**ANED 2018-19 Task 1.2**

**Living independently and being included in the community**

Country: Portugal

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# List of abbreviations

|  |  |
| --- | --- |
| CAVI | Centro de Apoio à Vida Independente (Independent Living Support Centre (under MAVI Programme) |
| CCISM | Rede Nacional de Cuidados Continuados Integrados de Saúde Mental (Network of Mental Health Integrated Continuing Care) |
| CML | Câmara Municipal de Lisboa (Lisbon City Council) |
| CVI | Centro da Vida Independente (Independent Living Centre, in Lisbon) |
| DPO | Disabled persons organisation |
| ENDEF | Estratégia Nacional para a Deficiência (National Disability Strategy) |
| ESF | European Structural Funds |
| INR, I.P. | Instituto Nacional para a Reabilitação, Instituto Publico (The National Institute for Rehabilitation) |
| IPSS | Instituições Particulares de Solidariedade Social (Institutions of the Social Security Administration) |
| ISS, I.P. | O Instituto da Segurança Social, Instituto Publico (Social Security Administration) |
| MAVI | Modelo de Apoio à Vida Independente (The Independent Living Support Scheme) |
| MTSSS | Ministério de Trabalho, Solidariedade e Segurança Social (The Ministry of Employment, Solidarity and Social Security) |
| NRP | National Reform Programme |
| ODDH | Observatório da Deficiência e Direitos Humanos (Disability and Human Rights Observatory) |
| PIAP | Plano Individualizado de Assistência Pessoal (Personalised Personal Assistance Plan) |
| PO ISE | Programa Operacional Inclusão Social e Emprego (Operation Programme for Social Inclusion and Employment) |
| PPVI | Projeto Piloto Vida Independente (Pilot Project on Independent Living in Lisbon) |
| RNCCI | Rede Nacional de Cuidados Continuados Integrados (The National Network of Integrated Continuing Care) |
| SNIPI | Sistema Nacional de Intervenção Precoce na Infância (The National Early Intervention System) |
| SNS | Serviço National de Saúde (The National Health Administration) |
| UNCRPD | United Nations Convention on the Rights of Persons with Disabilities |

# PART A – Factual information and statistical data

# Current situation and direction of travel

## Numbers and proportions of disabled children and adults residing in institutional care or community-based settings

### Current figures

In the reference documents indicated in the guidance manual, Portugal is not mentioned among the “Community Living for Europe: Structural Funds Watch country profiles”.[[1]](#footnote-1) The reports of the EU Agency for Fundamental Rights (FRA)[[2]](#footnote-2) provide very scarce information on the independent living measures in Portugal, mainly concerning general policy facts (Part I, p. 16); “private social solidarity institutions (IPSS) that run services for persons with disabilities” (Part II, p. 18); and “the personal assistance scheme introduced as a pilot project” (Part III, p. 20).

This scarce information is mainly due to the fact that, in Portugal, ‘institutionalisation’ (as such) has never been a huge problem and did never reach the scale it achieved in countries such as the UK or France (Fontes 2016)[[3]](#footnote-3) – however, most persons with disabilities are institutionalised within their families who, for lack of available supports are forced to care for them (Pinto, 2011).[[4]](#footnote-4) The state provides some benefits to persons with disabilities (and their families) and a few support services are available in the community. Persons with disabilities end up in residential care institutions only when families are not able to care for them, either due to the severity of their needs or due to lack of family members.

As confirmed by data presented by Carta Social, **in 2017 there were 6,659 places in 288 Residential Care facilities for persons with disabilities in Portugal** (these are larger institutions, with up to 30 places) and **384 places in Autonomous Homes** (smaller units such as apartments).[[5]](#footnote-5) The latter were introduced in 2015 by Ordinance 59/2015 of 02 March 2015.[[6]](#footnote-6) Some people with disabilities are also institutionalised in Elder Residential Care facilities, for lack of other options, but it is impossible to estimate their numbers, as such statistics are not available. Given that the population with disabilities in Portugal is estimated to be around 1,900,000 people, these numbers show the little impact of ‘typical’ institutionalisation in this country.

For people with mental illness and psychiatric disorders, large psychiatric hospitals have been closing over the last decade, but again very few places are available in community-based care services. Therefore, the majority of people with psychosocial disabilities are cared for by their families. Table 1 summarises the numbers of users of different community-based care services for persons with disabilities and persons with psychosocial disabilities.

**Table 1.Users of community-based services, (retrieved on 31 January 2019)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Day-care Centres (CAOs) | Residential care facility | Autonomous Homes | Socio-occupational forums\* | Autonomous Homes\* | Supported Homes\* | Protected Homes\* |
| 15,577 | 6,659 | 394 | 928 | 30 | 61 | 91 |

*Source: Carta Social, available at:* <http://www.cartasocial.pt/index2.php> *(retrieved on 31 January 2019)*

\*Services targeted to persons with psychosocial disabilities

In addition to these, through Order 1269/2017,[[7]](#footnote-7) of 06 February, which provisioned the establishment of 366 places in the Network of Mental Health Integrated Continuing Care (CCISM) up until 2018, 189 places were made available in all types of these facilities[[8]](#footnote-8) (including 24 home-based support services)and that the total number of beneficiaries comprised **96 persons**.

### Trend since 2013

Data retrieved from the Social Security Institute Reports (reporting social security expenditures for 2013, 2015, and 20160),[[9]](#footnote-9) presented in Table 2 below, show a gradual increase of the number of users, mainly in Occupational Activity Centers[[10]](#footnote-10) and Residential care facilities for people with disabilities.

**Table 2. Users of community-based care services in Mainland Portugal (2013-2016)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Type of service/number of beneficiaries** | **As per 31.12.2013** | | **As per 31.12.2015** | | **As per 31.12.2016** |
| **Persons with mental illnesses and psycho-social disorders** | **Fórum socio-ocupacional / Socio-occupational forums** | | | | | |
| *Nº. of users* | | 732 | | 737 | 692 |
| **Unidade vida apoiada (‘Supported Life units/residencies?)** | | | | | |
| *Nº. of users* | | 71 | | 71 | 71 |
| **Unidades vida protegida (Protected Life Units/residencies)** | | | | |  |
| *Nº. of users* | | 111 | | 112 | 112 |
| **Unidade vida autónoma (‘Autonomous Life Units/residencies’)** | | | | | |
| *Nº. of users* | | 24 | | 24 | 24 |
| **Adults with disabilities** | **Residência Autónoma / Autonomous Homes** | | | | | |
| *Nº. of users* | | 227 | | 326 | 336 |
| **CAOs / Occupational Activity Centres** | | | | | |
| *Nº. of users* | | 12,159 | | 13,028 | 13,644 |
| **Lar residencial / Residential Care Facilities** | | | | | |
| *Nº. of users* | | 4,695 | | 5,525 | 5,765 |
| **Apoio domiciliário - pessoas com deficiência /**  **Home-based care services for persons with disabilities** | | | | | |
| *Nº. of users* | | 465 | | 515 | 462 |

*Source: Retrieved from the Reports of ISS, I.P. ‘Conta da Segurança Social 2013, 2015, and 2016’ (data is not available for subsequent years)*

An important step towards the implementation of Independent Living in Portugal took place in 2015, when the first Pilot Project on Independent Living was launched by the Lisbon City Council (CML).[[11]](#footnote-11) Under this Project, the first Centre for Independent Living (CVI)[[12]](#footnote-12) in the country was established in the city of Lisbon. It has been providing personal assistance and accommodation services for just **five persons with disabilities** to pilot-test the concept of independent living in the country.

In 2017, the government launched a national programme of support to independent living **- The Independent Living Support Scheme** (MAVI) through Decree-Law 129/2017, of 09 October.[[13]](#footnote-13) MAVI is to be developed for a period of three years — 2017-2020, funded within the framework of Portugal 2020, through the ESF. It provisions to pilot a network of Independent Living Support Centres (CAVIs) throughout the country that will implement personal assistance projects.

Following the adoption of MAVI in October 2017, a call for proposals for the accreditation of independent living centres (CAVIs) was launched. Once accredited, these centres applied for funds to develop personal assistance schemes for up to 50 beneficiaries each. This whole process was quite bureaucratic and long and only in January 2019, some Independent Living Centres are starting their activities of recruitment and training of personal assistants. According to the newspaper ‘Publico’ (as of 29 November 2018),[[14]](#footnote-14) and as officially confirmed by the INR, I.P.,[[15]](#footnote-15) in total, 51 applications were received, of which 30 were approved in the North, Centre and Alentejo regions of Portugal. The government is planning to sign the first 21 contracts for CAVIs that will assist approximately 722 persons with disabilities for whom they will hire about 522 personal assistants.

In the Mental Health sector, Decree 8/2010[[16]](#footnote-16) (Article 8), of 28 January, amended by Decree-Law 22/2011 of 10 February (Articles 8 and 9),[[17]](#footnote-17) established a set of mental health care services that constitute the Mental Health Network of Continuing Care. Existing services (such as the different types of residential units, the socio-occupational units, and the home-based care services that were formerly funded through Social Security) should gradually be integrated into this network and become the shared responsibility of the Ministry of Health and the Ministry of Labour and Social Solidarity. However, for seven years, the plan was not implemented and only in 2017 it gained renewed attention with the publication of Order 1269/2017[[18]](#footnote-18) and Ordinance 68/2017 of 16 February,[[19]](#footnote-19) this latter establishing the new norms and operational rules for service provision. Some of these new rules were quite demanding and different from previous one (for example in terms of the characteristics of the buildings, with no transition clauses that would enable service providers to adapt to the new rules over a number of years). All this created a lot of obstacles that delayed the implementation of the new network. This explains why, as of December 2017, only 96 users were benefitting from these sew services, across the whole country, and the numbers today continue very low.

## Overall spending on institutional care versus services for support for living independently and being included in the community, including information about proportion/amount of funding provided from EU funds

### Current figures

The OECD[[20]](#footnote-20) reports that public spending on long-term care in Portugal comprises 0.5 % of GDP (as of 2014) or USD 1,150 million, which is much lower than in other European countries.

The funding for residential care facilities is provided by the Institute for Social Security. Overall, as reported by Carta Social,[[21]](#footnote-21) **in 2017, the total public spending on all social care programmes amounted to EUR 1,340 million.** However, the total public spending on social care services for persons with disabilities (which comprises more than just residential care facilities), amounted to just 13,4 % of total expenditure (compared to 39,3 % for children and youth and 43,1 % for the elderly). Yet, there was a slight increase compared to the 11,5 %[[22]](#footnote-22) spent in 2013.

Funding for mental health units integrated in the Network of Mental Health Integrated Continuing Care (CCISM) is provided by both the Ministry of Health and the Ministry of Labour, Solidarity and Social Security - MTSSS (through the ISS,I.P.). **The total spending in 2017** of the ISS,I.P. with the **CCISM amounted to EUR 10,995.52.**[[23]](#footnote-23) Unfortunately it is unknown the corresponding contribution to the same services from the Ministry of Health.

The independent living projects that are about to start in the country will be funded **with a total amount of EUR 23,506,254,**[[24]](#footnote-24) of which 85 % comes through the ESF and 15 % from the State Budget.

### Trend since 2013

As shown in Table 3 below, since 2013, spending in residential care facilities for persons with disabilities has been gradually increasing, especially on Occupational Activity Centres for people with disabilities (CAOs) and residential facilities of up to 30 places (Lar residencial). In contrast, spending on the provision of services for people with psychosocial disabilities has barely changed over the period under analysis.

**Table 3. Social Security Expenditures per type of residential facility in Mainland Portugal, 2013 – 2016, in euros**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Residential facility/expenditures** | | **As per 31.12.2013** | **As per 31.12.2015** | **As per 31.12.2016** |
| **For persons with psychosocial disabilities** | Fórum socio-ocupacional | 2,629,461.16 | 2,789,084.06 | 2,826,730.03 |
| Unidade vida apoiada | 434,483.52 | 443,657.16 | 449,423.98 |
| Unidades vida protegida | 848,815.71 | 863,465.36 | 876,253.26 |
| Unidade vida autónoma | 48,730.85 | 49,840.72 | 50,488.58 |
| **For persons with disabilities** | Residência Autónoma | 1,852,801.41 | 3,325,429.03 | 3,587,405.34 |
| CAOs | 66,038,362.63 | 76,916,047.06 | 80,699,035.45 |
| Lar residencial | 47,865,935.17 | 61,759,504.59 | 65,937,464.34 |
| Apoio domiciliário - pessoas com deficiência | 1,329,442.96 | 1,468,776.86 | 1,393,820.39 |
| **Total spending in social care services** | | **1,209,620,295.00** | **1,281,011,747.95** | **1,308,640,873.45** |

*Source: Retrieved from Reports of ISS, I.P. ‘Conta da Segurança Social 2013, 2015, and 2016’:[[25]](#footnote-25)*

*2013, Part II (Quadro ‘Acordos de Cooperação (Orçamento Corrente + Programa’, p. 417);*

*2015 Part II (‘Quadro 124 ‘Dados financeiros e físicos dos Acordos de Cooperação, pp. 427-428);*

*2016 Part II (Quadro 125, p. 405).*

The Social Security (ISS, I.P) spending on Mental Health units, under the Network of Mental Health Integrated Continuing Care (CCISM) has also increased, especially in 2017, as shown in Table 4 below.

**Table 4. Annual expenditure of ISS, I.P. on Mental Health units (2013-2017), Mainland Portugal, thousand euros**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Annual expenditures of ISS, I.P.** | **2013** | **2015** | **2016** | **2017** |
| CCISM | 55,000 | 617,800 | n/a[[26]](#footnote-26) | 10,995.52 |

*Source: Retrieved from the Reports of ISS, I.P. ‘Conta da Segurança Social 2013, 2015, and 2016’, available at:*

[*http://www.seg-social.pt/publicacoes?bundleId=15671250*](http://www.seg-social.pt/publicacoes?bundleId=15671250)(*milhares de euro*). The data for 2017 is retrieved from RNCCI Monitoring Report 2017 (Quadro 73, p. 124), available at: [*http://www.acss.min-saude.pt/wp-content/uploads/2018/11/Relatorio-de-Monitorizacao-da-RNCCI-2017.pdf*](http://www.acss.min-saude.pt/wp-content/uploads/2018/11/Relatorio-de-Monitorizacao-da-RNCCI-2017.pdf)*.*

This increase in funding can be explained by the fact that Mental Health Units as part of the RNCCI only started being implemented on the ground from June 2017 on. Before that, even though, they were mentioned in the law (see Section 1.2), their numbers in practice were very low.

Since the independent living schemes at national level are being launched right now, there is still no trend to observe in terms of spending.

# Government commitments on living independently and being included in the community including the transition from institutional care to community-based living

## In which document(s) are government commitments and plans concerning support for independent living in the community set out?

Commitments to support independent living have been mentioned in the following government documents:

* First National Disability Strategy (ENDEF I) 2011-2013;[[27]](#footnote-27)
* The Programme of the XXI Constitutional Government for 2015-2019;[[28]](#footnote-28)

Portugal 2020/ PO ISE (Operation Programme for Social Inclusion);[[29]](#footnote-29)

* The National Reform Programme (NRP);[[30]](#footnote-30)
* The National Plan of Mental Health 2007-2016[[31]](#footnote-31) and the new National Programme on Mental Health 2017-2020.[[32]](#footnote-32)

## What are the aims and objectives of relevant strategies, including relevant targets and milestones? Are they linked to ESIF?

The aims and objectives of relevant strategies/government documents that specifically targeted promoting independent living of persons with disabilities in Portugal were the following:

* In the ENDEF I, the government set out the goal of implementing the first pilot project that would create a personal assistance service in Portugal. However, by 2013, when the Strategy ended, this measure was not yet put in place.
* The Programme of the XXI Constitutional Government announced the inclusion of persons with disabilities as one of its strategic objectives. While, it did not explicitly mention the independent living programme, it did prevision the “transition of support provided on the basis of institutionalised models for the provision of services in the community”. Among other objectives, the Programme also gives importance to the establishment of the National Network of Continuing Mental Health units.
* The Portugal 2020 Programme (in Axis 3, Target 3.18) foresees the implementation of the Model to Support Independent Living (MAVI).
* The NRP 2016-2021 and 2017-2021 previsioned the establishment of the Independent living support model as a new measure, and the NRP 2018-2022 explicitly mentions the implementation of the Independent Living Model (MAVI) among its objectives.
* The National Plan of Mental Health 2007-2016 (1.2.) established the objectives of deinstitutionalisation and gradual closing of psychiatric hospitals (approved by the Resolution of the Council of Ministers 49 of 06 March 2008).[[33]](#footnote-33) The new 'National Programme on Mental Health 2017’ was extended up to 2020[[34]](#footnote-34) and among its goals it promotes the establishment of the Network of Integrated Continuing Mental Health Care to reduce the institutionalisation of people with severe mental illnesses and psycho-social disorders.[[35]](#footnote-35)

## Please summarise the planned approach and the actions to be taken in relevant strategies

The planned approaches as mentioned in relevant strategies were the following:

* In the ENDEF I, other than a reference to the implementation of a pilot project on Independent Living, there were no specific targets regarding the number of persons who would be included in the programme, budget, timelines for implementation and so on.
* The NRP 2018-2022 mentions as an important measure to combat poverty and social exclusion of persons with disabilities the launch of the MAVI Project (the Independent Living Pilot Scheme) and the functioning of CAVIs (the Centres for IL) in the first quarter of 2018, and its further implementation until 2020, which is considered an important measure to contribute to the EU2020 target of reducing poverty and social exclusion. According to the NRP 2018 (Medidas 1, ‘Indicadores Físicos’),[[36]](#footnote-36) between 240 to 500 persons with disabilities are expected to benefit from MAVI during 36 months until 2020. In addition, the NRP 2018 also indicates that pilot projects in mental health care will be set up (unidades pilotos de saúde mental) that will provide more than 366 places to people with severe mental health problems in 2017/2018 (according to Ordinance 1269/2017 of 06 February).
* The new 'National Programme on Mental Health' has emphasised, among other goals to be accomplished by 2020,[[37]](#footnote-37) the establishment of 1,500 places for adults and 500 places for children/adults in the Network of Integrated Continuing Mental Health Care (CCISM).

## What budgetary commitments are made to support these strategies, both for domestic and EU funds?

The ENDEF I had no budget attached, so no financial commitment was made.

According to the MAVI official announcement,[[38]](#footnote-38) the funding available for the current support to independent living programme is set at EUR 23,506,254 for three years. **Funding from the ESF amounts to 85 % of this total** while the national contribution is 15 %.

Despite our efforts we could not find how much is the financial commitment in the 2019 State Budget for the implementation of the Network of Continuing Mental Health Care.

## What is the (official) involvement of persons with disabilities and/or their representative organisations in the development of the strategies and plans

On 03 December 2013, the Portuguese Movement of the Outraged (dis)Abled People (Movimento dos (D)eficientes Indignados, in Portuguese) hosted a conference on Independent Living, supported by the Lisbon Municipality. From that conference, a Pilot Project on Independent Living was developed by the Lisbon Municipality, with public consultation and the assumption that it would be managed by disabled people.[[39]](#footnote-39) The project description (“*Bases para um Projecto-Piloto de Vida Independente)*”[[40]](#footnote-40) was available on the website of the Municipal Assembly of Lisbon, as well as on the websites of DPOs for public discussion from December 2014 until 03 February 2015. Input was collected through email, telephone, and three public meetings on 10, 23 and 29 of January 2015, in which about 80 people participated.

The proposal of the current national independent living pilot project (MAVI) opened for public consultation for 60 days in 2018.[[41]](#footnote-41) Three open public discussion sessions were held on 20 March in Lisbon and on 24 March 2017 in Coimbra and Porto. Altogether about 500 persons including persons with disabilities and DPOs participated in these discussions,[[42]](#footnote-42) and afterwards the government presented the document summarizing the discussions and suggestions received.[[43]](#footnote-43)

Nevertheless, many of these inputs were not taken into account in the legislation that ended up being adopted (MAVI) and even less in the rules of the grant through which the personal assistance scheme will be funded for the next three years in Portugal.

# Implementation and monitoring

## Summary of relevant calls for proposals

**Independent Living Pilot Project in Lisbon – 2015**

The first Pilot project was the initiative of the Lisbon City Council (CML). As a result, the first Centre for Independent Living was established to receive the funds from the City Council and to implement this pilot project in Lisbon. The Centre opened a call for potential beneficiaries to which people with disabilities could apply.

**National pilot projects for Independent Living - 2017/18**

Decree-Law 129/2017[[44]](#footnote-44) that regulates the MAVI and the process of accreditation of Centres for Independent Living – CAVIs was adopted on 09 October 2017. Within 60 days after the adoption of this legislation, disability organisations and service providers could apply to be recognized as Centre for Independent Living. Those centres which got the recognition were then able to submit an application for funding to implement the personal assistance scheme (T.O 3.18; POISE-38-2018-04).[[45]](#footnote-45) The calls for funding took place between 22 March 2018 and 28 May 2018[[46]](#footnote-46) for most regions of the country; from 23 May until 09 July 2018[[47]](#footnote-47) in Algarve; and in the region of Lisbon from 04 July 2018 to 04 September 2018.[[48]](#footnote-48)

## Summary of relevant projects funded

**The Pilot-project in Lisbon started in 2015 with five participants.** The Regulation document (“*Bases para um Projeto-Piloto Vida Independente*”,[[49]](#footnote-49) in Portuguese) established that the expenditures **could not exceed EUR 13,000 per person** **per year**, with eight hours of assistance per day on average (240 hours per month) allocated to each user. The Independent Living Project has been managed since by the Centre of Independent Living of Lisbon (CVI),[[50]](#footnote-50) a DPO in Lisbon.

**Pilot projects for Independent Living** are being implemented across the country **since 2017** but the process of implementation went through the following stages:

First, the organisations that wanted to implement personal assistance projects were required to submit a registration form to the INR, I.P. to be recognised as Centres for Independent Living (CAVIs) - **73 centres in total**[[51]](#footnote-51) **were accredited**: North (32), Centre (12), Alentejo (9), Algarve (4) and the cities of Lisbon (15) and Porto (1).

Second, accredited CAVIs submitted their project applications for implementing personal assistance schemes. The MAVI Application Guide[[52]](#footnote-52) indicates that the maximum amount to be financed per CAVI is set at **EUR 1,400,000 including** administrative expenditures such as wages of the staff and personal assistants, training and transportation expenditures, for the total period of 36 months. Each CAVI can assist from 10 to 50 persons with disabilities. Ordinance 342/2017 of 9 November[[53]](#footnote-53) establishes in Article 4 (a-c) the following financial limitations:

* Amounts for CAVIs functioning shall not exceed EUR 115,000 per CAVI for the total period of functioning; payment for personal assistants shall not exceed EUR 900 per month per person for 40 hours of weekly assistance; and payment for professional training shall not exceed EUR 4,000 per person during the total funding period.

**In total, 51 applications were received from CAVIs, of which 30 were approved**. As of January 2019, the government is planning to sign the first 21 contracts with CAVIs, that will assist approximately 722 persons with disabilities, for whom about 522 personal assistants will be hired.

## Overview of other relevant measures since 2013

Among other measures recently adopted that also contribute to independent living of persons with disabilities in Portugal it is important to mention the following:

* **A new unified disability benefit – the Social Benefit for Inclusion** (Prestação Social para Inclusão – PSI) for people with impairments of 60 % or over (approved by Decree-law 126-A/2017, of 6 October).[[54]](#footnote-54) The PSI benefit can be accumulated with other benefits and income from work, although with a cap for people with incapacity level 60-80 %.
* **The new Law 49/2018 that entered into force on 14 August 2018**[[55]](#footnote-55) which approves the new “regime of adult support” (o regime jurídico do maior acompanhado) that eliminates the previous regimes of *inabilitation* and *interdiction* and will also result in appropriate amendments in the Civil Code, and other related laws and regimes. ‘The regime of interdiction’ implied a severe containment to the exercise of rights, and could be assigned by the Court on the basis of a legal request (by a parent, the spouse, a child, the curator or the public attorney), a medical assessment of the individual, and statements of family members, friends, neighbours and others close to the person. Persons who were subjected to this regime remained in the status of minors, and could not exercise the right to vote, and were prevented from exercising paternity and testifying in court, and although they can marry, the marriage can be declared null. Once the status of interdiction was assigned, a Tutor/Guardian was designated. The ‘regime of inhabitation’ was also assigned by a Court, on the basis of a legal request and a medical assessment, but it implied only the suppression of the right to manage one's own property. A Curator was designated to assist the person in all acts related to property, or even to act on his/her behalf. In this latter case, a Family Council (composed of family members, neighbours, friends and others) was set in place, and a representative was nominated to supervise the acts of the Curator. In contrast to the previous regimes, the new “regime of adult support” aims to provide the support to the person to enable the full exercise of her/his rights. An ‘assistant assists the person in making decisions and the assistant should be chosen either by the persons who needs support herself, or his/her legal representative. This is considered an “historic moment in the promotion of the rights of persons with disabilities in Portugal alongside with the implementation of the UN CRPD”, as mentioned by the Secretary of State on Inclusion of Persons with Disabilities Mrs. Ana Sofia Antunes.
* **The new Decree-law 54/2018 on Inclusive Education,**[[56]](#footnote-56) which abolishes the term ‘special education needs’ and strengthens the path towards the inclusion of all children in mainstream schools, regardless the level of their disabilities.

## Monitoring mechanisms and approaches

### Monitoring mechanism(s)

According to the Regulation document,[[57]](#footnote-57) the final evaluation of the City of Lisbon Pilot Project on Independent Living has to be performed by the municipality, and shall take into account the following indicators: 1) the satisfaction level of the users/participants of the project; 2) changes at a personal level; 3) evaluation of personal assistance services provided; 4) future projects. Currently, a team of researchers under the Project DECIDE[[58]](#footnote-58) that started in June 2016 is conducting an external evaluation of the implementation of the project, compared to other living arrangements for people with disabilities – e.g. living in Institutions and living with families. The Project team has already made several presentations at different national and international events, but the final report is not yet available.

Regarding the implementation of the MAVI Programme, according to Article 44 of Decree-law 129/2017, of 09 October, the National Institute for Rehabilitation is responsible for defining indicators, monitoring and guaranteeing the completion of the CAVIs personal assistance projects. The mid-term and final evaluation shall also consider the contributions of persons with disabilities, but no information is provided as to how this will happen. As provisioned by the Decree-Law, each CAVI is supposed to evaluate its own activities and the satisfaction level of personal assistants, and afterwards submit its report to the INR. However, it is not yet known how this will be implemented in practice. So far, no reports are available as the project is only in its initial stage of implementation.

### Measurement and data collection

Since MAVI has just been launched as a pilot project, there is no mechanism in place to monitor the transition from institutional care to community-based living. The INR is responsible for doing the evaluation of the project’s implementation. An indicator has already been announced, regarding the evaluation of the projects that will be implemented by the Centres for Independent Living: that is, the number of Implemented Individual Plans over the overall number of Individual Plans established.

# Impact and outcomes

## Progress against explicit targets and milestones

As the Independent Living Model is only now being implemented it is not yet possible to measure the progress, as to how many persons with disabilities have been assisted and how many personal assistants have been recruited. However, according to official information, the 21 selected CAVIs will assist approximately 722 persons with disabilities for whom about 522 personal assistants will be hired This is more than it was announced in the NRP 2018 (Medidas 1, ‘Indicadores Físicos’),[[59]](#footnote-59) which indicated that “**between 240 to 500 persons with disabilities are expected to benefit from MAVI** during 36 months until 2020.”

## What is replacing institutional care?

### At the point that persons with disabilities are being moved out of institutional care facilities, what types of accommodation and support are they being moved into?

As mentioned above in section 1, there is not a significant move in Portugal from institutions to community care as most people with disabilities have always lived in the community, although not independently, but ‘institutionalised’ within their families.

The main idea with the introduction of the MAVI is to pilot a network of Independent Living Centres (CAVIs) which will serve as the so-called ‘contact points’ to receive requests from persons with disabilities who need personal assistance and allocate the required personal assistants services. The provision of personal assistance will follow an individual plan. This plan will be defined by the person with disabilities in collaboration with the CAVI and it will identify:

* the specific assistance needs of the person;
* how support activities are to be carried out;
* how the assistance will be monitored and evaluated.

The individual assistance plan will state the number of hours of weekly support the person is entitled to. Each person can receive up to 40 hours of support per week. Exceptionally, more hours of support can be provided — up to 24 hours a day. However, each CAVI can only provide more than 40 hours a week of support to a maximum of 30 % of its clients.

In addition to this new Independent Living Scheme, which is now being piloted in the country, people with disabilities used Home Care Support Services. However, these services are targeted to provide assistance with personal care and domestic work only, and not to provide inclusion in the community. The service is only provided in the home of the beneficiaries.

For persons with psychosocial disabilities, there is a huge lack of community-based services – the big psychiatric hospitals are all closed now, and people were sent back to families with very few care services provided in the community.

### What services, supports and measures are being developed and instituted to build long term support for the right to live independently and to be included in the community?

MAVI is a nation-wide pilot project that will last only three years: from 2017 to 2020 and is funded mainly through the ESF. For the moment, there is no guarantee that after this period a long-term programme will follow to support independent living in Portugal.

In the mental health care area, in addition to the independent living scheme, there are plans to develop a Network of Continuing Mental Health care that will include various kinds of small size, community-based, residential and social care facilities, but their implementation has been very slow, and they are unevenly distributed in the country. According to the State Budget 2019,[[60]](#footnote-60) some new measures are planned to be introduced in 2019 such as support provided by RNCCI to ‘informal carers’ (‘cuidadores informais’, as mentioned in Articles 117 and 118), and the establishment of ‘Community Teams of Mental Health Care” (‘Equipas de Saúde Mental Comunitária’, Article 210) as pilot-projects at regional health centres.

## Satisfaction levels among persons with disabilities

The implementation of MAVI has faced a number of delays: there are not yet persons with disabilities receiving personal assistance, which has caused a lot of criticism from the disability community.

Moreover, the scheme is being introduced through pilot projects, manly funded through the ESF, and will cover around 700 persons with disabilities across the country, which is clearly insufficient. The future sustainability of the programme, after the three-year trial, is also a concern.

This conclusion is supported by a number of publications, e.g. the online Journal Publico which presented an interview with the disabled activist Eduardo Jorge (of 22 November 2018),[[61]](#footnote-61) who complained about the delay in the implementation of the programme and also about the exclusion of persons living in institutions (who are not so far entitled to apply for personal assistance). However, after his protest in front of the National Assembly in December 2018, the Secretary of State announced that an amendment would be introduced to the law to create a transitional period of six months enabling persons to apply for personal assistance even while living in an institution.

Another critique, according to researcher Fernando Fontes in his interview of 22 November 2018[[62]](#footnote-62) is that “many of the established CAVIs will be run by existing service provider organisations. As such, the same provider that offers residential care may apply to become a CAVI”. Fernando Fontes suggests that, instead, CAVIs should be managed only by disabled people’s organisations.

Some other critiques have been raised by Jorge Falcato, a disabled deputy in the Parliament.[[63]](#footnote-63) He stated that “40 hours of assistance a week is not enough for those in need of constant care, and he doesn’t see why the minimum age for the program should be 16. Disabled people should be able to choose their own personal assistant, pay them directly, and define their own individual care plan.”[[64]](#footnote-64)

As for the residential homes, cases of maltreatment of old persons and persons with disabilities are still being reported, especially regarding persons with psychosocial disabilities (see e.g. the case of Lar de Alijó[[65]](#footnote-65) and Casa dos Rapazes de Viana do Castelo).[[66]](#footnote-66) A complaint about the use of ESF funds to build an institution in Azores has also been filed with the European Commission.[[67]](#footnote-67)

# PART B – Critique and evaluation

# Observations and recommendations of official bodies

## Observations by the UN Committee on the Rights of Persons with Disabilities on Article 19

Among the recommendations that the UN Committee made for Portugal on the right to live independently in the community (Article 19 CRPD) are the following: to adopt a national strategy for independent living; to **regulate in the field of personal assistance;** and offer wider access to sign language interpreters and deafblind sign language interpretation in its public services, as well as to establish **community-based support services for persons with intellectual and psychosocial disabilities.**

## Recent observations by other official European and international bodies

The Council of Europe Commissioner for Human Rights raised concerns in its report of 10 July 2012[[68]](#footnote-68) about institutionalisation in Portugal, referring to the “measures towards the deinstitutionalisation of the elderly and about the vulnerability of this category of persons, particularly of those living alone and in isolated areas.”

## Observations and recommendations by national human rights bodies

According to the last report of the Ombudsman[[69]](#footnote-69) (2017), the telephone line for persons with disabilities received in total 642 calls, (35 more calls than in 2016). Among the questions received, 124 concerned maltreatment at different institutions and domestic violence.

## Observations and recommendations by national or regional/devolved Parliaments and assemblies

The Monitoring Mechanism on the Implementation of the CRPD has also provided recommendations during the public consultation of the Independent Living Support Model legislation. Among the recommendations provided, the following were the most important (although they were not considered in the final design of the scheme): to abandon the medical assessment and threshold of 60 % incapacity in the eligibility criteria for the scheme; to give full choice to the person with disabilities in relation to the selection of his/her Personal Assistant(s); to not limit to 40, the number of hours provided to each person; to not impose that CAVIs had a majority of professional staff; to allow small disabled people organisations to apply to become a CAVI (in order to ensure that disabled people, rather than large organisations control Personal Assistant schemes).

# Views and perspectives of civil society including DPOs

## UNCRPD civil society shadow and alternative reports

Portugal presented the first report on the implementation of the CRPD on 08 August 2012. The Disability and Human Rights Observatory (ODDH) and the disabled people’s organisations that constitute its Advisory Board, representing altogether 182 DPOs, submitted the Parallel Report on the Monitoring of the Rights of Persons with Disabilities in June 2015 to the UN Committee. A Response to the List of Issues was also submitted by the ODDH to the UN Committee in January 2016.

In relation to independent living and inclusion in the community, the Parallel Report[[70]](#footnote-70) recommended “to create a new legal framework to support independent living, to establish the professional role of Personal Assistant and implement a pilot-project of Personal Assistance, as it was already foreseen in the ENDEF I (the National Strategy for Disability I), while providing for its progressive enlargement and including in this service the provision of Sign Language interpretation services.”

In the Responses to the List of issues[[71]](#footnote-71) the ODDH stressed the same issues and recommended again: to create a new legal framework to support independent living, to establish the professional role of Personal Assistant and implement a pilot project of Personal Assistance, as it was already foreseen in ENDEF I; to extend the supply of home care services (24h/day), adjusted to the reality of persons with disabilities; to increase the provision of social care services for persons with disabilities, notably, through the creation of group homes; and to provide more Sign Language interpreters in public services, and, in particular, in the health services.

## ‘Grey literature’ at the national level

Many organisations of persons with disabilities disseminate information on independent living and share their views on the Independent Living Scheme. For instance, ACAPO – the Association of Blind persons in Portugal[[72]](#footnote-72) mentions that the new project on independent living – MAVI – is innovative and has a great potential for many persons with disabilities in Portugal. However, they stress that this Project shall promote autonomy, but not replace the development of personal skills. In another online forum[[73]](#footnote-73) editors discussed the independent living project in Portugal criticising the lack funds and the delays in establishing the projects. The electronic journal Plural & Singular[[74]](#footnote-74) published one issue in 2016 (16th edition) on ‘Independent Living: Emancipation of persons with disabilities’,[[75]](#footnote-75) and ‘Informal caregivers: invisible guard’ (in 2018, 20th edition).[[76]](#footnote-76) These publications touched upon the situation of persons with disabilities, their need of personal assistance, and the needs of those who assist them. It is mentioned that due to lack of other supports, many persons with disabilities look for a place in residential facilities, yet there the waiting lists are often long. These publications also address such issues as the training of personal assistants, lack of funding and the functioning of CAVIs, as well as the need to legally recognise the status of ‘informal caregivers’ in Portugal (and provision of support and assistance for them and respite care).

**The CVI** has also released a promotional video[[77]](#footnote-77) to increase public awareness about the importance of personal assistance for supporting independent living of persons with disabilities, where the participants of the Pilot Project in Lisbon (CVI in Lisbon) share their experiences. In addition, Miguel Fonseca, one of the beneficiaries of the Lisbon independent living project made a presentation about independent living of persons with disabilities based on his personal experience during the TED event 2013 in Portugal.[[78]](#footnote-78)

Besides these, a number of master theses and doctoral dissertations are available that research different topics on persons with disabilities, residential structures for old people or de-institutionalisation of adults and children with disabilities, that can be found in the repository of each university.[[79]](#footnote-79)

Many publications on the ‘social’ issues are regularly published in the local press, e.g. Online Journal Publico[[80]](#footnote-80) provides a large number of papers on independent living[[81]](#footnote-81) and persons with disabilities.

## Pan-European and international civil society organisations

The pan-European civil society organisations (e.g. ENIL platform - the European Network on Independent Living) have contributed to raise awareness about independent living in Portugal. FENACERCI[[82]](#footnote-82) (The National Federation of Social Solidarity Cooperatives) disseminated information about the Independent Living Project and presents on its website the document ‘Demolidor de Mitos Vida Independente’ translated in Portuguese from the leaflet originally created by ENIL – “Myth Buster Independent Living”. In addition, representatives of the Portuguese DPOs publish their views on the ENIL platform.[[83]](#footnote-83) The most recent article published on 28 February 2019 is entitled “(In)dependent Living in Portugal” by Fátima Paulo[[84]](#footnote-84) (a Portuguese activist). She criticises the new legislation on Independent Living and Personal assistance in Portugal saying that the “legislative scenario does not respect basic Personal Assistance requirements and represents an abusive appropriation of the Independent Living concept”, making the implementation of Article 19 of the CRPD “a distant dream”.

# Academic research

DECIDE (full title ‘Disability and self-determination: the challenge of Independent living in Portugal’)[[85]](#footnote-85) is a research project launched in June 2016 and funded through the Foundation for Science and Technology that aims to analyse the living conditions and inclusion of persons with disabilities in Portugal. The Project team will also assess the impact of the independent living project of the municipality of Lisbon. The Project team has organised a number of events, including the International Colloquium “Disability and Self-Determination: The Challenge of Independent Living” that took place in Lisbon on 18 June 2018.[[86]](#footnote-86) The project will publish its final results in 2019.

From 2009 to 2014[[87]](#footnote-87) the project “Trajectories of Mental health Care” was implemented by the Association for the Promotion of Mental health ‘Encontrar-Se’ in Portugal on the issue of de-institutionalization of persons with psychosocial disabilities. The report, by Almeida et al. (2015)[[88]](#footnote-88) presents a detailed analysis of the de-institutionalisation process in Portugal and provides a list of recommendations, including to integrate mental health care into the network of the “integrated continuing care” and to develop specialized community-based mental health services (e.g. centres and teams of mental health care).

# PART C – Key points

# Positive developments, including promising practice examples

From 2006 onward, at least at the policy level, the deinstitutionalisation process of persons with mental health illnesses started in Portugal with the closing down of the big psychiatric hospitals and the slow opening of alternative community-based services, including different types of residential care facilities, home-based services and units and teams of integrated continuing mental health care (CCISM). These types of residential care provide from maximum to medium support and the necessary assistance to persons with psychosocial disabilities in their integration into education and/or work training programmes or any other activities.

Second, it is important to acknowledge an increased attention paid to independent living of persons with disabilities in Portugal over the last five years and the introduction of the new personal assistance programme (MAVI) that offers personal assistance to persons with disabilities for the exercise of their rights of citizenship and participation in different contexts of life. This new programme can be mentioned as a ‘promising practice’. In parallel, other important reforms have been introduced such as the PSI benefit in 2017 and the abolishment of the previous regimes of inhabitation and interdiction (see explanation in 3.3) with the new “regime of adult support” (*o regime jurídico do maior acompanhado*), as well as the adoption in 2018 of the new Inclusive School Act, which can also contribute to supporting independent living and the inclusion in the community of persons with disabilities in Portugal.

# Negative developments including examples of poor practice

Despite the positive developments mentioned above, there are still drawbacks in the implementation of independent living of persons with disabilities in Portugal. Despite an increased number of residential care services for persons with psychosocial disabilities, the number of users is still very low (see Table 2). There is also a lack of monitoring and evaluation reports and a lack of publicly available statistical data that would provide information on how the money is spent, on which services and for whom.

After the official launch of the MAVI programme in 2017/2018, many persons with disabilities have been complaining that the implementation of MAVI is delayed. Moreover, MAVI is only a pilot project, largely funded through the ESF, available only for those 16 years old and over. Furthermore, currently persons with disabilities who are living in institutions and elder care facilities are not allowed to apply for personal assistance (although this may change after the introduction of an amendment to the Decree-law 129/2017 already announced by the government). Finally, many of the recognised CAVIs are residential service providers, and there is a risk that they will continue to provide services in a very traditional way. Since personal assistants are provided only through the CAVIs, persons with disabilities do not have total control over the service provided and do not have access to a personal budget.

# Recommendations

Based on all the information gathered in this report, we present the following recommendations:

* To strengthen the implementation of community-based care to persons with psychosocial disabilities in order to ensure their right to living independently and being included in the community;
* To pilot test the provision of ‘personal budgets’, in addition to allocating personal assistance through the CAVIs;
* To implement regular monitoring mechanisms and an independent evaluation of the personal assistance pilot project results;
* To ensure the future sustainability of the personal assistance scheme, after the pilot period.

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5. Ordinance 59/2015, of 2 March on “Establishment and Functioning of Residential care facilities and Autonomous Homes for persons with disabilities”: <https://dre.pt/application/file/a/66639423>. [↑](#footnote-ref-5)
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