



# Supporting carers by removing obstacles in the development of respite solutions



Report

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# SUMMARY

[1] Within the framework of the governmental strategy “Action for Carers 2020-2022”, the delegated Minister for Independence and the Secretary of State responsible for disabled people referred a mission to the General Inspectorate of Social Affairs (IGAS) relating to the evolution of the legal and financial framework of the respite offering for carers of elderly, disabled and sick people.

[2] The mission took place in a context marked by the effects of the Covid pandemic and in a sector which moreover is experiencing significant recruitment difficulties.

[3] It targeted its work at four respite solutions, without claiming to be exhaustive, considering the variety of the offering and the diversity of the carers concerned:

- support and respite platforms, which inform and advise carers;
- home respite solutions, which stand in for the carer;
- care home respite solutions, including the different forms of temporary placement and the “respite homes” experiment;
- respite holidays.

[4] The mission draws up an overview of the existing respite solutions, presents the obstacles to their expansion, and makes recommendations to remove those obstacles. On some subjects, the mission proposes scenarios which must be looked into further.

## **Given that the role of caregivers is going to increase in the coming years, the respite solutions must prevent the risk of their exhaustion**

[5] Carers<sup>1</sup>, who are not limited to family carers, play an essential role in the support of elderly, disabled and sick people. Their role is going to increase in the coming years, owing to demographic changes (ageing population, rise in prevalence of chronic illnesses) and societal demands (preference for staying at home, inclusion of disabled people, expansion of outpatient care). In the latest available survey, which dates back to 2008, the Directorate of Research, Studies, Evaluation and Statistics (DREES) estimates the number of carers at 8 million, but with highly variable implications.

[6] The role of carer frequently has negative consequences on people’s professional and private life and on their health, with a risk of exhaustion and sometimes social isolation. The development of support for carers and respite solutions thus aims to limit these consequences, within a strategy of both health prevention and social cohesion.

[7] Access to respite solutions is not the primary concern of carers, who mainly stress the importance of appropriate medical and social care support for the people cared for. However, they

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<sup>1</sup> In 2010 the High Health Authority (HAS) gave the following definition for carers: “Carers are non-professional people who help principally, partially or totally, a dependent person from their family or social circle with day-to-day living activities”.

may express the need for respite time, in the sense of a person who can take over so they may take a breath and take care of themselves.

**The support and respite platforms, poorly coordinated with the offering of the *départements*, must be strengthened in order to improve the identification and referral of carers within a support offering that is still difficult to interpret**

[8] In line with public health plans, in 2019 the national “Action for Carers” strategy provided for reinforcement of the support and respite platforms (SRP) funded via the regional health agencies (ARS). Initially designed for carers of people living with Alzheimer’s disease, this was widened to all carers of elderly, disabled and sick people in 2021.

[9] In 2022, more than 250 platforms had been set up. But their territorial networking is unequal (5 *départements* without SRP, 10% concentrated in Hauts-de-France) and their activity is highly variable: some are focused on advice, information and guidance to carers, while others also provide services, for example psychological support, or themselves develop respite solutions, such as “break” services (taking over for a few hours at home).

[10] **One of the main limits to the development of SRPs relates to their very limited coordination with the policies of the departmental councils.** And yet, the *départements* have authority for the “cared for” populations targeted by the SRPs (elderly and disabled people), and some of them have developed policies for carers. Furthermore, their medical and social teams visit the homes of elderly people to assess the situation of the carer at the same time as the person cared for.

[11] **The legal status of SRPs also constitutes a limit to the development of SRPs** outside of the medical and social field. The specifications of SRPs stipulate that they must be attached to a medical and social service or facility (ESMS) funded by the Health Insurance Scheme<sup>2</sup>.

[12] To **reinforce the pivotal role of SRPs on a territory**, the following are in particular proposed:

- revision of the legal status of SRPs, which would become medical and social services attached to the 11<sup>th</sup> category of point I of Article L. 312-1 of the French Code of Social Welfare and Families (CASF), as “resource centres” in order to guarantee their autonomy and enable their direct funding by the ARS;
- the choice of a unifying and more fitting national name such as **Carer Centre** and pooling their telephone and digital service;
- the construction or reinforcement of partnerships with all stakeholders supporting the carers or those they care for<sup>3</sup> within a strategy of subsidiarity;
- the effective broadening of SRPs to the carers of sick people, initially targeting certain chronic diseases which are the most demanding on carers.

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<sup>2</sup> Since the creation of the independence branch on 1<sup>st</sup> January 2021, ESMS, previously funded by the Health Insurance Scheme, have fallen within the overall expenses target (OGD) managed by the National Solidarity Fund for Independence (CNSA).

<sup>3</sup> Medical and social teams of the *départements*, MDPH, CLIC, Communautés 360, coordination support mechanisms, etc.

[13] Furthermore, better identification of carers must enable the SRPs to intervene preventively rather than in emergency situations. In that way, the report identifies several drivers **to raise awareness and empower the numerous professionals who work alongside the carers.**

**While home respite care has been trialled in many forms, its generalisation and expansion, eagerly awaited by carers, requires more sustained funding and a stable legal framework in order to structure the offering**

[14] The “Action for Carers” strategy provided for a trial of derogation from employment law in order to expand respite at home on the Quebec “*baluchonnage*” respite model<sup>4</sup>. The home respite care model developed in that context remained very modest, while **numerous other home respite care plans have been developed in very recent years for carers of elderly people without however using this derogatory framework.**

[15] **For carers of disabled people, the home respite care offering is still in its infancy,** subject to the specific support to parents of disabled children offered by some family allowance funds.

[16] **For carers of sick people under the age of 60, and in particular for parents of sick children, the offering is still pretty much non-existent,** save in certain cases of discharge from hospital (such as with the Health Insurance Scheme discharge programme - PRADO).

[17] **The obstacles to the expansion of the home respite care offering** relate mainly, on the demand front, to funding, which remains very isolated, rather little known and complex to claim; and, on the supply front, the recruitment difficulties in the sector and a legal and economic model which is still undetermined, particularly in terms of pricing and qualifications.

[18] The mission gives proposals to support the expansion of the home respite care offering according to four areas:

- **the organisation, in all SRPs, of a respite offering for a period of less than 4 hours (“break”), with a symbolic patient contribution;**
- **the structuring of a respite offering of 4 to 48 consecutive hours, relying preferentially on the home help services;**
- **the expansion of funding solutions;**
- **a redefinition of the cases allowing exemption from employment law for home respite provision of over 48 hours,** which should be restricted to people whose state of health could suffer from the provision of multiple carers.

**The offering of temporary placements in a care home must be adapted according to carers’ expectations**

[19] Carer exhaustion or unavailability – in particular owing to hospitalisation – are among the main reasons for temporary placement. The temporary placement offering remains however a small proportion of the offering of care homes for elderly and disabled people, and is not always adapted to the expectations of the users.

[20] **Within the sector of elderly people, the day care and temporary accommodation offering is relatively underused.** This underuse contrasts with demand for temporary

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<sup>4</sup> There are other models overseas; the mission describes a few of these in appendix.

placement which cannot be met, particularly for certain populations (those presenting behavioural disorders, “atypical” profiles such as young patients, etc.) or for certain placement types (emergency placement, very short stays, etc.).

[21] **Within the sector of disability and chronic illness, the needs expressed by the stakeholders particularly raise deficiencies in the offering of medical and social coverage.** For example, many respite applications relate to the placement of children at the weekend or school holidays, implicitly emphasising the unsuitability of the offering provided by facilities for children. **A huge obstacle to the demand for care home respite relates to the legislation on temporary placements**, which makes access to care homes conditional on an administrative decision, with practices of the departmental disability care homes (MDPH) varying greatly between *départements*. The other obstacles are linked to the patient contribution to the temporary accommodation or day care and the cost of transport, in spite of a regulation which stipulates their coverage under certain conditions.

[22] The “Action for Carers” strategy initially set **an objective of expansion of temporary placements** with the ambition of doubling the number of carers supported by temporary placements in 2022. The national guidance framework drafted in 2021 to set out this strategy was counting on **a reconfiguration of the offering towards greater flexibility and modularity**. With the exception of disabled children, **the outcome of the strategy is well below the initial ambitions**.

[23] **The mission believes that the ARS and the départements should more actively drive the expansion or conversion of temporary placement places in the care homes of both sectors, drawing on territorialised analyses of needs.** The writing of service projects dedicated to temporary placements, with organisations adapted to temporary placement, to sequential placement or to more flexible forms of placement, and to emergency placement, must be encouraged.

[24] Within the sector of disability and chronic illness, the mission recommends **facilitating access to temporary care home placements by making the placement unconditional in emergency situations. The increased opening of care homes for children at weekends and school holidays must be financially supported.** Regarding care homes for elderly people, the mission explores several options to reduce the patient contribution for users.

**To meet the respite needs of carers and those they care for, “respite homes” are being piloted, but at this stage their outcome is not encouraging their generalisation.**

[25] **Neither the expansion of respite homes nor the creation of a new legal category of “respite home” facility currently appears appropriate.** The results of the respite home of Lyon (temporary accommodation facility and mobile team) are still mixed after four years of activity, which questions both the positioning of the two systems and their economic model.

[26] For all that, numerous teachings can be drawn, in particular the importance of developing support systems for carers within a “go to” strategy and the existence of needs that are insufficiently covered, at the overlap between the medical and social health sectors. In the absence of quantification of the need, it remains tricky to calibrate this care home respite offering.

[27] Rather than the creation of care homes dedicated to the temporary placement of sick people, which would risk being costly and make it difficult to draft a local offering, **the mission recommends broadening the options of temporary accommodation in healthcare facilities**

**in order to relieve the carers and promote home care, while encouraging respite stays in three sectors:** palliative care, medical and rehabilitation care (SMR) and the future complex extended stay units (USPC).

### **Respite holidays, for the carers and the people they care for, are worth supporting**

[28] Respite holidays can be targeted solely at the people cared for, the carers, or even simultaneously at carer and the person cared for. The expansion of this latter offering, which is still limited, is particularly desired by carers who, like the rest of society, prefer family holidays in an ordinary environment, within a strategy of inclusion.

[29] They can be organised by travel agents, often from social tourism, or by medical and social facilities, but very rarely jointly by both sectors.

[30] **The principal obstacle to the expansion of respite holidays relates to the high cost of adapted stays.** There are however several individual funding mechanisms making it possible to cover part of the cost of respite holidays for carers and/or those they care for, but **the financial grants are very diverse, which makes them complex to claim, and very often little known.**

[31] **The results of the Action for Carers strategy are inconclusive in the matter of respite holiday and trips.** At the end of 2021, virtually no credits had been consumed by the ARS, which can in particular be explained by their reluctance to fund stays provided by travel agents and the creation of medical and social facilities dedicated to respite holidays.

[32] **The mission in particular recommends conferring on the CNAF a mission of expansion of the family holiday offering for disabled children,** supporting the project invitations of the National Holiday Voucher Agency (ANCV), by partnering the National Solidarity Fund for Independence (CNSA) in their administration, and fostering the funding of joint projects of the travel and medical and social sectors within the framework of cooperation groups.

### **Paradoxically, although the development of respite solutions is firstly hindered by a lack of funding, the existing funding is little claimed, as it is scattered and little known, which means the existing grants should be clarified.**

[33] **There are numerous options for individual grants for respite solutions but they are complex to implement and leave the beneficiary to pay a financial contribution that is sometimes large:**

- For carers of elderly people, the funding of certain respite solutions is possible through the personalised independence allowance (APA), in particular within the framework of the “right to respite” created in 2015, but it remains however very little claimed;
- For disabled people, the funding of costs linked to holidays (in particular transport) is possible within the framework of the disability compensation benefit (PCH) and supplements to the disabled child education allowance (AEEH);
- Numerous “extra-legal” grants exist but depend on the social welfare policies of the local social security or complementary pension funds;

- For the home respite care, the tax credit provided to encourage the use of the personal help services remains the most powerful funding mechanism, but it does not yet benefit from the direct advance.

[34] **Similarly, the consumption of credits of the Action for Carers strategy is well below the initial ambitions concerning the respite offering:** only 22% of the 52.5 million euros of new measures had been consumed by mid-2022, even though the feedback of the ARS is showing an acceleration of the programmes.

[35] **The mission makes proposals to clarify and reinforce the funding of respite solutions by the existing individual benefits (APA, PCH, AEEH), which is the solution that it favours in the short term.** Furthermore, the mission sketches out two scenarios to decorrelate the carer's support from the benefits linked to the person cared for, and to create a "respite" benefit dedicated to the carer, which could constitute a medium-term solution:

- The creation of a "**carer respite allowance**" (cash benefit) could be easy to implement, if it is a flat-rate and paid through a financial circuit similar to the daily caregiver's allowance (AJPA), but, being little targeted, its impact would be difficult to measure and its windfall effects would be high;
- The establishment of a benefit in kind (or "**carer respite voucher**") seems more relevant, but much more complex to implement. A prefunded payment voucher, such as CESU, targeted to funding the takeover of care at home, seems the most appropriate, because it's already used in other contexts. It would furthermore bring together several financial contributors.

[36] These two options would be worth examining in greater depth, in order to assess their feasibility and their financial impact in greater detail before a potential pilot experiment.

[37] Lastly, **the financial framework of the respite offering should be revamped.** The mission in particular recommends better identifying in the CNSA initiatives the effort of the independence branch devoted to carers, and broadening the jurisdiction of the funding conferences from the prevention of loss of independence to the scope of disabled people, bringing the CAFs into the picture, so they foreshadow the territorial conferences on independence desired by the 2022 Libault report on the public territorial independence service.

[38] **The recommendations of the mission have the aim of fuelling the new strategy for carers announced for the year 2023, which constitutes an opportunity to promote the expansion of respite solutions at a more significant scale and support the carers who play an essential role for national solidarity.** In addition to the associations, the preparatory works to draft this strategy should include representatives of the *départements*, which are the key stakeholders of the carer support policy. The CNAF, the social agricultural mutual fund (MSA), and the ANCV could also be brought in as partners, for the respite solutions they provide and the grants they fund.

[39] **The expansion of respite solutions to support carers must not be implemented to the detriment of a more comprehensive support policy for the persons cared for, which is essential to respond to the insufficiency or unsuitability of support of some people, in care home or at home.**