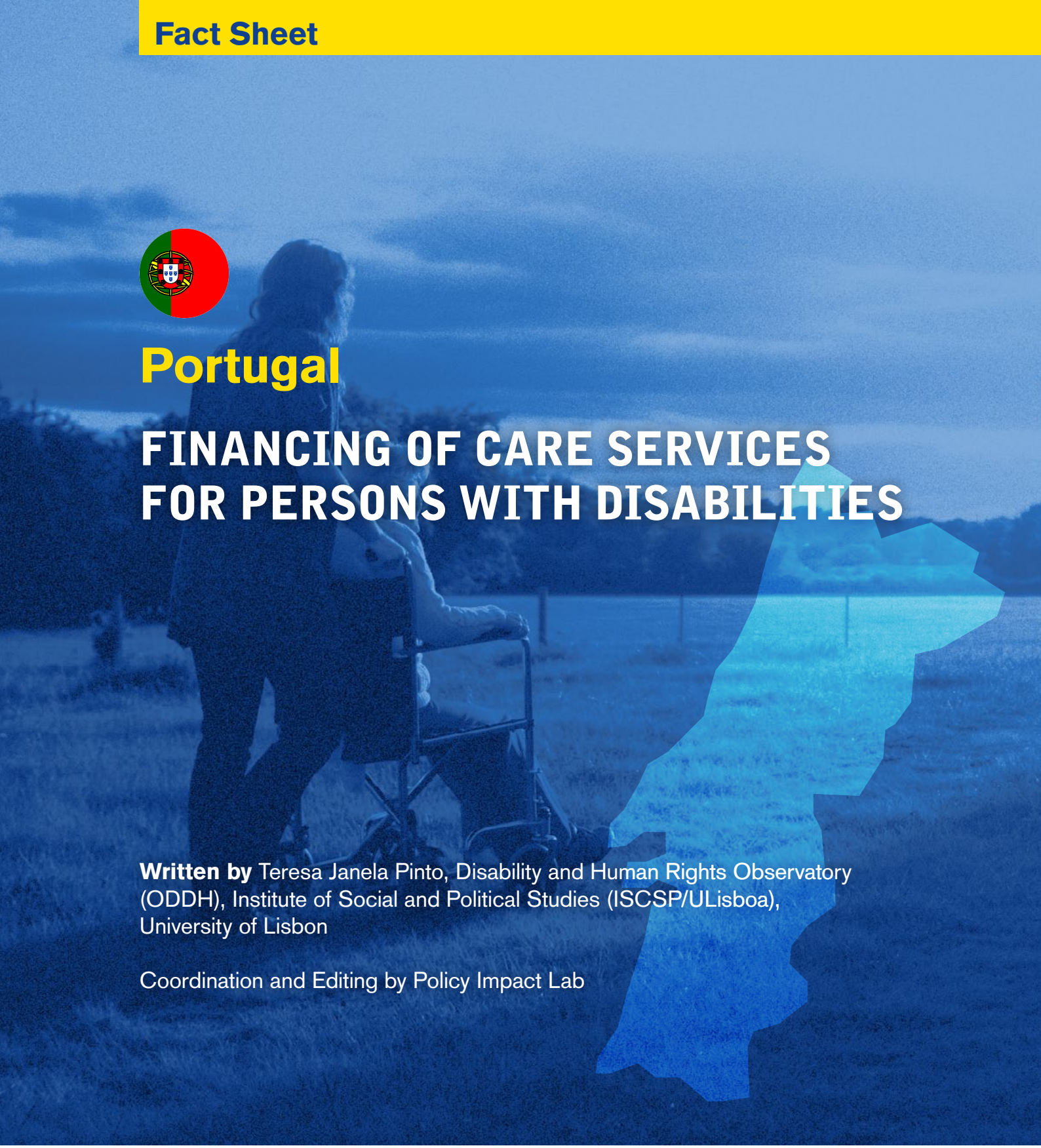
Fact Sheet



# Portugal

# FINANCING OF CARE SERVICES FOR PERSONS WITH DISABILITIES

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# Contents

# Executive Summary

Disability care services, in Portugal, rely heavily on private non-profit initiative, with public funding. Services first developed through charities and other non-profit organisations, with unequal territorial coverage. The strategic relevance of the social sector was recognized in the '*Pact of Cooperation for Social Solidarity*', signed in 1996. The State and social sector representatives regularly update this cooperation model, through biennial commitment protocols.

The State regulates, coordinates, and funds care services for persons with disabilities. The majority of these services are included in the ,*Network of Social Services and Facilities*'[1] - RSES, coordinated by the Social Security. In time, all services of support to persons with psychosocial disabilities are expected to transition to joint Health and Social Security coordination, under the *'National Integrated Continuing Care Network*'[2] (RNCCI), but some services for persons with psychosocial disabilities remain with the RSES. These networks include most day care, long-term institutional, and home care services for persons with disabilities, funded mainly through **service agreements within a reserved market**. Service agreements are established between the coordinating structures and the service providers for a two-year period, renewable after positive assessment. Disability care services can be standardized ('typical'), whereby service providers receive a fixed monthly payment per user (see subsections for funding amounts per service), or non-standardized ('atypical'), in which case funding varies depending on the context and activities developed, and is defined in the service agreement. The majority of care services for persons with disabilities are 'typical services', with standardized funding, included in the RSES network, and provided by non-profit organisations.

**User fees** constitute another funding source. User fees are set on a means-tested basis, in view of the household's per capita income. The formulas for calculating user co-payments are established in the diplomas regulating these services (see Introduction and subsections for further information). In the case of RNCCI services, public funding through service agreements covers the difference between the co-payments and the actual cost of the service.

Support to independent living, more specifically personal assistance services, is provided through a pilot programme (Independent Living Support Scheme - MAVI[3]), which combines features of different funding models. MAVI is a pilot programme, funded through **European Structural Funds** (ESF) and national public funds, initially set for a three-year period, with a recent announcement of a six-month extension. The programme includes a network of CAVI's (Independent Living Support Centres). The selection of the CAVI's integrated in the pilot programme was made through a **public-procurement-like competitive procedure within a reserved market**, open only to non-profit organisations recognised as Private Social Solidarity Institutions (IPSS)[4] or equivalent organisations. A "personal assistance plan" should be drafted by the service providers and users, detailing and justifying the number of hours of personal assistance required per user. However, no personal budgets are in place, since funding is still disbursed to the organisations, rather than to the users themselves. These organisations are in turn responsible for hiring and paying the personal assistants. Several issues were raised regarding the impact of this funding model. Firstly, since funding is deemed insufficient to cover personal assistance needs, persons with disabilities may have to continue relying on family members and other support networks. In this sense, despite being recognised as an important policy change, MAVI's funding model and functioning can limit its impact, functioning as an "upgraded home care service", which allows greater autonomy to persons with disabilities, but does not fully enable independent living. The fact that this funding model does not foresee personal budgets managed by the service users themselves, or at least a hybrid system including that option, is criticised by the organisations, since it compromises one of the key principles of independent living, namely "exercising freedom of choice and control over decisions affecting one's life with the maximum level of self-determination"

1 'Rede de Equipamentos e Serviços Sociais' — RSES.
2 'Rede Nacional de Cuidados Continuados Integrados' (RNCCI).
3 'Modelo de Apoio à Vida Independente' - MAVI.
4 'Instituições Particulares de Solidariedade Social' — IPSS.

(UNCRPD General Comment no. 5). The absence of personal budgets has been justified by public authorities with constrains related to public procurement and ESF management rules. The uncertainty surrounding the continuity of these services is also an important limitation of the current funding model (i.e. temporary pilot programme).

Other funding models, but less relevant in the case of disability care services, include private investment, subsidies for non-profit service providers, and social economy activities.

## Main findings

★ **Funding models**: The majority of care services for persons with disabilities (day care, long-term institutional care and home care services) are provided by non-profit organisations with public funding through *service agreements within a reserved market*[5], including 'typical' service agreements (fixed payment per service/user), or 'atypical' services (variable amounts set in the service-level agreements). Funding for these service agreements comes mostly from the State budget, with a small share supported by social gambling revenues[6]. This funding is supplemented by *user co-payments* (user fees), and in some cases by *other income-generating activities* developed by the service providers. Independent Living Support Centres integrated in MAVI (a pilot project) are funded by *European Structural Funds* and national public funds, and service providers were selected through a *public-procurement-like competitive procedure*. Within limits set by the diploma regulating MAVI, service providers and users establish a plan detailing the number of hours of personal assistance, but no personal budgets are in place, since all payments are managed by the organisations. Other less significant sources of funding for disability care services include subsidies for non-profit service providers and private investment.

★ **Types of service providers**: Following the principle of subsidiarity established in the Social Security Law (see Introduction), the majority of social care services in Portugal are managed by *non-profit organisations*. For instance, in the case of services included in the RSES network, 71% of service providers were non-profit (public and private), with a majority of private non-profit organisations (61% of all service providers) (GEP-MTSSS, 2019). Non-profit organisations (public and private) managed 83% of care services, in 2018[7] (GEP-MTSSS, 2019). In the case of independent living (MAVI), all CAVIs are managed by private non-profit organisations.

★ User fees can vary widely, depending on the type of service and household income, but tend to be low.

★ Services with standardized funding per user end up not taking fully into account the profile of users (e.g. percentage of users at risk of poverty or social exclusion, paying very low or no user fees; complexity of the users' needs which may have important financial consequences, for instance regarding user/staff ratios and other technical requirements; the type of activities developed, for instance, community-based empowerment and capacity-building activities can be more resource-intensive than more passive interventions).

★ Funding can be insufficient to cover operational costs. Financial sustainability of service providers was further challenged by the COVID-19 pandemic, due to an increase of operational costs (e.g. staff, equipment) and decrease in revenues.

★ Funding for the Independent Living Support Scheme (MAVI) may be insufficient to cover personal assistance needs, implying persons with disabilities may have to continue relying on family members and other support networks. Moreover, the fact that this service is funded through a pilot project raises concerns with its continuity and its impact on the users, organisations and personal assistants. The lack of personalized budgets with direct payments to the personal assistance users, justified by public authorities with constrains related to public procurement and ESF management rules, also compromises its potential in enabling independent living.

5 Service agreements take the largest share of the total public expenditure with social action (which includes other adult care services, general family and community care services, and services for children and youth). In 2018, expenditure with these service agreements amounted to 1.451.217.360€, 76,2% of the overall public investment in social action measures. By comparison, subsidies to non-profit organisations (IPSS) amounted only to 0,4% of social action expenditure (IGFSS, 2018).

6 In 2018, transfers from the State budget amounted to 94,2% (1.367.233.019€) of funding for service agreements in the social sector (all groups considered), whereas social gambling accounted for the remaining 5,8% (83.984.341€) (IGFSS, 2018).

7 This includes all services integrated in the RSES, not just disability care services, since specific data for these services is not available. Still, withdrawing other services, namely residential facilities for older people, this ratio is expected to be even higher.

- ★ Several measures were introduced to help service providers (and other organisations) cope with problems raised by the pandemic (e.g. support to lay-off and post-lay-off recovery; employment programme to reinforce personnel in strategic sectors - MARESS; delivery of personal protection equipment; funding programme for extension of social service capacity – PARES 3.0.).
- ★ Even if no integrated system is in place to adequately and regularly monitor current and prospective users, waiting lists were reported for all types of services.

# Introduction

The 2007 **Social Security Law** (Law 4/2007[8]) recognises the collective responsibility of ensuring social security for all, namely through redistribution mechanisms (art. 8). According to the principle of **public responsibility** (art. 14), the State must ensure the necessary conditions to fulfil the right to social security, including the organization, coordination and funding of the social security system. However, the system relies heavily on **subsidiarity** (art. 11), and complementarity (art. 15), through an articulation between various forms of social protection provision (public, social, cooperative, mutual, private) to ensure coverage.

The strategic importance of the social and solidarity sector was recognized in the '**Pact of Cooperation for Social Solidarity'**, established in 1996, whereby the State, and the representatives of social sector organisations set out to cooperate in the development of a 'network of integrated social support, thus contributing to an equitable coverage in the country of social services and facilities', and to make good use of available resources, in order to provide better services, taking into account a 'cost/benefit/quality' analysis. This cooperation agreement between the State and social institutions is revised on a regular basis, through biennial commitment protocols.

The social protection model established by Social Security Law includes social action, solidarity, and family protection subsystems. The **social action subsystem** aims to prevent or redress situations of economic or social vulnerability, by promoting inclusion in the community, skills development and protection of vulnerable groups, including persons with disabilities, namely through social care and support services.

The majority of these services are provided by non-profit organisations and funded through **service agreements** (IGFSS, 2018; GEP-MTSSS, 2019). To be eligible for funding through service agreements, service providers must follow certain conditions (e.g. comply by norms concerning facilities, functioning, staff and user/personnel ratios; provide monthly attendance reports; biennial assessment; ethical requirements).

Most disability care services are included in the **Network of Social Services and Facilities**[9] - **RSES**, coordinated by the Ministry of Labour, Solidarity and Social Security[10] - MTSSS (GEP-MTSSS, 2019). Services to support persons with psychosocial disabilities can be included in RSES, or in the **National Integrated Continuing Care Network11 - RNCCI**. Both networks follow similar models, and in time, all services for persons with psychosocial disabilities are expected to transition to the RNCCI network, under joint management of the Ministries of Health (MH), and Social Security (MTSSS)[12].

## Funding models

In Portugal, disability care services under study here (day care, independent living, long-term institutional care and respite care) are funded using the following models[13]:

8 Law 4/2007 from January 16th 'Social Security Base Law'. Available at: https://dre.pt/web/guest/legislacao-consolidada/-/lc/66798712/view?consolidacaoTag=Seguran%C3%A7a+Social

9 'Rede de Equipamentos e Serviços Sociais' — RSES.

10 'Ministério do Trabalho, Solidariedade e Segurança Social' — MTSSS.

11 'Rede Nacional de Cuidados Continuados Integrados' (RNCCI).

12 Some of these facilities are similar to institutions for persons with psychosocial disabilities integrated in RSES (supported by Social Security services). In time, most if not all social care and support services for persons with psychosocial disabilities are expected to transition to the RNCCI – Mental Health network.

13 Listed from most to least used based on qualitative assessment as comparative values are not available.

- ★ Service agreements between the State and service providers (mostly non-profit).
- ★ Public procurement-like competitive bidding within a reserved market
- ★ ESF funds
- ★ User fees
- ★ Grants and subsidies
- ★ Social economy activities of service providers
- ★ Private investment

## Service agreements within a reserved market

The majority of social care services for persons with disabilities (particularly day care, long-term institutional care and home care services) are funded through **service agreements** between the State and non-profit service providers. These agreements are established for a two-year period, renewable after positive assessment, based on a report presented to social security services. The agreements set the type of service, maximum number of users, and staff requirements. Funding amounts per user/month are also included in the agreements. Most services are standardized or 'typical', meaning the funding per user/month is fixed and equal for every provider (see subsections for specific values). Some services (e.g. day care 'centres of support, care and social rehabilitation for persons with disabilities', or long-term residential homes for persons with severe disabilities), however, are considered 'atypical', in which case funding amounts vary based on a case by case assessment of contextual factors, and the activities and services to be provided. Service agreements apply to typical and atypical services.

## Public procurement-like competitive procedures

The selection procedure for the Independent Living Support Scheme[14] (MAVI) could be said to rely on a public-procurement-like competitive procedure. Within the scope of this program, short duration contracts were established with private non-profit organisations, which applied to an open tender procedure to be recognised as CAVIs (Independent Living Support Centres) and receive funding for provision of personal assistant services (through subcontracting of personal assistants). To apply to this programme, organisations had to be registered as IPSS or equivalent organisations (reserved market). For more information, see the Independent/Supported Living subsection.

## EU funds

European Structural Funds may be used in several social programs. In the case of care services for persons with disabilities, the pilot project of support to independent living (MAVI; see other sections for further information) is largely supported by EU funds.

## User fees

In the case of care services subject to social agreements, users are expected to make a co-payment (user fee or 'family co-payment'), according to the rules established in the diplomas regulating these services[15]. Unlike Residential Care Structures for Elderly People (ERPI), where the unit considered for calculating this contribution is only the user himself/herself[16], the majority of services, including social care and support services for persons with disabilities integrated in the RSES and RNCCI networks, consider the household's per capita income. The formula for calculating per capita income takes into account the household's income and fixed expenses (e.g. taxes, rent or mortgage, transportation, health expenses and costs with chronic illness medicine). Service providers can establish a threshold for these expenses, as long as it is not inferior to the minimum guaranteed monthly wage (RMMG)[17]. User fees cannot exceed the average effective cost per user (in the case of RSES, calculated based on costs incurred in the previous year and adjusted for inflation, or in the case of new services, taking into account projected expenses/users). When a user is absent for more than 15 days in a row, user fees can be reduced by 10%. User fees can be revised based on changes in household income. For details on user fees per type of service, see the specific subsections.

14 'Modelo de Apoio à Vida Independente' - MAVI.

15 Ordinance 196-A/2015 (RSES network) and Order 14-A/2015 (RNCCI network).

16 Clause 3.2 of the Annex to Ordinance 196-A/2015.

17 'Remuneração Mensal Mínima Garantida' (RMMG). As of January 1st 2021, this value was set at € 665,00, a 4,7% increase from the previous year. Established by Decree-Law 109-A/2020 from December 31st. Available at: https://www.dgert.gov.pt/wp-content/uploads/2021/01/Decreto-Lei-n.o-109-A-2020.pdf.

### Grants and subsidies

Non-profit service providers may apply for subsidies and grants within specific programmes, even if funding disbursed through this model is less significant, particularly when compared with service agreements. There is no disagreggated data for the disability sector, but the analysis of global expenditure in social action programmes, in 2018, shows that funding for service agreements accounted for 76,2% of social action expenses, contrasting with 4,2% for programmes and projects, 6,6% for social projects co-funding, and 0,4% for subsidies to non-profit organisations (IGFSS, 2018). Among these programmes is PARES - Programme of Extension of the Social Facilities Network[18], funded by revenues from social games, managed through the MTSSS[19]. In the last trimester of 2020, a new edition of this programme (PARES 3.0) was launched[20], included in the measures to address the social emergency situation due to COVID-19, in accordance to Social and Economic Stabilization Programme (PEES)[21], with a budget of €110.000.000[22].

### Social economy activities/income generating activities of the organisations

Some service providers, particularly the largest ones and/or who develop professional training and employment support activities, mention relying on some social economy/income generating activities (e.g. income from the sale of products or services produced by persons with disabilities in sheltered employment or in other productive settings) to supplement funding for social care services.

### Private investment

Care services may also rely on private investment, though information on the weight and type of private investment in disability care services in Portugal is not available.

## Impacts of funding models on the providers and the services

★ Over the past decades (1998-2018), care services for persons with disabilities have doubled in size (+116%), presenting the greatest increase in all care service sectors (GEP-MTSSS, 2019). In 2018, there were around 1000 services for persons with disabilities in Portugal (GEP-MTSSS, 2019). This ***reinforcement of coverage was largely anchored on service agreements***. Considering the whole social care sector in Portugal, there are approximately 6500 care service providers, 71,3% of which non-profit, for the most part, private non-profit organisations (61,3% of all service providers) (GEP-MTSSS, 2019). Public funding through service agreements takes the largest share of social action expenditure: 1.451.217.360€, more than three quarters (76,2%) of the global public investment in social action, in 2018 (IGFSS, 2018).

★ Service agreements foresee co-payment and these user fees can vary widely, depending on family income. Still, as persons with disabilities and their families face important financial challenges in Portugal, ***user fees tend to be low***. In some contexts (e.g. rural areas, with a large proportion of low-income primary sector workers), this effect can be compounded, creating additional funding challenges for service providers. Families may also show resistance in paying user fees for social care services, since they feel they are already under considerable financial and emotional burden, and these services should be offered for free.

★ Other impacts of funding based on service agreements, particularly in the case of ‚typical' (i.e. standardized) services, which follow a flat-rate per user, is that it fails to take into account the ***diversity of user profiles and its financial implications***. Firstly, it does not fully consider the complexity of needs: even in services catered to persons with severe disabilities, there may be significant differences according to the users profile (e.g. users with multiple disabilities may

18 Established by Ordinance 426/2006, from May 2nd. Available at: https://dre.pt/pesquisa/-/search/659940/details/maximized

19 In accordance with no. 5 of article 3 of Decree-Law 56/2006, from March 15th, and Ordinance 1057/2005, from November 10th.

20 Set by Ordinance 201-A/2020 from August 19th, available at: https://dre.pt/home/-/dre/140631220/details/maximized.

21 'Programa de Estabilização Económica e Financeira' (PEES), approved by the Council of Ministers' Resolution 41/2020. Available at: https://dre.pt/home/-/dre/135391594/details/maximized.

22 According to Order 9952/2020 from the Ministry of Labour, Solidarity, and Social Security, available at: https://dre.pt/home/-/dre/145438892/details/maximized.

require larger staff/user ratios and more expensive equipment). Public funding does not compensate for services with a large ratio of users at risk of poverty, or without family support, where user fees are extremely reduced. Additionally, since funding for most services is adjusted based on monthly attendance registrations, when users are absent for long periods, as in the case of hospitalization, payment may be reduced accordingly, despite fixed costs (e.g. staff).

★ Another issue that affects service providers, particularly in the scope of service agreements, are the ***increasing requirements*** regarding facilities and service provision (e.g. health and safety measures, equipment, salaries), not fully compensated by an equivalent increase in funding which, for some years, increased below inflation.

★ As a result of all these factors, ***funding for non-profit service providers can be insufficient to cover operational costs***, particularly in the case of services with a large proportion of users with severe and complex needs. A recent study addressed this deficit in public funding for social care and support services[23] (Carvalho & Oliveira, 2020).

★ Service providers try to cope with this through an ***integrated financial management*** (e.g. relying on other sources of funding, such as social economy activities, or optimising financial and technical resources from other services to support care services that are not profitable).

★ Several issues were raised regarding the funding model adopted for the Independent Living Support Scheme (MAVI). The fact that this service is funded through a limited-duration pilot project raises ***concerns with its continuity*** and how this will affect users. Issues regarding the financial implications for the organisations that manage these services were also mentioned. For instance, costs related to the termination of contracts with personal asssistants due to dismissal or when the programme ends are not elegible and must be supported by the organisations themselves. Considering the high number of labour contracts involved, this is an important cause of concern for organisations.

★ Despite being hailed as an important policy change[24], MAVI's ***funding model and budget*** creates constraints to the number of hours of personal assistance per user. Since many users do not have access to the daily hours of assistance they require, they continue having to depend on family members and other informal caregivers for support, compromising MAVI's impact in enabling independent living.

★ The ***lack of personalized budgets with payments managed by the personal assistance users***, justified by public authorities with constrains related to public procurement and ESF management rules, also compromises its potential in enabling independent living. Several DPOs and service providers defend that after the pilot programme, a future law on independent living in Portugal should overcome this issue and introduce direct payments, for instance through a hybrid system, where users with greater autonomy levels can have access to direct payments and hire their personal assistants themselves, whereas in the case of users with more reduced autonomy levels and/or who do not wish to take on this responsibility, this could be ensured through an organisation/service provider.

★ Some issues are ***not related to a specific funding model, but to the system as a whole***. Several stakeholders (users, service providers, DPOs and experts) addressed the challenges of transitioning towards ***care services more compliant with a rights-based perspective***. This shift seems to be under way, at least in the formal intentions behind recent policy changes, such as the introduction of support to independent living or the announcement of changes in day care services, but it continues to raise debates about the best approach to support this change (e.g. reinforcement of funding for independent living vs.

23 The goal set in 1996 ‚Pact of Cooperation for Social Solidarity' was a public funding of no less than 50% of service providers' costs. Currently, this value is at 38% (Carvalho & Oliveira, 2020).

24 Support to independent living is a recent breakthrough, in Portugal. A series of protests by persons with disabilities helped raise awareness to the claims for independent living. Through open community meetings and negotiations, emerged a local personal assistance project, in 2015, funded by the Lisbon Municipality, and managed by a DPO ('Centro de Vida Independente' - CVI). A national pilot programme (MAVI) was created in 2017, by the recently appointed socialist government, which for the first time included a Secretary of State for the Inclusion of Persons with Disabilities, who set MAVI as one of the first major goals of the newly appointed cabinet.

increase in overall service capacity). Moreover, care services often operate in a compartimentalized way, due to the way the system is structured and funded, and users often have to adjust to specific types of services, rather than making full use of a plethora of community-based services to better cater to their needs. As such, some DPOs and public providers suggest services should make a progressive transition towards a more flexible and ***person-centered funding and governance model***. This would imply more flexible funding criteria, better coordination of services, and providing training to workers, families, and other target groups, to help support this transition.

★ Another issue that was raised across different funding models, concerns ***coordinating structures***. Payment procedures and delays can vary according to who bears the responsability for coordinating and managing funding. Interviewees reported Social Security tends to be timely and regular in payments to service providers, which is positively valued by service providers. Delays were reported in other sectors (health, and employment and professional training).

★ ***Financial sustainability was further challenged by COVID-19***, due to an increase of operational costs (e.g. increased staff due to more frequent sanitizing, covering workers in sick leave or preventive isolation, or to split teams and adjust shifts to reduce chances of contamination; investment in personal protection equipment and sanitation materials), and decrease in revenues (e.g. reduction in revenues from social economy, service provision and other activities; decrease in payment for social services during the first lockdown period, in the case of CAO users[25]). Service providers reported dealing with these challenges through integrated management, loans, and use of public support measures.

★ Several ***measures*** were introduced to help service providers cope with problems raised by the ***COVID-19 pandemic***. For instance: maintaining payment of residential services during the lockdown period taking into account attendance tables from previous months; regular delivery of some personal protection equipment; emergency social security brigades to support residential facilities in the case of COVID-19 outbreaks; employment programme to reinforce personnel in strategic sectors, including social services (MARESS); funding programme for extension of social service capacity (PARES 3.0). Service providers could also apply to other support programmes, open to all sectors, for instance support to lay-off and post-lay-off recovery.

★ Another cross-cutting issue concerns working conditions of staff in these services. The majority of care services for persons with disabilities are provided by non-profit organisations. As such, the table of ***earnings*** established in the collective contract for workers of the ***social and solidarity sector*** applies, which is ***below payment for equivalent functions in the public sector***. Several historic and cultural factors may play a role in the undervalorisation of this sector, but a significant increase in earnings can be difficult, since many organisations struggle with financial sustainability, and/or small structures. At the same time, this work is ever more demanding, and professionals often face high pressure and are in added risk of burn-out.

## Day Care

Day care services for adults with disabilities, in Portugal, are strongly reliant on service agreements with private non-profit service providers, complemented by user fees (co-payments). The majority of these services are included in the RSES network. In 2018, there were 492 active day care service agreements, supporting 14676 adults with disabilities through Occupational Activity Centres (CAO) and Socio-Occupational Forums. Public expenditure with these services reached 89 861 930,97€ in the same period, the greatest sum of all the subsectors considered in this report (see Table 1).

25 In the first stage of the pandemic management (from March 2020), the country imposed a country-wide lockdown. Some services (e.g. Residential Autonomous Homes, and Home Care Services), continued to work, even if with restrictions, but the majority of day care services for persons with disabilities (e.g. Occupational Activity Centres – CAOs) were closed, creating significant challenges for persons with disabilities and their families (Pinto & Neca, 2020). On a second stage, of progressive re-opening of public and private services and economic activity, the Social Security Institute (ISS) issued guidelines for a safe re-opening of CAOs (ISS & DGS, 2020), and these services have been returning to regular functioning ever since, with adjustments on the part of service providers.

TABLE 1 | Expenditure, number of service agreements and number of users, per type of day care service (RSES network), 2018

| | Expenditure € | No. service agreements | No. users |
|---|---|---|---|
| Occupational Activity Centres | 86 986 896,84 | 463 | 13 964 |
| Socio-Occupational Forums | 2 875 034,13 | 29 | 712 |
| **Day care services (RSES) - Total** | **89 861 930,97** | **492** | **14 676** |

*Source: IGFSS (2018)*

**Occupational Activity Centres26** (CAO) were intended to target only persons with severe disabilities, aged 16 or above, but are the most frequent day care service for persons with disabilities, with 13964 users, in 2018 (see Table 1). The government recently announced CAOs will be replaced by Activity and Capacity-building for Inclusion Centres (CACI), community-based services aimed at promoting the autonomy, quality of life, social inclusion, and personal and professional skills of persons with disabilities[27], but no details are yet available, regarding their target group, functioning, and how the transition from CAOs to CACIs will take place.

Adults with psychosocial disabilities can access a service similar to CAOs, also designed to offer day care activities that promote autonomy, emotional stability and social participation of persons with disabilities who are not employed. These include the **Socio-Occupational Forums28** integrated in the RSES network (social security), and the **Socio-Occupational Units29**, that are already under joint social security/health coordination, through the RNCCI network. Public spending with Socio-Occupational Units integrated in the RNCCI network is presented in Table 2.

TABLE 2 | Expenditure with day care services, per type of service and funding source (RNCCI network), 2019

| Day care services (RNCCI) | Health funding € | Social Security funding € | Total |
|---|---|---|---|
| Socio-occupational units | 205 742,60 € | 107 887,72 € | 313 630,32 € |

*Source: ACSS (2019)*

CAOs are considered 'typical' services, with standardized funding per user. In addition to these services, day care services for persons with disabilities included in the RSES network also include 'atypical' services (i.e. non-standardized and with variable funding), such as centres of support, care and social rehabilitation for persons with disabilities. Public funding for services included in the RNCCI network is variable. Funding amounts per user and per month for each type of day care service are presented in Table 3.

TABLE 3 | Amount paid by social security services per user and per month, 2019-2020

| Type of service | Value (per user/month) |
|---|---|
| Occupational Activity Centres | €538,35 |
| Socio-Occupational Units (RNCCI) | Variable. Difference between cost per user and the user fee. |

*Source: Commitment of Cooperation for the Social and Solidarity Sector: Protocol for the 2019-2020 biennium ('Compromisso de Cooperação para o Sector Social e Solidário: Protocolo para o Biénio 2019-2020').*

26 'Centros de Atividades Ocupacionais' – CAO.

27 Council of Ministers' press release from January 4th 2020. Available at: https://www.portugal.gov.pt/pt/gc22/governo/comunicado-de-conselho-de-ministros?i=387.

28 'Fóruns sócio-ocupacionais'.

29 'Unidade Socio-Ocupacional' – USO.

User fees for 'typical' services depend on the type of service. Table 4 presents the maximum co-payment as a percentage of per capita income, for the main day care services for persons with disabilities. Note that user fees cannot exceed the effective cost of the service (see Introduction).

TABLE 4 | User fees of day care services for persons with disabilities as percentage of household's per capita income, per type of service

| Type of service | User fee (percentage of per capita income) |
|---|---|
| Occupational Activity Centre – users not in residential homes | 65% |
| Occupational Activity Centre – users in residential homes | Variable. Cannot exceed 100% |
| Socio-Occupational Units | 15% (min.) – 50% (max.) |

*Source: Ordinance 196-A/2015; Order 14-A/2015.*

Some issues were raised regarding the **impact** of this funding model. Since funding for day care services is disbursed through specific *service agreements* for each type of service, rather than as the result of an integrated assessment of the users' profile and needs, service providers may face challenges related to funding. For instance, in the case of one non-profit service provider, users with a certain degree of autonomy, but not able to take on a full-time occupation, are part-time developing ‚socially-useful activities' in a productive unit, and part-time in day care services (CAO). In this case, they receive an allowance from the Institute for Employment and Professional Training (IEFP) for the time spent in the productive unit, but do not pay a user fee for CAO, so the service providers have to partially subsidize access to this service. In the case of this service provider, almost a third of CAO users were in this situation.

Another issue connected to this funding model that may create sustainability challenges to providers of day care services is the *fixed payment* for CAO users. The financial requirements for developing these services can vary widely, depending on the activities that are developed and on the profile of users. Offering services aimed at promoting skill-development, wellbeing, and autonomy of users, can be highly resource-consuming (e.g. time; personnel/user ratios), particularly in the case of users with severe and multiple disabilities. However, public funding is the same, regardless of these factors. As such, *funding for services for users with complex needs tends to be insufficient.*

Another issue concerns the limitations of *user fees* as a funding source for disability care services. These co-payments can vary widely, and since they are calculated with reference to household income, they tend to be low[30].

Some non-profit service providers mention they cope with these financial challenges through *integrated financial management*, whereby funding from social economy and income-generating activities (e.g. selling products made by productive units employing persons with disabilities) and other services, helps subsidize services that are insuficiently funded.

The *COVID-19 pandemic* placed added financial burdens on service providers, who saw their operational costs increase (e.g. individual social protection equipment, personnel), while their revenues diminished (e.g. users that did not attend day care services for persons with disabilities due the public health emergency, less revenues from productive units and other sources), sometimes leading them to resort to loans.

Service providers, DPOs and users report there are often significant *waiting lists* for day care services for persons with disabilities (e.g. CAO), but since there is no integrated system to monitor these requests, this is supported only by anedoctal evidence and the informal lists put together by service providers.

30 For instance, in the case of one of the service providers, for full support in CAO, including transportation, food, activities and therapies, user fees ranged from 15€ per month to near 500€, but only 3% of users paid the maximum amount.

# Independent/Supported Living

Support to independent living, more specifically personal assistance services, is provided through a pilot programme (Independent Living Support Scheme - MAVI[31]), established in 2017[32]. MAVI is a short-term programme, initially set for a three-year period, with a recent announcement of a six-month extension (in all, maximum 42 months), funded through European Structural Funds (ESF) and national co-funding. In most cases, the National Institute for Rehabilitation (INR) acts as the Intermediate Body in ESF management, with the exception of the Lisbon area, where the Lisbon Metropolitan Area (AML) acts as the Intermediate Body. Structural funds come from different ESF operational programmes (see Table 5).

TABLE 5 | MAVI projects and funding, per region

| Region | No. CAVI | Funding |
|---|---|---|
| North | 13 | PO ISE – Social Inclusion and Employment OP |
| Centre | 9 | |
| Alentejo | 5 | |
| Lisbon | 6 | POR Lisboa – Lisbon Regional OP |
| Algarve | 2 | CRESC Algarve – Algarve Regional OP |

** Note: OP - Operational Programme*

MAVI operates through a network of CAVI's (Independent Living Support Centres[33]), managed by **private non-profit organisations**, who are considered, for the purpose of this programme, as the programme's beneficiaries. Funding is disbursed to these organisations who are responsible for selecting the personal assistance users (target group), for hiring and training the personal assistants, and managing all operational activities. These organisations were selected through a **public-procurement-like competitive bidding procedure within a reserved market**, launched at regional level, open only to non-profit organisations recognised as an IPSS or equivalent organisation. The project funds 35 CAVI in mainland Portugal, providing personal assistance to 884 persons with disabilities – 395 in the North, 177 in the Centre, 102 in Alentejo, 39 in the Algarve, and 171 in the Lisbon area, aged 16 to 97 years-old (the average age of users was 44). Since its beginning, MAVI has provided more than 1.048.034 hours of personal assistance (INR, 2020). An "individualized personal assistance plan" (PIAP) is drafted one-on-one by the service providers and personal assistance users, detailing and justifying the number of hours of personal assistance required per user, providing a sort of semi-personalized budget, but without direct payments managed by service users themselves, which are a key feature of the personalized budget model.

Several issues related to the **impact** of this funding model were reported. Despite being hailed as an important policy change, MAVI's funding model can greatly limit its impact in supporting independent living. Initially, MAVI was supposed to include circa 200-300 persons. This goal was extended and currently the programme supports 884 users. The programme's regulation established thresholds for the hours of assistance (PA) per centre (i.e. each CAVI could not have more than 30% of its users with over 40 hours of PA per week). But even if this limit was considered, the allocated budget would be insufficient to cover both the maximum number of users and hours of support established by MAVI[34]. Recent adjustments have been made to the programme, with a reinforcement in funding (from maximum 1 400 000,00€ per CAVI to 1 750 000,00€) and revision of some expense tresholds, but these changes are still deemed insufficient to allow for a project extension *and* a reinforcement of personal assistance hours, to better

31 'Modelo de Apoio à Vida Independente' - MAVI.

32 Decree-Law 129/2017 ('Modelo de Apoio à Vida Independente'). Available at: https://dre.pt/pesquisa/-/search/108265124/details/maximized.

33 ‚Centros de Apoio à Vida Independente' (CAVI).

34 The maximum funding per CAVI was set at €1.400.000, for a three-year period.

respond to users' needs. Despite being a new service, valued by the users and DPOs, the average number of hours of personal assistance per user is rather low – for instance, as of December 2020, the average was 2,2 hours of personal assistance per user per day. As such, persons with disabilities may have to continue relying on family members and other support networks, which led some DPOs to characterise it as an "upgraded home care service", which allows greater autonomy to personal assistance users, but does not fully enable independent living.

Other issues raised concerned the absence of personalized budgets with direct payments to the personal assistance users, justified by public authorities with constrains related to public procurement and ESF management rules, or the uncertainty regarding the continuity of the programme. This issue continues to raise some discussion and several DPOs and service providers sustain that after the pilot programme, a future law on independent living in Portugal should consider the introduction of direct payments, for instance through a hybrid system, where users could opt for direct payments, and hiring and paying their personal assistants themselves, while in the case of users with reduced autonomy levels and/or who did not wish to take on this responsibility, this could be ensured through an organisation/service provider (as happens now). Another issue that was raised concerned the link between direct payments and labour relations – the fact that payment of personal assistants is mediated by the organisations may lead some personal assistants to recognise these organisations as their employers (e.g. situations where holidays or absences are communicated to the organisation, rather than to the user himself/herself ).

MAVI was created as a pilot programme, with limited duration (now 42 months), subject to a type of public procurement procedure, after which it will be evaluated with a view to adjusting the model and expanding it nationwide. However, this model creates some uncertainty for the service providers/DPOs who manage the CAVIs, for the personal assistance users, and for the personal assistants. For instance, costs related to the termination of contracts with personal asssistants (i.e. due to dismissal or when the programme ends) are not elegible and must be supported by the organisations themselves. Considering the high number of labour contracts involved, this is an important cause of concern for organisations. There are also wider concerns regarding the sustainability of these services. Support to independent living is expected to continue, in some form or another, after the pilot programme, but there is high degree of uncertainty regarding when that will take place, what will happen to current MAVI service providers, users and personal assistants, and if and how the programme will be expanded to other regions and beneficiaries.

Other issues were raised in regards to the *labour conditions* of personal assistants. This type of service creates specific challenges that are not encountered in more conventional services. For instance, one personal assistant may have to support several users, which can create limitations for finding schedules compatible with each user, and that do not pose significant constraints to user's autonomy. On the other hand, the labour code also sets clear limitations to the amount of daily (8h) and weekly (40h) hours of work, which creates added challenges for this management. These are common challenges among personal assistance programmes, but are heightned by financial constraints.

Since independent living is a relatively new concept in Portugal and in the beginning many service providers and persons with disabilities were not familiar with its core assumptions and procedures (e.g. how to estimate the number of hours of assistance they would require), there has been growing awareness and interest in this service. However, due to limited funding and the restrictions of a pilot programme, CAVIs cannot extend the number of participants, so *waiting lists* for this service are growing.

Persons with disabilities living in non-residential settings who do not benefit from MAVI may receive support from specific **home care services**[35] included in the RSES, including personal care and hygiene, meal services, home assistance, and other forms of living support. See Table 6 for information on funding and coverage of these services.

35 'Serviços de Apoio Domiciliário'.

TABLE 6 | Expenditure, number of service agreements and number of users of home care services (RSES network), 2018

| Type of service | Expenditure € | No. service agreements | No. Users |
|---|---|---|---|
| Home Care Services – Disability (RSES) | 1.502.485,65 | 21 | 486 |

*Source: IGFSS (2018).*

The RNCCI network also includes home care services for persons with psychosocial disabilities. For information on expenditure with these services per funding source, see Table 7.

TABLE 7 | Expenditure with home care services (RNCCI network), per funding source, 2019

| Long-term institutional care services (RNCCI) | Health funding € | Social Security funding € | Total |
|---|---|---|---|
| Home care services | 140 368,32 € | 24 678,13 € | 165 046,45 € |

*Source: ACSS (2019)*

Funding amounts for home care services included in the RSES and RNCCI networks are presented in Table 8.

TABLE 8 | Table 8: Amount paid by social security services per user and per month, 2019-2020

| Type of service | Value (per user/month) |
|---|---|
| Home Care Services – Disability (RSES) | €269,63 |
| Home Care Services (RNCCI) | Variable. Difference between cost per user and the user fee. |

*Source: Commitment of Cooperation for the Social and Solidarity Sector: Protocol for the 2019-2020 biennium ('Compromisso de Cooperação para o Sector Social e Solidário: Protocolo para o Biénio 2019-2020').*

Table 9 presents user fees for home care services. As noted before, these cannot exceed the effective cost of the service.

TABLE 9 | Table 9: User fees of home care services as percentage of household's per capita income, per type of service

| Type of service | User fee (percentage of per capita income) |
|---|---|
| Home Care Services (RSES) | 65% (max.) |
| Home Care Services (RNCCI) | 5% (min.) – 35% (max.) |

*Source: Ordinance 196-A/2015; Order 14-A/2015.*

# Long Term Institutional Care

As in the case of day care services, funding for long-term institutional care is strongly reliant on service agreements with private non-profit organisations, supplemented by user fees (co-payments).

The majority of these services are included in the RSES network. In 2018, there were 393 long-term residential care agreements for adults with disabilities, supporting 6402 users, and public expenditure with these services reached 76 563 094,73€ (see Table 10).

TABLE 10 | Expenditure, number of service agreements and number of users, per type of long-term institutional care services (RSES network), 2018

| | Expenditure € | No. service agreements | No. users |
|---|---|---|---|
| Residential Home | 71 365 857,39 | 300 | 5857 |
| Autonomous Home | 3 907 010,82 | 70 | 369 |
| Supported Life Units | 443 040,96 | 3 | 61 |
| Protected Life Units | 808 956,94 | 17 | 98 |
| Autonomous Life Units | 38 228,62 | 3 | 17 |
| **Long-term institutional care services (RSES) - Total** | **76 563 094,73** | **393** | **6402** |

*Source: IGFSS (2018)*

Adults with disabilities can access long-term institutional care facilities included in the RSES network, such as **Residential Homes**[36], units of up to 30 people, targeted at persons with disabilities aged 16 or older, and **Autonomous Homes**[37], units of up to five people, targeted at persons with disabilities aged 18 or older that, with adequate support, can live an autonomous life[38]. Persons with psychosocial disabilities can access three types of long-care institutional care facilities integrated in RSES: **Protected Life Units**[39], aimed at adults with severe psychosocial disabilities, clinically stable, and in need of autonomy training; **Autonomous Life Units**[40], targeted at adults with severe psychosocial disabilities, clinically stable, without other satisfactory residential options, but autonomous and capable of integrating vocational training, employment in the labour market or sheltered employment; **Supported Life Units41**, aimed at adults with severe and chronic psychosocial disabilities, considered unable to organize their daily tasks without support, but with no need of frequent medical care.

Other long-term institutional care facilities for persons with psychosocial disabilities are integrated in RNCCI. These include: **Autonomy Training Homes (RTA)**[42], to support the acquisition of autonomy and other basic skills for persons with mild to moderate psychosocial disabilities, for a period no longer than 12 months; **Autonomous Homes (RA)**[43] targeted at adults with mild psychosocial disabilities, without adequate family support and in need of supervision in daily activities, but capable of interacting

36 'Lares Residenciais'- LR.
37 'Residências Autónomas'- RA/RSES.
38 Ordinance no. 59/2015 from March 2nd.
39 'Unidades de Vida Protegida' - UVP.
40 'Unidades de Vida Autónoma' - UVAu.
41 'Unidades de Vida Apoiada' - UVAp.
42 'Residências de Treino de Autonomia' – RTA.
43 'Residências Autónomas' – RA/RNCCI.

and living in close proximity to the community; **Moderate Support Homes**[44] (RAMo) for adults with moderate disabilities; and **Maximum Support Homes**[45] (RAMa) for adults with severe disabilities. For information on expenditure with these services, per funding source, check Table 11.

TABLE 11 | Expenditure with long-term institutional care services, per type of service and funding source (RNCCI network), 2019

| | Health funding € | Social Security funding € | Total |
|---|---|---|---|
| RA | 48 610,90 € | 33 256,32 € | 81 867,22 € |
| RAMa | 562 974,00 € | 235 240,57 € | 798 214,57 € |
| RAMo | 114 554,64 € | 143 509,41 € | 258 064,05 € |
| RTA | 182 173,08 € | 115 716,11 € | 297 889,19 € |
| **Long-term institutional care services (RNCCI) - Total** | **908 312,62 €** | **527 722,41 €** | **1 436 035,03 €** |

*Source: ACSS (2019)*

Funding amounts for residential services integrated in the RSES and RNCCI networks are presented in Table 12.

TABLE 12 | Amount paid by social security services per user and per month, 2019-2020

| Type of service | Value (per user/month) |
|---|---|
| Residential Home (RSES) | 1062,98€ |
| Residential services included in RNCCI | Variable. Difference between cost per user and the user fee. |

*Source: Commitment of Cooperation for the Social and Solidarity Sector: Protocol for the 2019-2020 biennium ('Compromisso de Cooperação para o Sector Social e Solidário: Protocolo para o Biénio 2019-2020').*

User fees for residential services, as a percentage of the household's per capita income, are presented in Table 13.

TABLE 13 | User fees of residential care services for persons with disabilities as percentage of household's per capita income, per type of service

| Type of service | User fee (percentage of per capita income) |
|---|---|
| Autonomous Home (RSES) | 40% |
| Residential Home (without attending CAO) | 90% |
| Residential Home (attending CAO) | 65% |
| Autonomous Home (RNCCI) | 50% |
| All other residential units (except AH/RNCCI) | 30% (min.) – 60% (max.) |

*Source: Ordinance 196-A/2015 and Order 14-A/2015.*

44 'Residências de Apoio Moderado' – RAMo.

45 'Residências de Apoio Máximo' – RAMa.

Concerning the **impact** of the funding model for long-term institutional care services, many cross-cutting issues regarding service agreements and user fees apply (e.g. see Day care services subsection). Funding for residential facilities can be insufficient, particularly in the case of users with severe disabilities and/or complex needs. Moreover, public funding fails to take fully into account persons with disabilities with low revenues and no family support, which as users age, becomes an increasingly frequent issue. Since their revenues tend to be very low (e.g. often only the Social Inclusion Subsidy), and must cover all basic needs, and since funding per user is fixed, service providers may have to support the difference themselves.

Service providers report having *waiting lists* for residential homes for persons with disabilities, but since there is no integrated system to monitor these requests, this is supported only by anedoctal evidence and the internal lists assembled by service providers.

## Respite care

There are no specific respite care services to support persons with disabilities in Portugal, though the possibility of short-term institutionalization in residential care facilities during holidays or rest of the caregiver is foreseen. Respite care for persons with psychosocial disabilities may be provided by RAMo and RAMa facilities included in the RNCCI network for up to 45 days a year. Since services tend to be stretched to the limit of their capacity, there is still a general lack of awareness and use of respite care in Portugal, nor data available on availability or uptake of the service.

# Interviews

- ★ Carina Metelo, Regulator, Strategic Planning and Prospective Studies Department at the Cabinet for Strategy and Planning of the Ministry of Labour, Solidarity and Social Security (GEP-MTSSS), Interview on 4th of February, 2021
- ★ Paula Campos Pinto, Expert, President of the National CRPD Monitoring Mechanism, Coordinator of the Disability and Human Rights Observatory (ODDH, ISCSP/ULisboa), Interview on 31st of December, 2020
- ★ Cristina Silva, Provider and Employee, Director of ARCIL, Interview on 22nd of December, 2020
- ★ Rogério Cação, Provider and Umbrella Organization, President of the Portuguese Cooperatives' Confederation (CONFECOOP), Vice-President of FENACERCI, Interview on 30th of December, 2020
- ★ José Falcato, Provider and DPO, President of the Centre for Independent Living (Associação CVI), Interview on 21st of December, 2020
- ★ Mário Gonçalves, Employee and DPO, Coordinator of CVI's CAVI in the North region, Vice-President of the Centre for Independent Living (Associação CVI), Interview on 21st of December, 2020
- ★ Diana Santos, User and DPO, User of CVI's CAVI in Lisbon, Vice-President of the Centre for Independent Living (Associação CVI), Interview on 22nd of December, 2020
- ★ Joaquina Castelão, DPO/Family Member's Association, President of FamiliarMente, Member of the Workgroup revising Mental Health Law in Portugal, Interview on 11th of January, 2021

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