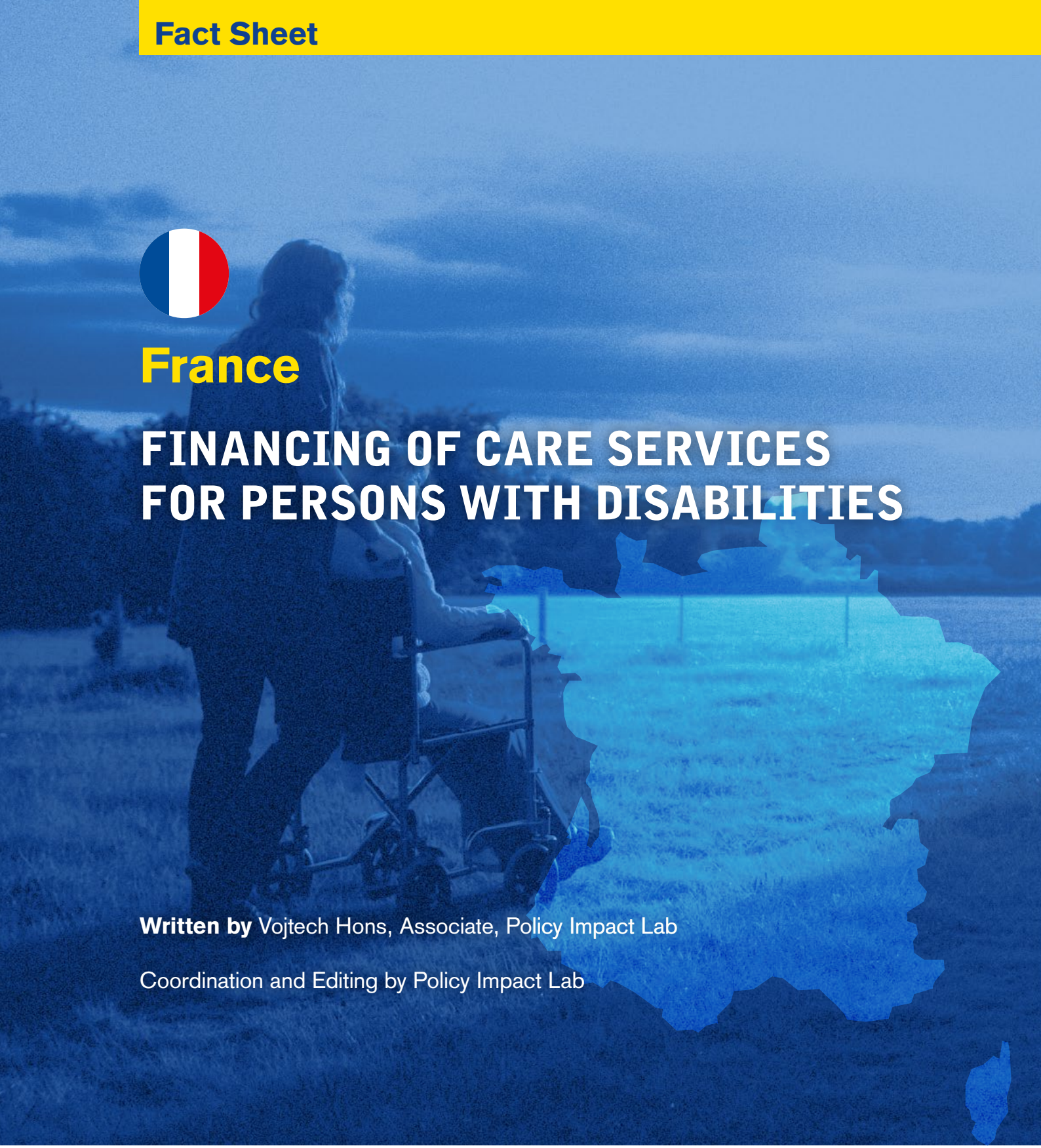
Fact Sheet



France

FINANCING OF CARE SERVICES FOR PERSONS WITH DISABILITIES

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Executive summary

In most cases, the providers of the services for PWDs are private organisations that work on a not-for-profit basis. In order to attain public funding, they must be accredited by the relevant body, depending on the type of care they wish to provide. The providers are reimbursed for services provided according to the user's needs by the relevant body, which authorises providers through tenders. Persons with disabilities rarely participate in the funding of institutional care through out of pocket fees without receiving any financial support from public funds. Their participation is more frequent in the case of assistance services at home. There are several large actors, generally private associations and foundations, grouping together providers of services for PWDs of various types and covering various needs, and a large number of small independent providers. The current tendency in calls for tenders is towards a greater variability of types of care offered to PWDs by the service providers.

For health care services, the National Solidarity Fund for Autonomy (CNSA) aims at providing a balanced funding across the territory. Social care services are governed by the departments and largely dependent on the amount of funding that the local authorities are willing and able to dedicate them. There have been issues with a lack of capacities of the various service providers in some areas, resulting in waiting lists of up to two years, often for PWDs with complex disabilities. The qualification of professionals involved in service provision for PWDs has been improving in the past years. The salaries of care professionals are an issue for many as they often do not correspond with their professional qualifications. In some cases, care professionals, notably those less qualified, are exposed to precarious job contracts on a short-term and/or part-time basis and frequent renewals.

The costs of day centres are generally covered by the person's disability pension allowance or local authority budget. Given the nature of the services and the fact that the PWDs have to organize transportation to the centres themselves, it happens that those who do not have a service provider in their vicinity are deprived of this type of care. Independent/supported living services are generally financed and governed by the local authority as the body responsible for provision of social care, but those that include a health care element are governed and financed jointly with the Regional Health Agencies (ARS). In terms of accessibility, there is an uneven regional distribution and issues with long waiting lists. There are two principal types of long-term institutional care providers that offer varying degree of medical attention. Their funding mechanism depends on the extent of health care they provide. There is a tendency for young adults to overstay in the establishments dedicated to children, resulting in unsuitable care provision. The PWDs from areas close to Belgium travel across the border to obtain the care, something that the French authorities are aware of, finance and tolerate.

Respite care services - which are not very well developed in France - are generally provided in short-stay institutions (*accueils temporaires*) which offer both day centre and short-term accommodation services. The financing is akin to that of day centres, with a fixed price per day and a partial contribution from the PWD.

In the light of the COVID-19 pandemic, the planned social expenditures have remained unchanged. However, already in spring 2020, the government anticipated the social security budget to face a considerable deficit due to the impact of the COVID-19 pandemic on the economy. In May 2020, the State announced that it would dedicate €700 million to bonuses for professionals working at the service provision for PWDs.

A long-awaited change to the current way of funding the disability services is the reform SERAFIN PH that was launched in late 2014. The aim of the reform is to facilitate the access to care for PWDs by allocating the funds on the basis of the real costs of care. While at the moment, the funding that each provider receives is calculated mainly on the basis of the number of users to which the provider caters, the reform will introduce a calculation on the basis of the different activity support provided. While there are several pilot providers working under the scheme, the general roll-out is expected in the coming years.

Main findings

- ★ In France, after a reform in 2009, the funding of services for adults with disabilities is partly done by public authorities through calls for tenders. In order to attain public funding, the service providers must be selected through the tender call and accredited by the relevant body, depending on the type of care they wish to provide. However, reserved markets remain the most used way for services for persons with disabilities funding. Persons with disabilities rarely participate in the funding through out of pocket fees without receiving any financial support from public funds.
- ★ For health care services, the National Solidarity Fund for Autonomy (CNSA) aims at providing a balanced funding across the territory. Social care services are governed by the departments and largely dependent on the amount of funding that the local authorities are willing and able to dedicate them.
- ★ The autonomy of local authorities in the allocation of social care funding might result in underfunded services for PWDs where the local authorities place less emphasis on this type of care. The current funding mechanism through publishing tender calls is built on the presumption that the relevant authority understands the current needs in the department or region. If the demand is not thoroughly understood, it might result in funding services that do not fully cover all the needs.

Introduction

Legal framework for governance and delivery of services

The key legal text concerning care services for PWDs in France is the law of 2 January 2002 on the reform of the social and medical-social intervention.[1] The text establishes the social and medical-social interventions aimed at the promotion of autonomy and protection of PWDs, at social cohesion and their active citizenship. Important changes were brought about by the law of 21 July 2009 on the reform of the hospitals and on patients, health and territories (the HPST law).[2] Building on the law of 2002, the 2009 law put in place a new organisation of the medical and medical-social sector, a modernisation of the public health institutions and improvement of access to care across the country. The main tools in achieving this have been the creation of Regional Health Agencies (*agences régionales de santé, ARS*), the establishment of the Regional Health Projects (*projets régionaux de santé, PRS*), and the introduction of a new procedure of authorisation of service providers through calls for tenders.[3]

A plethora of legal texts defines the details of financing and organisation of care services in France. The most prominent legal body on the national level is the Social Action and Family Code (the CASF).[4] It contains provisions on the various types of funding available to PWDs and on the various types of services and their providers. On the regional level, the PRS assist in the improvement of the accessibility of services, their quality and efficiency.[5] On the departmental level, the Departmental Regulations of Social Assistance (*règlements départementaux d'aide sociale*) contain more detailed provisions on the types of aid, conditions etc.[6] They are entrenched in the article L. 121-3 of the CASF.

1 In French: *loi du 2 janvier 2002 de rénovation et de modernisation de l'action sociale.*

2 In French: *loi du 21 juillet 2009 portant réforme de l'hôpital et relative aux patients, à la santé et aux territoires.*

3 Interview with a national expert/professional.

4 In French: *Code de l'action sociale et des familles.*

5 Caisse nationale de solidarité pour l'autonomie. (2019). *Les projets régionaux de santé.* 14 May 2019. Available from: https://www.cnsa.fr/outils-methodes-et-territoires-organisation-de-loffre/programmation-et-creation-de-places-en-etablissement-ou-service/les-projets-regionaux-de-sante.

6 See for example the departmental regulation of Ile et Vilaine: https://www.ille-et-vilaine.fr/sites/default/files/asset/document/reglementdepartementalaidesociale.pdf.

Management of care services

The key public bodies involved in the management of funding of services for PWDs include the National Solidarity Fund for Autonomy (*Caisse nationale de solidarité pour l'autonomie, CNSA*) – which manages the funding for all care services for PWDs - on the national level along with the various Regional Health Agencies (ARS), one in each region. On the local level, authorities manage the funding of services not falling under the scope of the ARS. Additionally, there are Departmental Homes for PWDs (*maison départementale des personnes handicapées, MDPH*) that work both with the ARS and the local authorities in order to determine the amounts of funding available for each individual for all types of services.

The CNSA was established in 2005 in order to centralise the management of public funds intended for persons with limited autonomy, notably PWDs but also elderly persons.[7] This centralisation had several aims, notably ensuring equal access to services across the country.[8] Several legal texts determine the scope of the funding managed by CNSA, mainly the CASF but also various decrees, bylaws, laws on the financing of social security etc. Article L. 14-10-5 of CASF prescribes the structure of CNSA's budget, which is primarily funded by social security. As a public institution, the CNSA falls under supervision of the Directorate-General of Social Cohesion (*Direction générale de la cohésion sociale,* DGCS) mainly depending on the Ministry of Solidarity and Health (*Ministère des solidarités et de la santé*).

There are 14 ARS across the country entrusted with four key missions related to disability services: planning, authorisation, supervision and financing. As for planning, in the context of the PRS, the ARS determine the programming of the care for PWDs on the territory and the corresponding types and numbers of places to be opened. As for the authorisation, openings and extensions of new service providing institutions need to be authorised by an order of an ARS. Some types of institutions need to be authorised jointly by an ARS and a local authority; notably medical care homes (*foyers d'accueil médicalisé, FAM*) and multifunctional nursing and assistance home services (*services polyvalents d'aide et de soins à domicile, SPASAD*), as will be discussed below. As for supervision, the providers are subject to regular checks and inspections. Directorates-General of Social Cohesion (DGCS) and High Health Authorities (*Haute authorité de santé, HAS*) set out the regulations on internal and external evaluations according to which the institutions must submit regular evaluations. Lastly, as for financing of activities, institutions and services, ARS participates in the funding of some services for PWDs, while others are funded jointly by an ARS and a local authority.[9] For the large part, the budget of the ARS consists of funds determined by the CNSA.

In each department, the local authority is responsible for funding the social services, including those for PWDs. A certain portion of these expenses is compensated by the CNSA, but the remaining funds are allocated from the departmental budget. This important role of the departments in the delivery of social services is entrenched in the decentralisation reform of 1982 and 1983.[10] This includes social assistance to PWDs through services such as those offered by the MDPH as well as financial aid in the form of the various benefits.

The MDPH take decisions on the attribution of grants and benefits to PWDs and provide essential assistance such as information on the services and providers available.[11] The MDPH were created by the law of 11 February 2005 on the equality of rights and opportunities, the participation and the citizenship of persons with

7 Ministère des solidarités et de la santé. (2019). *La Caisse nationale de solidarité pour l'autonomie.* 27 February 2019. Available from: https://solidarites-sante.gouv.fr/ministere/acteurs/agences-et-operateurs/article/cnsa-caisse-nationale-de-solidarite-pour-l-autonomie.

8 Caisse nationale de solidarité pour l'autonomie. (2015). *Budget.* 3 June 2020. Available from: https://www.cnsa.fr/budget-et-financement/budget.

9 Agence régionale de santé de Grand Est. (2019). *Structures d'accompagnement pour personnes en situation de handicap.* 7 August 2019. Available from: https://www.grand-est.ars.sante.fr/handicap-2.

10 The so-called Defferre reforms that began with the law of 2 mars 1982 on the rights and freedoms of municipalities, departments and regions (*loi de 2 mars 1982 relative aux droits et libertés des communes, des départements et des régions*).

11 Secrétariat d'Etat chargé des personnes handicapées. (2017). *Maison départementale des personnes handicapées.* 30 March 2020. Available from: https://handicap.gouv.fr/les-aides-et-les-prestations/maison-departementale-du-handicap/article/maison-departementale-des-personnes-handicapees-mdph.

disabilities[12] and further defined by a decree 2005-1587 of 19 December 2005.[13] While they play an important role in determining the financial amounts of compensation for which the individual PWDs are eligible based on their circumstances, they do not directly manage any funds.

Disability budgets

As part of the budget discussions each year, the Parliament agrees on the National Goal of Health Insurance Spending (*Objectif national de dépenses d'assurance maladie, ONDAM*) which is structured in several categories. In 2019, the ONDAM medical-social, which covers the various services for PWDs, amounted to €20,7 billion, or some 2% of the total ONDAM set on €200,3 billion. Against the ONDAM 2018, in 2019, there has been an increase of 2.5%.[14] Of the €20,7 billion, €11,3 billion was dedicated to minor and adult PWDs.[15] While the ONDAM is not a ceiling but rather an objective, it is an important indicator of the expected funding for the medical-social sector.

As was noted above, in 2005, the National Solidarity Fund for Autonomy (CNSA) was established to centralise the management of funds dedicated to PWDs in a single body, with the exception of the local authority budgets. The entire ONDAM medical-social has since then been managed by the CNSA, both in terms of funds for PWDs and for aged persons. For 2019, the total amount of funds managed by the CNSA was €26,8 billion. €20,935 billion came from the ONDAM medical-social, while the remaining €5,920 billion came from other sources of funding such as the solidarity contributions from employers and the generalised social contribution which is a form of tax.[16]

In addition to the funds from the CNSA, the local-level budgets of each department, as mentioned previously, participate in funding of the services for PWDs on their territory. In 2018, these departmental funds amounted to €11,819 billion coming from, besides health insurance, the general departmental budget.[17] For health care services, the funds are provided by the health insurance and the relevant bodies for allocating the funding to the providers are the Regional Health Agencies (ARS). There is no participation of the regional budgets on financing the services for PWDs.

Types of payments

There are a number of benefits available to PWDs, depending on the type of disability and the type of care they are entitled to receive, and they are awarded upon evaluation of the MDPH. The key benefits available to adults with disabilities are the disability compensation benefit (*prestation de compensation du handicap*, *PCH*), the disability pension (*allocation aux adultes handicapés*, *AAH*), and the Self-Sufficiency Subsidy (*majoration pour la vie autonome, MVA*).[18]

The PCH are paid out to the PWDs by departments which are then partially reimbursed by the CNSA. In 2019, the amount of PCH paid out by the departments in 2019 was €2,1 billion, of which €616 million – or 29% - was reimbursed by the CNSA. The participation of CNSA on the total funds remained constant while the overall volume of funds paid by the departments has been

12 In French: *loi du 11 février 2005 portant sur l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées.*

13 Secrétariat d'Etat chargé des personnes handicapées. (2017). *Maison départementale des personnes handicapées.* 30 March 2020. Available from: https://handicap.gouv.fr/les-aides-et-les-prestations/maison-departementale-du-handicap/article/maison-departementale-des-personnes-handicapees-mdph.

14 Law on the Social Security for 2019, Article 82. In French: *Loi de financement de la sécurité sociale 2019.*

15 Sécurité sociale. (2019) *Projet de la loi de financement de la sécurité sociale. Annexe 7 : ONDAM et dépenses de santé.* 1 October 2019. Available from: https://www.securite-sociale.fr/files/live/sites/SSFR/files/medias/PLFSS/2020/PLFSS-2020-ANNEXE%207.pdf

16 Caisse nationale de solidarité pour l'autonomie (2020). *Chiffres clés de l'aide à l'autonomie.* June 2020. Available from: https://www.cnsa.fr/documentation/chiffres_cles_2020.pdf.

17 Caisse nationale de solidarité pour l'autonomie (2020). Rapport annuel 2019. April 2020. Available from: https://www.cnsa.fr/documentation/cnsa_20-04_rapport_activite_2019_exe1_5sc_web.pdf

18 Service public. (2020). *Handicap : allocations (AAH, AEEH) et aides.* 22 September 2020. Available from: https://www.service-public.fr/particuliers/vosdroits/N12230.

gradually increasing, shifting increasingly more weight on the departmental budgets.[19] The PCH can be used by the PWD to cover the cost of a variety of services, both in terms of human assistance and contribution to costs. The amount allocated to each person and the type of services it can be used to cover is determined by the MDPH.

The AAH is an aid that serves to complement other financial resources of the PWD. The amount allocated to the person depends on the evaluation of the MDPH of its needs and financial means. It is generally awarded to persons with severe disability. According to the Directorate of Research, Studies, Evaluation and Statistics (*Direction de la recherche, des études, de l'évaluation et des statistiques, DREES*) €9 708 million in 2018 was paid out in AAH.[20] This aid is frequently used to cover the costs of services, notably the social care services, that are incurred directly by the PWD. The minimum AAH per person currently stands at €900 per month.[21]

The MVA is a benefit that is aimed to support the persons with severe disability that do not live in institutions. The amount is currently fixed to €104,77 per month. It is attributed automatically when the conditions are met. It is generally intended to contribute to expenses incurred by the adaptation of the home of the person to their disability, but as it is allocated automatically, it can in theory also be used to cover expenses incurred by social care services of assistance at home.[22]

The landscape of service providers

The French National Register of Health and Social Institutions (*Fichier national des établissements sanitaires et médicaux, FINESS*) provides a comprehensive database of all the institutions and service providers in health, social, and medical-social care in France. The below table contains the numbers of various categories of service providers for PWDs in France, along with information on their legal entity. At the first sight, it is evident that while the vast majority of providers are private entities, very few pursue their activity commercially. The relatively high number of commercial providers in the multi-clientele sector is explained by the fact that this category includes providers catering for both PWDs and elderly. The private non-profit sector is clearly prominent in all categories.

An overview of main types of service providers and their numbers in the entire territory of France as of September 2019.

	Public organisations	Private not-for-profit	Private for-profit
Accommodation (including Long-Term Care) services (code 4301)	543	4 490	22
Assistance at home (code 4305)	118	1409	1
Support services for PWDs and elderly (code 4605)[23]	2 125	6 029	2 876

Source: FINESS. The codes of establishments are taken from the FINESS database.[24]

19 Conseil départemental du Pas-de-Calais. (2020). *La prestation de compensation du handicap (PCH).* 19 January 2020. Available from: https://www.pasdecalais.fr/Solidarite-Sante/Personnes-en-situation-de-handicap/Ma-MDPH/De-quelles-prestations-puis-je-beneficier/Les-aides/Aides-humaines-et-techniques-et-amenagement-du-vehicule-du-logement-et-aides-exceptionnelles/La-Prestation-de-Compensation-du-Handicap-PCH.

20 Direction de la recherche, des études, de l'évaluation et des statistiques (DREES). (2020). La protection sociale en France et en Europe en 2018. Accessed on 22 September 2020. Available from: https://drees.solidarites-sante.gouv.fr/IMG/pdf/cps20.pdf.

21 Cour de comptes. (2019). *L'allocation aux adultes handicapés (AAH).* 25 November 2019. Available from: https://www.vie-publique.fr/rapport/272010-lallocation-aux-adultes-handicapes

22 Service public (2020). *Handicap : majoration pour la vie autonome (MVA).* 3 March 2020. Available from: https://www.service-public.fr/particuliers/vosdroits/F12903

23 This includes the SPASAD, SSIAD and SAAD.

24 The database of the *Fichier national des établissements sanitaires et médicaux* (FINESS). Accessed on 15 September 2020. Available from: http://finess.sante.gouv.fr/fininter/jsp/rechercheSimple.jsp?coche=ok. The codes of establishments can be found here: http://finess.sante.gouv.fr/fininter/jsp/nomenclatures.do.

In France, there are several large actors that are generally private associations and foundations grouping together providers of services for PWDs of various types and covering various needs. They can do so in a region or department but also on the national level. That said, most service providers manage only a single or very few establishments. Such a constellation has proven inconvenient in the past several years: increasingly, the authorities responsible for the provision of care for PWDs on their territory have been favouring larger provider networks in their calls for tenders necessary to obtain authorisation to receive public funding. The current tendency is towards a greater variability of types of care offered to the PWDs by the service providers, something that smaller establishments and networks struggle to provide. Even larger structures seek to join together in order to diversify their portfolio of services offered and to ensure they would be able to look after even the most complex cases.[25]

Key funding models

In most cases, the providers of the services for PWDs are private organisations that work on a not-for-profit basis. [26] They are complemented by for-profit private enterprises and public organisations, as seen above. In order to attain the public funding, they must be accredited by the relevant body, depending on the type of care they wish to provide.

Following the analysis of the PWD's needs by the Departmental Homes for PWDs (MDPH), the PWD approach the various service providers to obtain the necessary type and extent of services. The providers are then reimbursed (through tenders issued by the public authority) for those services by the relevant body. As will be discussed below, the direct participation on the funding by the PWD is rare, and mostly occurs only in cases where the PWD wishes to obtain a level of care higher than that recognised as necessary by the MDPH.

The support services for PWDs in France that fall within the scope of social services, and are therefore primarily financed by the departments, are set out in the departmental regulations on social aid as prescribed by article L.121-3 of the CASF. The departmental regulations on social aid contain all the key information about the types of services, the conditions for obtaining them and the extent of financial coverage by the department.[27] For the social care services, the user generally participates in the costs of the care.

As mentioned previously, the funding of social care services for PWDs is managed by the local authorities. For the assistance at home, the funding originates in the budget of the departments, which are then partially reimbursed from the allocated social security funds through the National Solidarity Fund for Autonomy (CNSA). The amount of aid available to the PWD to use the various services depends on their financial means; the mechanisms for determining the amount are described in the departmental regulations on social aid.

The health care services recognised and covered by the Regional Health Agencies (ARS) are funded by the health insurance. The allocation of funding to the providers, including the tariff determination, is done by the ARS, while the funds themselves are provided by the health insurance funds. The CNSA determines the amounts of funding available to each ARS depending on the needs in the respective regions.

Authorisation of providers

The article L.313-1-1 of the CASF sets out the general rule for the authorisation procedure of the providers of services for PWDs. The authorisation is required and driven by the relevant financing bodies, i.e. the local authorities and the ARS, depending on the type of services offered.[28] The authorisation is required for the establishment, transformation as well as extension of the existing institutions. The authorisations are awarded through tenders that the relevant governing institutions use as a tool to define the offering of services in their territory.[29] These needs are set out by the regional health scheme or by the scheme of social and health/social organisation in the relevant territory.

25 Interview with a service provider working on a national level.

26 Interview with a national expert/professional.

27 Conseil départemental de l'Ille-et-Vilaine. (2012). *Règlement départemental de l'aide sociale.* November 2012. Available from: https://www.ille-et-vilaine.fr/sites/default/files/asset/document/reglementdepartementalaidesociale.pdf

28 Article L.313-3 of the CASF.

29 Fédération des Etablissements Hospitaliers et d'Aide à la Personne privés solidaires. (2019). *Fiche technique. La procédure d'autorisation des ESSMS.* 26 August 2019. Available from: https://www.fehap.fr/upload/docs/application/pdf/2019-08/la_procedure_dautorisation_des_essms_actualisation_aout_19.pdf

The reform in preparation – SERAFIN PH

A long-awaited change to the current way of funding the disability services is the reform SERAFIN PH (Services and Institutions: Reform for Alignment of Financing of Offer for Persons with Disabilities)[30]. In preparation late 2014, it is expected to be introduced in the coming years. For the moment, several pilot providers work on this basis. While at the moment, the funding that each provider receives is calculated on the basis of the number of users to which the provider caters, the reform will introduced a calculation on the basis of the different activity support that are provided. The rationale behind this reform is that various users require variously demanding assistance and care, which in turn means that the real expenditures of the service providers vary greatly even for the same number of users.[31]

Availability of services in general

The availability of care services for PWDs in France is varied across the territory. There is no clear geographic distinction, as the availability of care generally depends on the economic capabilities of the relevant authorities. While in health care services, the CNSA aims at providing a balanced funding across the territory,[32] the social services funded by the departments are largely dependent on the amount of funding that the local authorities are willing and able to dedicate to this type of services.[33]

With regards to waiting lists, there is a double hurdle for the PWDs that often causes long waiting times. Firstly, the PWDs must in a majority of cases obtain an evaluation of their situation by an MDPH. The processing times of the requests can take from several months to over a year. Furthermore, while some providers do not have this issue, in many cases there are waiting lists that require the PWDs to wait up to two years in order to obtain a place at the provider of their choice. The issue with accessibility of services is generally more burning for PWDs with complex disabilities, which has led the relevant bodies to design tender calls so that they attract providers who would be able to cater for more complex users (as discussed above).[34] In general, the lack of places in social care services can be attributed to insufficient funding from the departments, which varies depending on the local authority's emphasis on this type of services.[35]

Quality of services in general

The qualification of the professionals in the area of service provision for PWDs has been on the rise in the past years. The initiatives to organise various trainings and workshops generally come from the providers themselves rather than from the relevant authorities.[36] Naturally, where the departments give more priority and make more funds available for social care services, the providers are able to in turn dedicate more funds for such trainings and the corresponding rise in salary expectations of the professionals.[37] The salaries of care professionals are an issue for many as they often do not correspond with their professional qualifications. In some cases, the professionals, notably those less qualified, are exposed to precarious job contracts on a short-term and/or part-time basis and frequent renewals.[38]

30 In French: *Serafin-PH — Services et Établissements: Réforme pour une Adéquation des Financements aux Parcours des Personnes Handicapées.*

31 Secrétariat d'État chargé des personnes handicapées. (2019). *Services et établissements : Réforme pour une adéquation des financements aux parcours des Personnes handicapées*. 5 September 2019. Available from: https://handicap.gouv.fr/les-aides-et-les-prestations/reforme-de-la-tarification-des-etablissements-de-services-pour-personnes/article/serafin-ph. Corroborated by an interview with a national regulator and policymaker.

32 CNSA. (2019). *Financement des établissements et services médico-sociaux*. 7 August 2019. Available from: https://www.cnsa.fr/budget-et-financement/financement-des-etablissements-et-services-medico-sociaux.

33 Interview with a service provider on a regional level.

34 Interview with a national regulator and policymaker, corroborated by interviews with an employee of a service provider and a service provider on a local level.

35 Interview with a service provider on a local level.

36 Interview with a service provider on a regional level, corroborated by an interview with an employee of a service provider.

37 Interview with a service provider on a regional level.

38 Interview with an employee of a service provider.

Day Care

The day centres (*foyers de vie, accueils de jour,* etc.) are regulated in the departmental regulations on social aid. They often offer both daily activities and short-term accommodation. The daily costs in day centres for adults with disabilities are set out on €13 per day.[39] These costs are generally covered by the person's disability pension (AAH) allowance.[40] The user therefore pays for the service provision, but the sum is then in most cases covered by its AAH and other allowances. In order to attain day care services, generally, the respective evaluation by the Departmental Homes for PWDs (MDPH) of the person's disability is required. The MDPH also determines to what extent will the user participate on the costs of the services.[41]

In the case of day care services, it is particularly important that they are available across the territory, which is not always the case in France. Given the nature of the services and the fact that the PWDs have to organize the transportation to the centres themselves, it happens that those who do not have a service provider in their vicinity are deprived of this type of care.[42]

Independent/Supported Living

There is a large number of types of services available to PWDs who are relatively independent but require support in certain acts of their daily lives. These services can be provided at the person's home but also in institutions providing long and short-term accommodation. They are generally financed and governed by the local authorities as they provide social care, but those that include a health care element are governed and financed jointly with the Regional Health Agencies (ARS). According to DREES, in 2018, €1 256 million were spent on assistance to adult PWDs.[43] The MDPH provides the persons information about the different providers available to them that cover their needs and it is then up to the PWD to select a provider that they find most suitable.

Notable examples of this type of services are the Home Aid and Assistance Services (*services d'aide et d'accompagnement à domicile, SAAD*) and the Social Support Services (*services d'accompagnement à la vie sociale, SAVS*). The daily fee for the care is generally set by a decree of the local authority and is deducted from the user's disability compensation benefit (PCH) allowance. There is no further financial participation required from the PWD on the cost of the service. In some cases, however, the fee is set by the provider (with a ceiling set up yearly by a decree of the local authority) and is deducted from the user's PCH allowance based on a fixed fee determined by the department. In the case of SAAD, any additional cost is covered from the user's own resources.[44]

The care services for PWDs that involve an element of health care are entirely managed and financed on the regional level by the ARS, a notable example being the Nursing Services at Home (*services de soins infirmiers à domicile, SSIAD*). The funds allocated to the service providers are based on a global sum calculated from the various costs that the provider incurs. However, this calculation does not take into account the varying needs by the patients, which thus result in varying needs of funding by the SSIAD. The providers therefore need to balance the numbers of more complex users with those who have lesser needs.

39 Service public. (2020). *Handicap : accueil temporaire en établissement.* 4 April 2020. Available from: https://www.service-public.fr/particuliers/vosdroits/F10468

40 Place Handicap. *Les Établissements Médico-Sociaux.* Accessed on 20 September 2020. Available from: https://place-handicap.fr/foyers-d-hebergement-pour-travailleurs-handicapes

41 Le Figaro. *Foyers d'hébergement.* Accessed on 20 September 2020. Available from: https://sante.lefigaro.fr/social/personnes-handicapees/foyers-dhebergement/quel-financement

42 Interview with an employee of a service provider.

43 Direction de la recherche, des études, de l'évaluation et des statistiques (DREES). (2020). *La protection sociale en France et en Europe en 2018.* Accessed on 22 September 2020. Available from: https://drees.solidarites-sante.gouv.fr/IMG/pdf/cps20.pdf.

44 Conseil départemental du Pas-de-Calais. *Les services d'aide et d'accompagnement à domicile.* Acessed on 20 September 2020. Available from: https://www.pasdecalais.fr/Solidarite-Sante/Personnes-en-situation-de-handicap/Ma-MDPH/De-quelles-prestations-puis-je-beneficier/Vivre-a-domicile/Les-Services-d-Aide-et-d-Accompagnement-a-Domicile-SAAD.

The Multifunctional Nursing and Assistance Home Services (*services polyvalents d'aide et de soins à domicile, SPASAD*) are a mixed type of service providers, combining both the social care provided by the SAAD and the health care provided by the SSIAD. The Specialised Medical-Social Services (*service d'accompagnement médico-social pour adultes handicapés, SAMSAH)* also combine social and health care services but place more emphasis on the person's autonomy within the society, often complementing the services provided by the SAVS.[45] This results in their joint funding and management by both the departments and the ARS, the social care being funded based on a daily fee and the health care services on the basis of a number of places occupied.[46]

In terms of accessibility of services, the situation in this area of services appears similar to the other categories, with an uneven regional distribution and issues with long waiting lists. In 2015, there were 13 983 adult PWDs on waiting lists for places at providers of supported/ independent living.[47] As an example, in the *Hautes* Alpes region, in 2016, there were 29 PWDs on waiting lists for SAMSAH and SAVS with the region's on the full capacity of 157.[48] It is notable that at the time, there were 2,8 places per 1000 inhabitants of the region while the French national average stood at 1,5 per 1000 for both types of services. 9 out of 37 service providers that were approached noted that they did not have any waiting lists.[49]

Long Term Institutional Care

According to DREES, in 2018, €7 537 million were spent on accommodation of adults with disabilities.[50] There are three principal types of institutions for long-term stay of PWDs: the residential homes (*foyers de vie, FV),* medical care homes (*foyers d'accueil médicalisé, FAM*) and the specialised nursing homes (*maison d'accueil spécialisé, MAS*). The key difference in terms of their service offering is in the degree of disability that they cater for, from the FV which do not involve medical care or oversight to the MAS which are reserved to the most severe cases of disability.

From this differentiation also stems the different type of funding and governance, in line with the general distinction between health and social care in France. The FV are funded by the local budget of the department, with participation of the PWD that is defined by the local authority.[51] The FAM rely on mixed funding of both the departments for the social elements of their services and the health insurance for the health care elements. The financial participation of the user also takes place in theory but is generally deducted from their AAH allowance. If the funding from AAH is insufficient, general social aids such as the social accommodation aid (*aide sociale à l'hébergement, ASH*) are used to cover the remainder of costs. Currently, the minimum financial contribution of the

45 SAMSAH & SAVS. *Financements.* Accessed on 29 September 2020. Available from: http://samsah-savs.fr/fr/dossiers-thematiques/financements.

46 Ministere des solidarités et de la santé. *Aides et soins à domicile.* Accessed on 29 September 2020. Available from: https://solidarites-sante.gouv.fr/affaires-sociales/personnes-agees/droits-et-aides/article/aides-et-soins-a-domicile.

47 L'Unapei. (2015). *Les Bannis de la République.* Accessed on 25 September 2020. Available from: https://en.calameo.com/read/004026746ca8adc9281f9

48 Centre Régional d'Études, d'Actions et d'Informations. (2016). *Analyse de l'offre et des listes d'attente dans les établissements et services médico-sociaux pour enfants et adultes dans les Hautes Alpes.* Accessed on 25 September 2020. Available from: http://ancreai.org/wp-content/uploads/2018/10/etudePACA_Hautes-Alpes.pdf.

49 Centre Régional d'Études, d'Actions et d'Informations. (2016). *Analyse de l'offre et des listes d'attente dans les établissements et services médico-sociaux pour enfants et adultes dans les Hautes Alpes.* Accessed on 25 September 2020. Available from: http://ancreai.org/wp-content/uploads/2018/10/etudePACA_Hautes-Alpes.pdf.

50 Direction de la recherche, des études, de l'évaluation et des statistiques (DREES). (2020). *La protection sociale en France et en Europe en 2018.* Accessed on 22 September 2020. Available from: https://drees.solidarites-sante.gouv.fr/IMG/pdf/cps20.pdf.

51 L'Agence Nationale d'Appui à la Performance des établissements de santé et médico-sociaux (l'ANAP). (2013). *Le secteur médico-social : Comprendre pour agir mieux.* Accessed on 28 November 2020. Available from: http://ressources.anap.fr/numerique/publication/1895-le-secteur-medico-social-comprendre-pour-agir-mieux/2817-les-foyers-de-vie.

user is €270,81 per month.[52] The governance of the FAM is also mixed, with both the ARS and the local authorities having stakes in their respective fields. [53]

The MAS, on the other hand, are entirely funded by the health insurance with the involvement of the CNSA and governed by the ARS.[54] The logic of the distinction revolves around the fact that the users of the MAS require constant medical oversight while in FAM this is not as prominent. In theory, the funding mechanism is based on a daily fee incurred by the person; in reality, this obligation is transferred to the CNSA which covers the fee from the health insurance. The ARS decides yearly on the tariffs according to which the daily fees are calculated.[55] A portion of the funding is, similarly to the FAM, covered by the person, ordinarily through their AAH allowance. This currently stands on at least 30% of the cost and in any case at least €270,81 per month.[56]

With regard to the availability of services, because of the lack of places for adults, there is a tendency for young adults to overstay in the establishments dedicated to children. In 2015, this was the case for 6 000 young adults.[57] This is not optimal as the type of care these establishments offer does not correspond to the needs of PWDs beyond the age of 18. A regional peculiarity can be observed in the north of the country, where PWDs (mainly children, but adults as well), with the appropriate authorisation of the authorities, travel to Belgium to obtain the care that is not available to them in France.[58] In 2015, there were 6 500 adult PWDs, generally with very complex disabilities, that had to resort to obtaining institutional care across the border.[59] In the whole territory, there were 6 827 adult PWDs on waiting lists for places at the MAS and other medicalised institutions.[60] As an example, in the *Hautes Alpes* region, in 2016, there were 100 PWDs on waiting lists with the region's FAM and MAS on the full capacity of 215. It is notable that at the time, there were 2,1 and 1,3 places in FAM and MAS respectively per 1000 inhabitants of the region while the French national average stood at 0,8 per 1000 for both types of services.[61]

Respite care

In France, the right to respite care was established by the law of 28 December 2015 on the adaptation of the society regarding aging.[62] While the text targets primarily the elderly (that is, providing respite for carers for elderly), its effects have been applied to persons with disabilities as well. The law limits this right to PWDs who are cared

52 Service Public. (2020). *Handicap : foyer d'accueil médicalisé (Fam).* 1 April 2020. Available from: https://www.service-public.fr/particuliers/vosdroits/F15255.

53 Place Handicap. *Les Établissements Médico-Sociaux.* Accessed on 22 September 2020. Available from: https://place-handicap.fr/foyers-d-hebergement-pour-travailleurs-handicapes.

54 Article L.344-1 CASF.

55 Caisse nationale de solidarité pour l'autonomie. (2017). *Analyse des comptes administratifs 2014 des MAS.* May 2017. Available from: https://www.cnsa.fr/documentation/reperes_statistiques_n6_mas.pdf.

56 Service Public. (2020). *Handicap : maison d'accueil spécialisé (Mas).* 1 April 2020. Available from: https://www.service-public.fr/particuliers/vosdroits/F2006.

57 L'Unapei. (2015). *Les Bannis de la République.* Accessed on 25 September 2020. Available from: https://en.calameo.com/read/004026746ca8adc9281f9.

58 Interview with a national regulator and policymaker, corroborated by an interview with a local-level service provider.

59 L'Unapei. (2015). *Les Bannis de la République.* Accessed on 25 September 2020. Available from: https://en.calameo.com/read/004026746ca8adc9281f9.

60 L'Unapei. (2015). *Les Bannis de la République.* Accessed on 25 September 2020. Available from: https://en.calameo.com/read/004026746ca8adc9281f9.

61 Centre Régional d'Études, d'Actions et d'Informations. (2016). *Analyse de l'offre et des listes d'attente dans les établissements et services médico-sociaux pour enfants et adultes dans les Hautes Alpes.* Accessed on 25 September 2020. Available from: http://ancreai.org/wp-content/uploads/2018/10/etudePACA_Hautes-Alpes.pdf.

62 Caisse nationale de solidarité pour l'autonomie. (2020). *Les nouvelles mesures de la loi de 28 décembre 2015 sur l'adaptation de la société au vieillissement (loi ASV).* 23 March 2020. Available from: https://www.pour-les-personnes-agees.gouv.fr/preserver-son-autonomie-s-informer-et-anticiper/les-politiques-du-grand-age/les-nouvelles-mesures-de-la-loi.

for by close relatives.[63] Respite care services - which are not very well developed in France - are generally provided in short-stay institutions (*accueils temporaires*) which offer both day centre and short-term accommodation services. The MDPH needs to first evaluate the PWD's situation to establish that the person is eligible for receiving this service. The financing is then akin to that of day centres, with a fixed price per day and a partial contribution from the PWD.[64]

Respite care services delivered at the PWD's home are less developed in France notably due to high costs of paying for a professional's extensive availability at the person's home in order for the primary carers to be able to take full advantage of the respite. The public funds, as they are currently available, are not sufficient to cover these services without leaving substantial costs to be paid by the PWD.[65]

The impact of COVID-19 on funding of services for PWDs

Unlike the budget plan for this year, the planned social expenditures have remained unchanged. However, already in spring, the government anticipated the social security budget to face a considerable deficit due to the impact of the COVID-19 pandemic on the economy. The predictions from June 2020 pointed towards a deficit of €31 billion in health insurance. The number might change given that the economic outlook by the Ministry of Finance has improved since, but it remains a fact that as it stands, substantial financial means will not be available in the public finances that would ordinarily be destined to the PWDs.[66] In May 2020, the State announced that it would dedicate €700 million to bonuses for professionals working at the service provision for PWDs. The sums per professional were established at €1 500 and €1 000, with the higher amount destined for professionals working in the 33 most affected departments.[67]

63 Association française des aidants. *Répit*. Accessed on 25 September 2020. Available from: https://www.aidants.fr/fonds-documentaire/dossiers-thematiques/repit-0.

64 Le Conseil départemental de l'Ain. (2018). *Le règlement départemental d'aide sociale*. December 2018. Available from: https://fr.calameo.com/read/00228662445f66be5c99e?page=141.

65 Interview with a national regulator and policymaker.

66 Sécurité sociale. (2020). *Les comptes de la Sécurité sociale : Résultats 2019 et prévisions 2020*. June 2020. Available from: https://www.securite-sociale.fr/la-secu-en-detail/comptes-de-la-securite-sociale/rapports-de-la-commission.

67 Secrétariat d'Etat chargé des personnes handicapées. (2020). *Versement d'une prime exceptionnelle aux professionnels des secteurs sociaux et médico-sociaux*. 8 May 2020. Available from: https://handicap.gouv.fr/presse/communiques-de-presse/article/versement-d-une-prime-exceptionnelle-aux-professionnels-des-secteurs-sociaux-et.

Interviews

★ Anonymous Expert

★ Anonymous Expert/Professional

★ Anonymous National Regulator and Policymaker

★ Anonymous National-level Provider

★ Anonymous Regional-level Provider

★ Anonymous Employee

★ Anonymous National-level Provider

★ Anonymous Local-level Provider

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