social integration of the disabled* <https://www.boe.es/buscar/doc.php?id=BOE-A-1982-9983>

7 Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia. *Law 39/2006, of December 14, on the Promotion of Personal Autonomy and Attention to people in a situation of dependency.* <https://www.boe.es/buscar/act.php?id=BOE-A-2006-21990>

8 Real Decreto Legislativo 1/2013, de 29 de noviembre, por el que se aprueba el Texto Refundido de la Ley General de derechos de las personas con discapacidad y de su inclusión social. *Royal Legislative Decree 1/2013, of November 29, which approves the Consolidated Text of the General Law on the rights of people with disabilities and their social inclusion.* <https://www.boe.es/buscar/act.php?id=BOE-A-2013-12632>

9 Estrategia Española sobre Discapacidad 2012-2020. Spanish Strategy on Disability 2012-2020. https://sid.usal.es/idocs/F8/FD026112/Estrategia2012_2020.pdf

10 Ley 38/2003 de 17 de noviembre General de Subvenciones. *Law 38/2003 of November 17, General Grants* <https://www.boe.es/buscar/act.php?id=BOE-A-2003-20977>

11 Resolution of the annual call for grants of the tax allocation of personal income tax of 2020 https://www.mscbs.gob.es/ssi/familiasInfancia/ongVoluntariado/subvenciones/IRPF/IRPF_2020/Extracto_resolucion_IRPF2020.pdf

The Ministry of Social Services is involved in the design, implementation and financing of these policies, directly funding part of the services overseen by the autonomous regions. Through the IMSERSO, the State provides services directly through six State Reference Centers for PWD¹² which are focused on studies and data collection on rather than on the provision of long-term care services.

A large number of additional regional laws regulate different rights, benefits and services in the seventeen regional governments¹³. The autonomous regions are responsible for the implementation of most of these measures relating to persons with disabilities, and although the Spanish Disability Strategy¹⁴ is not legally binding, it must be enforced by the regional administrations.

The autonomous regions decide the extent of financial support for care services, which explains differences in the extent of provision throughout the country. In some of them there are very large non-profit organizations that cover the whole region and in others there are many small entities, but also many profit-oriented companies can provide services. Many providers are organized in different umbrella associations, depending on the type of disability which they provide care for, some of them are grouped into the “Plena Inclusión” and CERMI (Spanish Committee of Representatives of Persons with Disabilities).

Municipalities (the smaller local governments) provide some social services such as care services through their social workers. Day care, supported / independent living services, long-term institutional care and respite service

are financed and controlled by the autonomous regions. In some cases, local corporations and other private entities also provides such services.

Financing of care services

The National Disability Budget in 2018 amounted to EUR 28,300 million of which EUR 2,500 million were directly transferred to the autonomous regions and cities and the other 25,800 million were distributed directly by the State. It corresponds to cash benefits and the provision of services including, apart from the disability sector, also the elderly sector and social pensions¹⁵.

The main model of care is public-private collaboration¹⁶. As established in art. 38 of the first main law for PWD, “social services may be provided both by public administrations and by private non-profit institutions or legal persons”¹⁷. Private non-profit entities have achieved recognition as social partners through the Law 43/2015, October 9¹⁸, of the Third Sector of Social Action¹⁹. Due to the strong impact of the financial crisis of 2008, most of long-term care services have undergone several adjustments, making access more complicated, measures which continue nowadays as in many cases users contribute based on their economic capacity through co-payment.

Since the financing of social services is managed by the Autonomous Regions, there are large differences in their reporting of budgetary information. The collection of data in each region follows different criteria, which is unclear

12 In addition to being the one who carries out the monetary transfers to the autonomous regions, it has six State Reference Centers for PWD; the five Centers for the Recovery of People with Physical Disabilities; and Center for Attention to People with Physical Disabilities. All these centers offer a wide variety of services for people with different types of disabilities, trying to guarantee a territorial balance. The IMSERSO is also in charge of tourism and hydrotherapy programs for PWD, and the Telephone Intermediation Center for people who are deaf or hard of hearing and / or by telephone. In the aforementioned Ministry, the Royal Board on Disability offers different services through the Spanish Center for Subtitling and Audio-description.

13 IMSERSO compilation of regulations on dependency at the state and regional levels https://www.imsero.es/InterPresent2/groups/imsero/documents/binario/ie_2011_12_anexos.pdf

14 Estrategia Española sobre Discapacidad 2012-2020. Spanish Strategy on Disability 2012-2020. https://sid.usal.es/idocs/F8/FDO26112/Estrategia2012_2020.pdf

15 Olivenza Report 2019, on the general situation of disability in Spain. <https://drive.google.com/open?id=1mLyQEYD2Mlez8YXYdMX3e3huJcqMxGbc>

16 Interview with director of public services provided by State, 18 August 2020

17 Article 34 Law 13/1982, of April 7, on the social integration of the disabled <https://www.boe.es/buscar/doc.php?id=BOE-A-1982-9983>

18 Law 43/2015, of October 9, of the Third Sector of Social Action. https://www.boe.es/diario_boe/txt.php?id=BOE-A-2015-10922

19 Montagud Mayor, X Other consequences of the crisis on the sustainability of local social services in the Valencian Region. Social Services Magazine. N°. 65, 2018, págs. 65-81.

and, according to the Olivenza Report, makes it virtually impossible to trace how much of, and how, the money is spent.

Differences in the budget dedicated to persons with disabilities among the Autonomous Regions (according to the Olivenza 2019 Report²⁰) are significant. In 2018, the regions spending the highest percentage of their budget on PWD were Basque Country and Madrid with 2.57% and 2.30% respectively, which means an expense of EUR 2,169.28 and EUR 1,445.76 on average per PWD. The regions which spent the lowest percentage of their budget on PWDs were Balearic Islands and Cantabria, with 0.14% and 0.35% respectively, spending EUR 131.10 and EUR 173.68 on average per PWD.

Since 2016, there has been a significant trend of regional legislative changes aimed at redefining the financing for the provision of social services, in particular due to the publication, in the Official Journal of the European Union, of the new Public Procurement Directives No. 23²¹ and 24²² 2014, 28 March 2014 and also on the basis of the impact of the case-law of the Court of Justice of the European Union on its judgments of 11 December 2014 (C-113/2014)²³ and 28 January 2016 (C-50/14)²⁴. These changes affect the habitual annual grants and direct contracting, which becomes regulated by a public system of social services called "*Concierto Social*" (*Social Partnership Agreement*). The most relevant points of the reform are: a) A new denomination has been coined: Social Partnership Agreement; (b) it is formally stated that the "Partnership Agreement" is excluded from the scope of public sector procurement rules; and c) non-profits emerge as a key element of the

redevelopment of regional social systems.²⁵ In spite of the introduction of the social partnership agreement, all the previous funding systems still co-exist: the same services are also provided through grants, private procurement as well as the current partnership agreements. Despite the coexistence of funding systems, the tendency is that most long-term services are provided through the social partnership agreements.

During the past ten years, but with more intensity during the last five, the care sector has attracted more profit-oriented companies, which participate in social partnership through non-profit entities created specifically for this purpose. Initially commonplace in residential services, this practice has expanded to day care centers. An interviewed expert²⁶ believes that due to the increasing complexity and lower profitability of services for PWDs, the role of NGOs will remain important²⁷.

This factsheet study focuses on services provided to persons over the age of 16 and under the age of 65, mainly with intellectual disability or mental health problems, and for persons with severe physical or sensory disabilities, or chronic or degenerative neurological disease.

The Valencian Region

Of the nearly 47 million Spaniards, 4.96 million reside in the Valencian Region, which is located in the eastern part of the Iberian Peninsula. Among them, there are 346,662 persons with a disability certificate. In 2018, the region spent 1% of its budget for social care services, that is, EUR 547,37 per person per year on average²⁸.

20 Table 167 Synthetic index of effort in disability in autonomous regions. Olivenza 2019 report, on the general situation of disability in Spain. <https://drive.google.com/open?id=1mLyQEYd2Mlez8YXYdMX3e3huJcqMxGbc>

21 Directive 2014/23/EU of the European Parliament and the Council of 26 February 2014 on the award of concession contracts <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:32014L0023>

22 Directive 2014/24/EU of the European Parliament and the Council of 26 February 2014 on public procurement and repealing Directive 2004/18/EC <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32014L0024&rid=1>

23 Judgment of the Court (Fifth Chamber) 11 December 2014 In Case C-113/13 <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:62013CJ0113&from=ES>

24 Judgment of the Court (Fifth Chamber) 28 January 2016 In Case C-50/14 <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:62014CJ0050&from=ES>

25 Ximena Lazo Vitoria. Observatorio de Contratación Pública. <http://obcp.es/opiniones/la-figura-del-concierto-social-tras-las-directivas-europeas-de-contratacion-publica>

26 Interview with expert on social services, 20 August 2020

27 Eloisa del Pino, Spain Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities EASPD fact sheets. https://www.easpd.eu/sites/default/files/sites/default/files/Publications/countryreports1/easpd-spain_fact_sheet.pdf

28 Table 167 Synthetic index of effort in disability in autonomous regions. Olivenza 2019 report, on the general situation of disability in Spain. <https://drive.google.com/open?id=1mLyQEYd2Mlez8YXYdMX3e3huJcqMxGbc>

This Region has its own legislation on social services, currently Law 3/2019, of 18 February, on inclusive social services of the Valencian Region²⁹, which recognizes the responsibility of the administration in the planning, management and evaluation of those resources that promote the freedom and effective equality of individuals and groups. It determines, in its article 104 on sources of funding, that the Valencian Public System of Social Services will be financed from the budgets of the Generalitat Valenciana (Valencian Government), the budgets of the municipalities, provincial councils and the rest of local entities of the Valencian Region and contributions of the general budgets of the State and the European Union, and also they may be financed by user contributions.

Each year, funding is regulated through annual grants, the latest being the Resolution of December 18, 2019³⁰ of the Generalitat Valenciana, which convenes agreements for social partnership action on social services in the sector of care for persons with functional diversity. This rule determines the amounts to be paid for that period by the administration, both jointly between the state and regional governments, and separately for each of the services, setting an estimated maximum amount of EUR 113.8 million for these actions yearly. Part of this amount is paid directly by the regional government to service providers, and another part by the State Government through an IMSERSO transfer of EUR 54.18 million. Almost 114 million euros are spent on early care centers, day care centers, residences for PWDs, sheltered housing and also in activities and services complementary to the support of independent living.

The refurbishment of social services funding mentioned above has required the reform of the corresponding regional laws of Social Services in the financing of services of day care centers, sheltered housing and residences. The government of the Valencian Region has a system of social partnership with providers, which, since 2018, is signed for one year with an extension of another year. The aim is to evolve to a four year social partnership agreement to give more stability to entities, staff and users, avoiding unnecessary bureaucracy. To be part of the partnerships, service providers must be

registered and must also prove compliance with basic requirements and seniority of provision of services, as well as other evaluation criteria. This model outperforms the previous grant system which was a more “ex gratia” and less controlled model, depending on the final decision of politicians and civil servants. Social Partnership Agreements mean that the provision of social services is to be carried out through solidarity and non-profit management. Under such partnerships, service providers must be instruments for the achievement of the objectives of solidarity and budgetary efficiency, in the provision of services to people, control of the costs of these services, and ensuring that no benefit is gained through the provision³¹, but some of these services are being provided by profit-oriented companies.

Day care

The ownership and management of most day care centers in Spain belongs to private non-profit entities, parent associations or foundations, which are financed by regional governments, mostly through social partnerships. The places are public and the administration decides who will occupy them. In the Valencian Region, service users do not have to pay for this service.

There are significant differences in the way the Autonomous Regions have developed their systems of day care centres, as well as the costs of places provided. In the Valencian Region, there are three types of day care centres for the care of persons with disabilities aged between 16 and 65:

- ★ *Rehabilitation and Social Integration Centers* are day care services for persons with severe mental disorders, that function in an outpatient regime to provide care and preventive treatment of adults with severe mental illness. Such centres receive referrals from the Mental Health Unit (which are found in different towns) and develop proposals for joint action for the users.
- ★ *Occupational Centers* provide occupational therapy and personal and social adjustment services to persons with functional diversity for them to achieve their maximum personal development and, where

29 Ley 3/2019, de 18 de febrero, de servicios sociales inclusivos de la Comunitat Valenciana. Law 3/2019, of February 18, on inclusive social services of the Valencian Region. <https://www.boe.es/buscar/doc.php?id=BOE-A-2019-3489>

30 Resolution of December 18, 2019, of the Vice Presidency and Consellería of Equality and Inclusive Policies, by which the partnership agreements action are summoned in the matter of social services in the sector of attention to people with functional diversity for the period 2020. http://www.dogv.gva.es/datos/2019/12/23/pdf/2019_12323.pdf

31 Preamble III. Law 3/2019, 18th February of inclusive social services of Comunitat Valenciana.

possible, facilitate their training and preparation for access to employment. It is essentially a service for persons with intellectual disabilities but the place can also be occupied by persons with mental health issues, or persons with severe physical or sensory disabilities.

- ★ *Day care centres for persons with functional diversity* offer comprehensive care during the daytime period with the aim of improving or maintaining the best possible level of personal autonomy of persons with severe physical or intellectual disabilities and for persons with severe mental disorders, and support their families.

Each type of center has a different staff composition and cost of services. The cost of financing day care centers for persons with severe disabilities is much higher than that of Occupational Centers or The Rehabilitation and Social Integration Centers, due not only to the ratio of people working in care, but also to the professional profiles of the workers of the different services.

The general funding is carried out through the signing of social partnerships which are established by means of an order published in the official gazette of the Autonomous Region³². This agreement determines the prices of places and payment terms. Places are paid by the regional administration to service providers depending on the services they provides and also depending on the degree of disability of the user, determining an order in a scale of three general categories of support needs to establish the costs of each place.

According to the position in the scale, the rule sets the prices to be paid per day of service. The monthly cost paid by the administration in 2020 for places in the centres per month are as follows:

- ★ Rehabilitation and Social Integration Center - EUR 890.70;
- ★ Occupational Center (excluding transport services) - EUR 1,024.80 to 1,908.90;

- ★ Day care centres for Persons with Physical or Intellectual Functional Diversity or Persons with Severe Mental Disorder - EUR 1,728.90 to 2,9992.50.

The expenditure of day care centres in the Valencian Region is not separate from those of residences and sheltered housing. For the year 2020 the cost of a place at a day center ranges from EUR 890.70 to EUR 2,992.50 for the total of 4,224 places of day care centres offered in the region in 2020³³. In the rare cases of emergencies, new temporary places can be provided by means of grants, or private contracts with providers.³⁴

In order to qualify for social partnerships with the public administration, day care center service providers must first be accredited and enrolled in a census of social service providers. They must then get on the registry of the specific social service that they wish to provide, proving that they have sufficient facilities, staff and all the minimum requirements for each of the services. After the publication of the social partnership agreement, registered providers compete to manage public places of users. The administration values the following criteria: the provider's seniority in the provision of the service, the protocols of quality of the service, the provider's network with other services, having employees with disability, having gender equality protocols, the implementation and continuity of communication processes with users, family and professionals, as well as other requirements.

This social partnership system has only been implemented since 2018 and differs from grants and direct contract because it is less "ex gratia" and safer for service providers. However, while some providers have benefited because the fixed prices set in the contract are higher than the price they charged in the previous grants, others are forced to reduce the prices they were charging previously to provide the public service at the set value with this new system. In some cases, to "compensate" the reduced price, the Valencian administration is still paying entities through other grants that are not in the social partnership, so there is still a part of "ex gratia" aid³⁵. Furthermore,

32 Resolution of the social agreement for the period 2020: http://www.dogv.gva.es/datos/2019/12/23/pdf/2019_12323.pdf

33 Ibid

34 In march 2019, having already implemented the social partnership agreement, the Valencian Government signed a separate private contract with a day care center http://www.dogv.gva.es/datos/2019/03/04/pdf/2019_2035.pdf

35 Interview with day care, and sheltered houses service provider in Valencian Region, 26 July 2020, in the same sense Interview with expert in Valencian Region, 20 August 2020.

interviewed centre managers and experts only expect true stability to the social partnership system after the four-year partnership contracts come into effect. It should be noted that although the previous system was annual, the grants used to be repeated and re-negotiated year by year³⁶.

There are waiting lists to enter these day care services: families of children with disabilities report concerns as to whether their children will get a place in a day care centre when they get older, with the only alternative solution being care for at home. It often takes years to have an assigned place in a day care centre.

In urban areas, there are more day care centers than in rural ones, where many kilometres must be travelled daily to access their services. One of the experts³⁷ interviewed explains that in the Catalan Region, where the administration also matches users to places available, users are sometimes matched with centres very far from their home. In large cities, this generates great problems of displacement because sometimes the centers are not in areas which are well connected by public transport.

Day center workers earn according to what the collective agreement of the sector establishes for their professional category. While there is a national collective agreement for services of care for persons with disabilities, there is also one for the Valencian Region. It establishes the monthly and annual wages of the workers³⁸, ranging from EUR 1,1069.43 per month for the lowest category of auxiliary to EUR 2,397.01 for a psychologist with a higher education degree. The average weekly working hours in this service is 37.5 hours.

Interviewed experts and directors said that no changes are foreseen for the coming years beyond possible adjustments to current conditions and the extension of partnership to four years rather than the yearly extension in the current system.

Independent/supported living

Within the national framework of the Dependency Law, independent living support systems are part of a catalogue of services and benefits intended to support daily life and are as follows: home help, benefits for the care of the family environment, telecare, personal assistant services and sheltered housing.

Cost for service fees and the contributions that users of these centres must disburse range considerably in each Autonomous Region. However, there are many similarities in the way these co-payments are established, taking into account the nature and cost of the service and the economic capacity of the user.

The Personal Assistant service is almost non-existent in the Valencian Region, and the most used “service” is financial support benefits to cover the care received from family members. Telecare and home support are services that are widely used by persons with severe physical disabilities and also by the elderly, but persons with intellectual disabilities and those with mental health problems receive a wider range of services in sheltered housing to achieve and maintain a life within the community.

All these services have associated co-payments. The user pays according to their economic capacity, and the economic benefits also can be affected depending on it: if the user has no kind of income, the service will be provided for free.

Home support services, telecare and personal assistant services are provided by for-profit companies and by non-profit providers, accredited by the administration, or where appropriate, by individuals. There are no advantages or special contracts for non-profit entities. In all cases, the theoretical and practical capacity to perform services must be demonstrated to the administration. On most cases the administration pays a service provider to which it assigns users.

36 All interviewees, service providers and experts of the Valencian Region.

37 Interview with service provider, and expert of EASPD, of Catalan Region, 17 august 2020.

38 Resolution of May 8, 2019, agreement of the joint committee of the collective agreement of the sector of centers and services for the care of people with disabilities for the year 2019 http://www.dogv.gva.es/datos/2019/06/06/pdf/2019_5130.pdf

Telecare is a technological device that allows hands-free communication from home via a remote control with a contact center that operates 24 hours a day, 365 days a year. These services allow people to be cared for and live in their usual environment with a certain degree of autonomy. This service is funded by the regional administration and also by the municipalities. It is financed not by social partnerships but through public contracts. In March 2019, two contracts were established with one non-profit entity and another for profit one, for EUR 1.08 million and 2,68 million to serve 3,922 and 7,678 users, respectively. Telecare, like day care centers, is completely free service for the user.

The financing of home help services comes from the regional administration and also the municipalities through public tender contracts, as well as some co-payment. In 2020, it is being provided to 1,332³⁹ persons in Valencian Region. Companies must be accredited by the Regional Administration to provide services related to personal care in the performance of the activities of daily life (hygiene, personal care and grooming, postural changes, mobilizations, basic medication control and activities directly related to the empowerment of personal autonomy) and also services related to the care of domestic or home needs.

The provision for care in the family environment and support to non-professional caregivers is the most widespread service in the catalogue of dependency rights in the Valencian Region, being provided to 61,603 persons⁴⁰. Although at first such support was limited to

caregivers within the family, it was extended to other non-professional caregivers. This benefit can only be received by the person in a situation of dependency to pay the caregiver. The regional administration pays the users through their own and also state funds. The benefit is between EUR 153.00 and 442.59⁴¹, depending on the degree and level of dependence and economic capacity of the user. Users can register their caregiver as an employee with Social Security at no cost to them: the State pays the contribution corresponding to that expense.

The economic benefit of personal assistant⁴² service aims to promote the autonomy of persons in dependency of any degree. Its objective is to contribute to the hiring of personal assistance that facilitates the beneficiary's access to education and/or work, or to enable greater autonomy in the exercise of the basic activities of daily life, inclusion and participation in the community.

In Spain, in September 2020, while some autonomous regions continue without any Personal Assistant services, others such as the Basque Country have 6,234, and Castile and León have 1,322 economic benefits for personal assistants, each region, assigned to PWDs.⁴³

In the Valencian Region, to provide personal assistant services, persons, as well as companies, must be accredited; and there are currently 13 companies, profit and non-profit, accredited to perform the service⁴⁴. However, in December 2017, personal assistant service was provided only to 7 persons⁴⁵, and in September 2020

39 Data referring to July 2020 extracted from the IMSERSO website https://www.imserso.es/InterPresent1/groups/imserso/documents/binario/im_061364.pdf

40 Data referring to September 2020 extracted from the IMSERSO website https://www.imserso.es/InterPresent1/groups/imserso/documents/binario/im_061364.pdf

41 Data referring extracted from the Generalitat Valenciana social services website <http://www.inclusio.gva.es/es/web/dependencia/cuantias>

42 Carbonell Aparici, G. J. The experience of the personal assistant in the Comunitat Valenciana. <https://dialnet.unirioja.es/descarga/articulo/7009229.pdf>

43 Data referring to September 2020 extracted from the IMSERSO website https://www.imserso.es/InterPresent1/groups/imserso/documents/binario/im_061364.pdf

44 Generalitat Valenciana website: list of companies accredited for the personal assistance service <http://www.inclusio.gva.es/documents/610662/164359384/LISTADO%20DE%20EMPRESAS%20ACREDITADAS%20PARA%20EL%20SERVICIO%20DE%20ASISTENCIA%20PERSONAL/66504fc2-9f24-4ded-a56b-be3f796974a3>

45 State disability Observatory. Comparative measurement of socioeconomic impact and budgeting of personal assistance against other traditional care benefits dependency situations. December 2017. Table 3. <https://observatoriodeladiscapacidad.info/wp-content/uploads/2018/09/MEDICION-IMPACTO-SOCIOECONOMICO-AP.pdf>

still continues to be provided to a small number of persons (30)⁴⁶, despite children aged 3 years to persons over 65 being entitled to it. There is no clear reason as to why the administration does not yet fully implement this service. In this Region there is co-payment for this service, and also if the user receives other subsidies with supplements, those can be discounted depending on their amount.

Sheltered houses are configured as homes. They are adapted to the number and characteristics of users, and must be inserted into the community environment, in urban centers where a homogeneous group of persons with intermittent or limited support needs, coexist in a stable manner over time, under partially self-managed operations.

The Valencian Region, in 2020, offered, through social partnership, 505 places of sheltered housing⁴⁷, which are generally managed by non-profit entities. The administration pays the entities providing the housing services between EUR 1,921.50 and 3749,70€, per person per month depending on the degree of dependence of the person. Of these amounts, users pay the administration a portion, or pay nothing, depending on their economic capacity.

Experts⁴⁸ indicate that in line with the paradigm shift towards inclusion and support for the autonomous life of people with disabilities many for-profit companies have started providing this service. Some regions have penalized more than one of such companies for not meeting their commitments to ratios and quality of services. The same experts indicate that it is necessary to increase the supervision and ensure that the attention is adequate.

Support staff in sheltered houses earn according to the wages applicable to their professional category in the collective agreement of the sector. Besides a National

collective agreement for all care services for persons with disabilities, there is also one for the Valencian Region that sets the monthly and annual wages that sets the monthly and annual wages of the sheltered house support staff, ranging from EUR 1,1069.43 for the lowest category of assistant to 2,397.01 for psychologists with a higher education degree⁴⁹. The average weekly working hours in sheltered house support is 38 hours when the national average working hour is close to 40 hours per week.

Long-Term Institutional Care

To access residential care, persons with disabilities must apply for a dependency assessment by the autonomous regions. According to the EASPD country factsheet on social care services for PWDs⁵⁰, in Spain in 2016, 18% of users in need of long-term care received residential care, consuming 52.4% of the system's economic resources.

These residences have different characteristics, depending on the type and degree of disability, and whether the person with a disability is dependent or not. Most residences for PWD are privately owned. Only about 25% are public, both for children and the elderly under 65 years of age.

In the Valencian Region through social partnerships, a total of 1,098 residential places were offered in 2020. The administration pays non-profit private entities, through the social partnership agreement, between EUR 2,801.70 and 4,020.00 per place and month, according to the needs of support of the person. Users pay the administration according to their economic capacity for the places in which they reside, also as in other co-payment services, in some cases users prefer to look for private places that are economically more favourable to them.

46 Generalitat Valenciana website: list of companies accredited for the personal assistance service <http://www.inclusio.gva.es/documents/610662/164359384/LISTADO%20DE%20EMPRESAS%20ACREDITADAS%20PARA%20EL%20SERVICIO%20DE%20ASISTENCIA%20PERSONAL/66504fc2-9f24-4ded-a56b-be3f796974a3>

47 Resolution of December 18, 2019, of the Vice Presidency and Consellería of Equality and Inclusive Policies, by which the agreements of concerted action are summoned in the matter of social services in the sector of attention to people with functional diversity for the period 2020 http://www.dogv.gva.es/datos/2019/12/23/pdf/2019_12323.pdf

48 Interview with Director of public services provided by State, 18 August 2020

49 Resolution of May 8, 2019, agreement of the joint committee of the collective agreement of the sector of centers and services for the care of people with disabilities for the year 2019 http://www.dogv.gva.es/datos/2019/06/06/pdf/2019_5130.pdf

50 Eloisa del Pino, Spain Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities EASPD fact sheets. https://www.easpd.eu/sites/default/files/sites/default/files/Publications/countryreports1/easpd-spain_fact_sheet.pdf

The waiting lists of residences are very long. Interviewed experts and providers state that many times the only way to get a place, which may take years to become vacant, is to request a civil incapacitation of the person and the determination of the administration as legal guardian, with the resignation of custody or guardianship by the parents or relatives. In this way, the Valencian administration grants a place of residence. Interviewed stakeholders contend that the situation the Valencian Region⁵¹ is exceptional in Spain and possibly unique in Europe, undermining the right of persons with disabilities and being incredibly painful for those affected and their families. The need, in many cases, to resign the capacity to act and transfer the parental authority or the tutelage to the regional government in order to receive residential care services is seen a serious violation of the UN Convention on the Rights of Persons with Disabilities (CRPD). Furthermore, since the residences of PWD are saturated, some persons who have assigned places are taken to elderly residences, which are not the most suitable places for young people, because of the schedules and activities in such residences are aimed at their elderly population⁵².

Respite care

The respite care programs that are offered in Spain to PWDs and their families are commonly known as “family respite”. They cover services in day care centers and care through social, cultural and sports activities, also offering care for one or several days in sheltered houses or residences.

The regions regulate respite care services differently. In the Valencian Region there is no specific respite program for PWDs, although there is one for the elderly.

Order 1/2016, of January 20⁵³ of the Generalitat Valenciana establishes the regulatory basis for the granting of aid and subsidies in matters of care for people with functional diversity and promotion of personal autonomy, establishing a framework under which there are annual calls for aid in order to finance respite care for PWD.

The financing of respite care differs from other types of social services, not only because it does not have a specific rule, but also because only non-profit entities can participate as providers.

The prices of the services are not fixed, the entities offer services at certain fees which the administration decides upon, although the procedure for granting these aids is effected under a competitive regime. The entities receiving the grant proposal establish whether or not the user must make a co-payment for the services.

It is noteworthy that the regulation that finances respite care establishes that providers must comply with the obligations contained in Order 5/2015 of 23 October⁵⁴, regulating subsidies for the financing of projects and activities to promote and encourage volunteering. It therefore differs from services such as day care centres, sheltered houses and residences, which are completely professionalized.

The working conditions of the employees (not the volunteers) of the providers are governed by the collective agreements.

51 All interviewees: service providers of Valencian Region; experts of Valencian Region; service provider of Catalan Region & expert of EASPD.

52 Interview with day care, and sheltered houses service provider in Valencian Region, 26 July 2020, in the same sense Interview with expert in Valencian Region, 20 August 2020.

53 Order 1/2016, of January 20, of the Vice Presidency and Ministry of Equality and Inclusive Policies, which establishes the regulatory bases for the granting of aid and subsidies in terms of care for people with functional diversity, promotion of personal autonomy and accessibility. http://www.dogv.gva.es/portal/ficha_disposicion.jsp?L=1&sig=000508%2F2016&url_lista=

54 Order 5/2015, of October 23, of the Vice Presidency and Department of Equality and Inclusive Policies, which establishes the regulatory bases of subsidies for the financing of projects and activities to promote and encourage volunteerism in the Valencian Region http://www.dogv.gva.es/portal/ficha_disposicion_pc.jsp?sig=008543/2015&L=1#:~:text=2015%2F8804%5D-,ORDEN%205%2F2015%2C%20de%2023%20de%20octubre%2C%20de%20la,voluntariado%20en%20la%20Comunitat%20Valenciana.

Interviews

- ★ D. Josep Treserras Basela, Director of Services & EASPD expert, Interview on 17th of August, 2020
- ★ D^a. Charo García Sabater, Director of Services, Interview on 26th of July, 2020
- ★ D. Javier Vilalta Ibañez, Director of Services, Interview on 14th of August, 2020
- ★ D. Yago Cebolla Meliá, Director of Public State Services, Interview on 13th of August, 2020
- ★ Dr. D. José Vidagany Peláez, Expert social services PWD, Interview on 20th of August, 2020
- ★ Anonymous Worker at the Day Center, Interview on 21st of August, 2020
- ★ Anonymous Service User, Interview on 21st of August, 2020

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