

ANED country report on the implementation of policies supporting independent living for disabled people

Country: France

Authors: Catherine BARRAL, Jésus SANCHEZ and Pascale ROUSSEL with the collaboration of

Yvonne Bertrand (CTNERHI)

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PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

After a long tradition of institutionalization in the field of disability, French legislation and disability policies have significantly progressed towards a rights-based and independent living approach within the last ten years.

Before examining the main innovative measures and implementations regarding independent living and rights of persons with disabilities brought about by the 2005-102 Act 'Equal rights and opportunities, participation and citizenship of disabled persons' and the 2002-2 Act 'Renovation of social and medico-social action', we first recall briefly the specificity of the French disabled persons NGOs. Unlike in most other countries, organizations of disabled persons and organizations of parents have created in the past -and still manage- special institutions (with State funds), while simultaneously claiming for common rights, access to common services and resources for those of them who wish to live independently. Since the seventies, another stream of disabled persons' organizations appeared, clearly opposed to special institutions and claiming the right to independent living. (In this report we refer to the former organizations as managerial NGOs and to the latter as DPOs).

We describe the evolution of the French disability policy scene combining the Europeanization of the influential managerial NGOs via EDF and the impact of following major public initiatives, DPOs' movements and judicial events that took place in the country from the nineties on, and that led consistently to Act 2005-102.

Act 2005-102 defines the new policy according to two major aims: accessibility and compensation. The new accessibility regulations and time limits to comply with the law apply to the whole of society's equipment, services, buildings, etc. and thus contribute to set disability as a national issue. The second major improvement refers to a compensation scheme that includes the innovation of an individual budget -Disability Compensation Benefit- and the development of support services in the community.

If one may consider that the three main indicators of an independent living policy are support for living at home, freedom of choice and deinstitutionalization, French disability policy framed by the 2005-102 Act aims at the first two.

Indeed, while providing the disabled person with better resources and support to live at home, to have choice and control, French disability policy does not intend to switch radically to an independent living policy and deinstitutionalization is not on the agenda. Along with Act 2005-102 for independent living, Act n°2002-2 'renovating social and medico-social action' provides a framework for reforming the functioning of special institutions and access to rights for their residents. French disability policy could therefore be more adequately described as a twin-tracked policy, intended to provide the disabled person the choice to live independently or in institution if they so wish. This disability policy reflects a compromise with the institutionalization system and with the managerial organizations that run it, but it reflects also an approach of deinstitutionalization that intends to provide a variety of living modes adapted to the levels of autonomy of the concerned persons. The preferred terms of 'autonomy', 'autonomous life' to that of 'independent living' in French discourses, whether legislative, regulatory, professional or managerial refer to this type of approach.

Parts 3, 4 and 5 of the report provide data related to the individual budget scheme (allocation procedure, eligibility criteria, types and amounts of expenses covered), to support and assistive services available in the community (types, providers, funding agencies), to met and unmet needs, and to disabled persons' involvement in disability policy.







PART 2: LEGAL AND POLICY CONTEXT

Until 2005, disability policy in France was framed by the 1975 'Orientation Law in favor of Disabled People' (Loi d'orientation en faveur des personnes handicapées). This policy framework reflected the dominance of the individual model of disability and as such was twofold: (1) to acknowledge persons with disabilities as a specific population; (2) to harmonize the successive pieces of legislation and regulation related to disability accumulated since the fifties, and to provide special institutions with legal foundation and national management rules. During the last four decades of the twentieth century, France built up a daunting array of special institutions across the country for children and adults. Most of them were created by disabled persons and parents organisations, which currently still run these institutions by delegation of power from the State who, for its part, ensures their financing and defines national regulations.

Since the 1990s, French disability policy has slowly progressed towards a rights-based policy, through a number of laws, reforming sector-based aspects, such as school integration, special institutions, provisions for the elderly, accessibility, non-discrimination:

1990, Act n° 90-602 of July 12, related to a person's protection against discrimination due to their health condition or disability.

1991, Accessibility Act n°91-663 of July 13, 'On various measures in favour of housing, work places and equipment for public use accessibility for disabled persons'

1999, <u>School integration</u>, <u>Handiscol</u>: Promotion of individual plans and provisions for school integration; development of mobile educational services to children. *Handiscol* is a national plan launched jointly by the ministry of Education and the ministry of Labour and Solidarity to develop access to education for disabled children.

2001, Act n°2001-647 of July 20, regarding provision for loss of autonomy of aging persons and the individual allowance for autonomy

2002, Act n° 2002-303 of March 4, regarding patients' rights and quality of the health system. It refers namely to health democracy and the promotion of individual and collective users' rights, and patients' organizations say.

2002, Act n°2002-2 of January 2, 'renovating social and medico-social action', regarding special institutions and their users' rights. Act 2002-2, affirms the user's entitlement to basic civil rights. The Act and its implementation decrees impose new rules and regulations to institutions regarding provisions, quality criteria and choice of the users. An Entrance Booklet is required from the institution on admission, explaining the organization of the institution, functioning rules, role of the social life council which composition includes users' representatives as well as staff's and managerial NGO's. The council must meet three times a year to discuss the institution functioning, plans, provisions, etc. The user signs a contract stating respective obligations and the designation of a qualified person to whom the user can refer to assert her/his rights. Along with the Entrance Booklet an institutional plan presenting the main objectives is delivered as well as a User's rights and freedoms Chart stating the following rights: non discrimination, adapted provisions, information, free choice, participation and enlightened consent, refusal of proposed provision, family links, protection, autonomy, prevention and support, religious practice, dignity and intimacy. To assess the rights implementation and provisions quality in institutions and services, the 2002-2 Act established a national assessment agency (ANESM).

2004, Act n°2004-806 of Aug.9, regarding public health policy and particularly the national plan for improving the quality of life of persons with chronic diseases.







2005, Act n°2005-102 'Equal rights and opportunities, participation and citizenship of persons with disabilities', issued February 11 is a major law providing new foundations and a new disability policy framework. Its key features are described below.

Following this law, other pieces of legislation were issued to back it up and address specific sections of its implementation:

2005, Act n° 2005-841 of July 26, 'Development of services to the person and various measures in favour of social cohesion'.

2007, Act n° 2007-308 of March 5, reforming legal protection of adults.

The 2005-102 Act ('Equal rights and opportunities, citizenship and participation of persons with disabilities') reflects a clear political will for disability policy change at a global level. It emphasizes first the rights of people with disabilities:

Art.L114-1: 'Any disabled person has a right to the solidarity of the whole of national collectivity that ensures him/her access to all basic rights recognized to all citizens, as well as the exercise of his/her full citizenship.' Here, basic rights means education, health, employment, citizenship, freedom of movement, culture and social life.

To enforce the law over 100 implementation decrees, numerous guidelines and regulations have been issued within the two years following its promulgation.

Unlike the previous frame law (1975) that did not provide a definition of disability, leaving it to the local Commissions, responsible for the orientation of people with disabilities and the allocation of allowances, to define who was disabled and who was not, the Feb 11, 2005 Law defines disability as follows:

'a disability constitutes any activity limitation or participation restriction to life in society that a person may undergo in her/his environment, due to a significant, lasting or permanent alteration of one or more functions, be it physical, sensory, mental, cognitive or psychological, due to multiple disability or due to a disabling health condition.'

The criticism is often raised that this definition is more restrictive than the acknowledged international one (i.e. WHO's definition: 'Disability is the result of the interaction between individual characteristics and that of the environment') and still reflects a vision that burdens unequally the individual's impairment ('due to (...) an alteration of function'). However this legal definition of disability takes into account the various dimensions of disability (impairment, activity limitations, and social participation restrictions) and as such it can be considered as a significant improvement that provides a sounder basis for eligibility criteria to disability benefits than the previous incapacity rating. It is also a definition of disability that includes mental conditions, and thus entitles people who experience such conditions to disability benefits.

The general principle of the **2005-102 Act** refers to the freedom of choice of the disabled person and his/her participation in all decisions concerning her/him. It is based on two pillars: Accessibility and Compensation.

Accessibility is understood in a global sense, i.e. to provide environmental, social, economic and cultural adaptations and accommodations to give people with disabilities access to mainstream education, labour market, housing, culture, leisure. The principle of accessibility for all, whatever the disability (a principle already stated in the **Accessibility Act n°91-663** of July 13, 1991) is reaffirmed, but with new definitions of accessibility criteria and time limits to comply with the law.







Thus buildings open to the general public, public transport, municipalities and public communication services are given 10 years to become accessible, that is by 2015. Beyond built environments the principle of accessibility applies to all social fields and public policies.

A commission on accessibility, steered by the cross-ministerial delegate to disabled persons (DIPH) involving most ministries, gives the following definition of accessibility:

'Accessibility allows for disabled persons' autonomy and participation, by limiting, or indeed suppressing, discrepancies between their capacities, needs and expectations on one hand and the various physical, organizational and cultural components of their environment on the other hand. Accessibility requires to implement complementary elements, that any person with a permanent or temporary incapacity needs to move about and to access freely and safely the life frame as well as all places, services, products and activities. Society by such an approach of accessibility contributes to improve the quality of life of all its members'. There follows a list of specific definitions relevant to the action of each ministry.

In terms of compensation, Act n° 2002-2 ('renovating social and medico-social action'), Art.L114.1.1. stated that: 'The disabled person has a right to compensation for the consequences of her/his disability, whatever the origin and nature of the impairment, the age and type of dwelling (in institution or at home), and to the guarantee of minimum resources that allow to cover all the essential daily life needs.'

The 2005-102 Act extended this right to compensation by creating a Disability Compensation Benefit. This innovation reflects a conceptual shift from the notion of provision for disabled people to that of individual choice and freedom. It is part of the social protection non-contributory scheme. For a description of the six types of disability benefits see the French ANED 2008 Report on social protection and social inclusion.

Currently, with the implementation of the 2005-102 and 2002-2 Acts, French disability policy can be defined as a twin-tracked policy. The aim is twofold:

- (1) to develop accessibility measures and regulations for people with disabilities to access common services in the community and to provide them with better individual resources that will allow them to live independently;
- (2) to steer and monitor the evolution and the shift of special institutions from a traditional way of functioning as closed and segregated spaces to opened provisions of services in the community, while giving the person in institution access to the same rights and benefits as the independent living person.

In France, the shift towards a social model of disability does not mean to switch radically to independent living, but to give the person the possibility to choose either to live independently or in an institution, provided that the 2002-2 Act is implemented. Which means that norms of provisions and quality must be effectively put in practice in the institutions, that quality assessments (external and internal) must show evidence of the quality of life of the user, must show evidence of the implementation of the new institutional (rights-based and participatory) regulations, and that the traditional model of institutional provision reducing the individual to a captive user is effectively shifting to a new and open form of institutional life and support, respectful of the person's rights, dignity, choice and say. National indicators and qualitative assessments are still missing to show evidence that these improvements are in progress.

A disabled person whether living at home or in special institution is said to have the same civil rights as any other person.







However, it is a well known fact that in real life the effective exercise of their citizenship and basic rights is most often hindered or prevented because of lack of accessibility and personal assistance, lack of resources, lack of information about their rights and duties, or even active hindrances to their right and capacity to express themselves in matters that would be otherwise out of institutional control (sexuality being one them, but also attempts to organize themselves without supervision around common goals and claims) namely in institutions for persons with intellectual impairments. Acts 2002-2 and 2005-102 are meant to remedy for these tacit rights denials.

The procedure and mechanisms to assess the person's life conditions, to define the individual compensation plan, the type and amount of support she/he needs according to her/his expectations and life choice, the Disability Compensation Benefit, as well as policies assessments and control schemes are certainly significant steps forward. But in spite of the fact that these procedures apply also to the persons in institutions, there is still a serious ambiguity since being provided for in an institution is considered in the 2005-102 Act as one of the modalities of disability compensation.

The issue of legal capacity relates also to the case of adults under legal protection. It mainly concerns persons with intellectual impairment or a mental health condition, considered unable to assume one's rights and assets, and thus deprived of their civil rights, among others. In 1998, according to the national disability survey (HID), 519,872 persons were under legal protection, i.e. about 1 % of the population. 36 % of these persons were in institution and 64 % were living at home. Among the population in institution, 28 % were under legal protection. The rate of legal protection by type of special institutions was 11 % in those for children and teenagers (for economic or social reasons), 71 % in those for adults, 18 % in those for elderly, 29 % in long term hospital, and 49 % in psychiatric institutions. Today, approximately 700,000 persons are placed under a regime of legal protection. This number could rise up to 800,000 or one million in 2010, according to demographic projections. Consistently with the 2005-102 Act and its emphasis on rights and accessibility, a law was issued March 5, 2007 'to reform legal protection of adults'(Loi n° 2007-308 du 5 mars 2007 portant réforme de la protection juridique des majeurs).

With this Act the regimes of legal protection should now only apply to persons whose disabilities have been medically diagnosed. Persons whose impairment is the result of social or economic difficulties (and who were previously under a regime of legal protection) should be provided with adapted services and supports instead. The implementation of this reformed legislation is significantly delayed due to the ongoing congestion of the courts overwhelmed by the number of cases to deal with.

In terms of civil rights, the law states that the person under legal protection (guardianship) has the right to vote. According to Act 2005-102, polling stations and voting device should be accessible to disabled voters, should their disability be physical, sensory, intellectual or mental. Adaptations should be made as well in communication systems for persons with hearing, visual or aphasic impairments in order for the State and local authorities to avoid law suits for discrimination.

The 2005-102 Act requires that every three years, the government organizes a National Disability Conference with DPOs, representatives of special institutions and services, social security bodies, employees and employers unions, to discuss the orientations and means of the national disability policy. The first National Disability Conference was held in June 2008. Following the Conference, the government has to provide a 3-year appraisal of the implementation of the disability policy, that must be reviewed by the National Advisory Council of people with disabilities (Conseil national consultatif des personnes handicapées / CNCPH), before submission to the Parliament for approval.

In February 2009, the Secretary of State in charge of disability provided the appraisal of the 2005-2008 disability policy (Report of the Government to the Parliament on the appraisal and orientations of the disability policy / Rapport du Gouvernement au Parlement relatif au bilan et aux orientations de la politique du handicap, 12.02.2009).







The 130 p. report is divided into 4 chapters

- Compensation, major step of the 2005-102 Act
- Access of all to everything: a condition for equal opportunities
- Employment and resources: 3rd pillar of the disability policy
- Research, prevention and training: the future of the disability policy

While national efforts to improve disability policy in implementing the 2002-2 and 2005-102 Acts are significant, managerial NGOs as well as DPOs remain extremely watchful that the disability policy does not drift away or that its implementation slows down concerning rights and access. Thus the Government Report was severely criticized by the National Advisory Council of People with Disabilities, who considered that it reflected merely Government's self-satisfaction while a great number of the proposals, recommendations of the Council and even principles of the law itself were overlooked or bypassed, whether in education and schooling, employment and training, compensation and living resources, accessibility or institutional management. They also discussed the validity of the assessment carried out by non-independent bodies.

Besides the new regulations and measures improving independent living, the claim for a living income (equal to gross minimum guaranteed wage) for people with disabilities who cannot work that has been on DPOs agenda for years is still a pending issue.

The national agency for the assessment and quality of social and medico-social institutions and services (ANESM) was created in 2007 to see to the implementation of the (internal and external) assessments of institutions and services in the field of disability and old age required by the 2002-2 Act. Its two main missions are:

- to validate, develop and update procedures, norms of reference and recommendations of professional good practices and to circulate them.
- to accredit external bodies in charge of implementing external assessment of activities and provisions quality of institutions and community based services.

Amongst other current formal changes is a change in terminology. The expression 'person in a situation of disability' highly supported by organizations of people with disabilities instead of 'disabled person' has now passed in common language. In the view of people with disabilities this expression carries a more dynamic and proper image of disability by extending disability to the context in which a person lives. It implies that an individualized assessment cannot focus on the person's impairments and activity limitations (functional state) only, but on one's disabling environments as well (lack of accessibility, unavailability of devices that would be necessary for the person to live independently or to allow her/him to be as autonomous as possible). It is with this extended assessment of the situation of a person in mind that DPOs insist that the individual compensation plan ought to be carried out.

All the articles of the 2005-102 Act addressing specifically disability issues, are now incorporated into the different sections of the general legislative corpus (Codes de l'action sociale et des familles, de l'emploi, de l'urbanisme, etc.), which means an official inclusion of the disability perspective within common laws.

New ideas about independent living have come from various influences.

Independent living offices (sites pour la vie autonome): the 1975 Act recommended autonomy and independent living for people with disabilities (claimed by a number of DPOs), but did not effectively consider the means to be provided and left that recommendation not implemented and the claim unmet.







Since then, through recurrent mobilization, DPOs and managerial organizations (mainly physical and sensory impaired persons such as APF (Association of the paralyzed persons of France), AFM (French association against muscular dystrophy), GIHP (Group for the inclusion of physically disabled persons), visually and hearing impaired persons organizations) upheld their claim for independent living, access to technical aids, individualized adaptations of their life settings, development of human aids at home and outside their homes for social activities.

Between 1997 and 1999, an innovative scheme was experimented in four of the 100 French regional departments to tackle this issue: independent living offices.

<u>Aim</u>: In a global context of outburst of technical aids, these offices were intended to provide advice and access to technical aids and to individualized home adaptations. The aim of these offices was mainly threefold:

- to set up a multidisciplinary assessment team to assess the person's technical aids and financial needs:
- to provide enlightened advice on available technical aids, home adaptations, home automation and providers;
- to simplify access to funding by rationalizing and coordinating the various existing funds providers (principally State, General Council (local administrative authority), local and regional offices of social security, mutual insurance system for agriculture (Mutualité sociale agricole), Management Agency for people with disabilities integration in employment (AGEFIPH).

These Independent Living offices proved quite efficient and were progressively generalized (with State funds) to the 100 French departments between 2000 and 2004 (enforced by a June 2001 ministerial decision 'concerning the independent living device' (Circulaire GAS/PHAN/3 An° 2001-275 du 19 juin 2001 relative au dispositif pour la vie autonome) that stated:

'Equal opportunities imply to favour two complementary processes, that of accessibility of society by eliminating obstacles and that of autonomy of the persons facing situations of disability by providing them the possibility to express and put their capacities in practice.'

On the basis of a positive appraisal of these independent living offices (Sanchez J., <u>Nouveau dispositif pour la vie autonome. Evaluation. Rapport final</u>. Paris, CTNERHI, 2004, 144p.), a pilot study of a right to compensation was carried out. With the perspective of this new right, the vision of the influential managerial NGOs, who so far feared that a reform of the 1975 Law would reduce people with disabilities entitlements (positive discriminations/specific rights) on behalf of common rights, changed in favour of a global reform of the legislation.

The 'Perruche Case': among the various factors that come into play to allow disabled persons to live independently, the financial issue is of utmost importance. A major and stirring judicial event led to the promulgation of the 2002 law (Act n° 2002-2) and to the acknowledgement of the need for a disability compensation benefit: the 'Perruche Case'.

A disabled child, Nicolas Perruche (in fact his parents), claimed financial compensation for the consequences of his disability put on the account of a wrong medical diagnosis that had prevented his mother, who had contracted rubella when she was pregnant of him, to have an abortion. In 2000, the Court proved him right. This judgment caused great stir and led the then Minister of Health, J.- F. Mattei, to have a text voted in 2002 to stop other such claims and judgments.

This case highlighted the fact that if disabled persons benefitted from decent allowances and compensation benefits, they would not appeal to justice.







Following this case, one of the main points of the Act n° 2002-2 was to state that: 'the disabled person has the right to compensation for the consequences of his/her disability, whatever the origin and nature of the impairment, the age or the type of dwelling (in institution or at home), and to the guarantee of minimum resources that allow to cover all the essential daily life needs' (Code of social action and families – Art.L114.1.1). And that the compensation would be covered by national solidarity (non-contributory scheme, taxes).

Europeanisation of French disabled persons NGOs: the main managerial organizations of people with disabilities and of parents (mentioned above in introduction of §1 'legal context') have always played a double role (as partners of the State in managing the national infrastructure of special institutions and as a pressure group) and used a double discourse: claiming special treatment and institutions for people with disabilities on one hand, and on the other hand claiming common civil rights, access to mainstream settings and development of personal assistance and assistive devices. This somewhat paradoxical position long blurred and weakened the claim for independent living.

On the other hand, there were a number of non managerial DPOs, who refused institutionalization and claimed for decent resources for independent living and personal assistance (such as the French branch of Enable, of DPI, and others). But these DPOs had very little say, being excluded by the managerial organizations class from the negotiations with the government on disability policy design and planning.

However these non managerial DPOs, united in 1993 in the French Group of Disabled Persons (*Groupement français des personnes handicapées* / <u>GFPH</u>), gained strength and visibility in France through their involvement in the EDF and so did their claim for independent living and freedom of life choice.

At the same time, the managerial NGOs became aware of the growing European disabled people's movements and claims for independent living and acknowledgement of their rights. They got involved in the EDF through the French Council of Disabled people for European matters (*Conseil français des personnes handicapées pour les questions européennes* / CFHE) also created in 1993. The influence of EDF practices - exchange of experience and practice, direct say of disabled persons, disability perspective and mainstream in the orientations of the EU disability policy, non discrimination, etc. - played a significant role in the evolution of these managerial NGOs and in the clarification of their claims for independent living.

This process of Europeanization of French DPOs and managerial NGOs developed through EDF, but also through the Non discrimination Art.13 of Amsterdam Treaty, the circulation of the WHO's *International classification of functioning, disability and health*, or the promotion of a social model of disability by the academic network of disability studies (who was asked to contribute to the governmental think tank for the reform of the 1975 Law, in 2002).

The following examples provide a sample of pro-independent living DPOs:

Coordination Handicap Autonomie (CHA) is a DPO founded in 2002 by persons totally dependent on assistance for essential activities of daily living. Its members struggled (namely a hunger strike in the entrance hall of the ministry of Social Affairs by Marcel Nuss) and obtained that the Disability Compensation Benefit (established by the 2005-102 Act) be tailored to the person's needs at home and covers 24h.personal assistance instead of the 12h.initially provided by that Act. Action of CHA focuses on 'proposals of devices and concrete actions to be submitted to public authorities regarding disability compensation and human aids'.







Hand in Cap, Mouvement pour la vie indépendante: a DPO linked to Enable. Its claims focus on personal assistance and living income. Its arguments include: - 'The weakness of the allowance for assistance by a third party does not allow a decent 24h.personal assistance wage. Then one is obliged to enter an institution which is unacceptable for a person psychologically autonomous.' - 'Personal assistance means that it must be possible for the independent disabled person to recruit, train, manage and eventually lay off his/her assistants. In other words, personal assistance means that the user is the boss.'

Association Nationale Pour l'Intégration des personnes Handicapées Moteurs/ Anpihm (National Association for the integration of physically disabled persons): 'Defense and action movement for a national policy aiming to suppress or at least reduce and compensate whenever needed, situations of disability lived daily by several millions of citizens and their families'. Its claims focus on a living income equal to gross guaranteed minimum wage (SMIC), and accessibility.

Neither poor nor submissive Group (Collectif ni pauvres, ni soumis): focuses its claims on: 'a decent living income equal to gross guaranteed minimum wage for the hundreds of thousands of persons in a situation of disability, either because of disabling disease or professional injury who cannot work condemned to live all their life under poverty threshold.'

<u>GIHP</u> (Group for the insertion of physically disabled) is focused on accessibility. GIHP provides adapted transportation, adapted apartments and peer-counseling.

<u>ADVOCACY</u> (Users and ex-users of psychiatric services and professionals) provides peer-support, peer-counseling, mediation.

Forums of people with disabilities such as <u>Handicap-sentiment</u>, witnessing the lack of personal assistants and describing personal practices, suggestions, etc.







PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

As noted above, French disability policy is based on 'a twin-track' approach, combining social and individual models of disability, framed by Act 2005-102, but also Act 2002-2 that deals with institutions (and their reform). This approach could give account of the reason why, in most official texts, the notion of Independent living is referred to, or combined with, that of 'autonomy'. Supporting autonomy is understood as implementing accessibility and compensation means to allow for living independently and in community settings and spaces on the one hand, and as providing for the development of the individual's capacity for autonomy, referring to the individual model of disability, on the other hand.

Thus the policy does not intend to give up the institutional system (residential and non residential) but to improve it according to three main objectives:

- improvement of quality of life within institutions (with new rules, regulations and control)
- creation of new places better targeted to disabled groups' specificities and needs (namely for autism and multiple disabilities)
- promotion and further development of community-based services often linked with an institution (namely in the field of childhood) on the other hand, as part of a plan of opening the institutions.

The field of childhood and youth is one in which significant improvements have been made towards <u>school integration</u>, since the late 1990s.

NB: For adults, we suggest referring to the 2008 ANED French Report on Employment

According to the 1998-1999 national disability survey (HID/ Handicaps, Incapacités, Dépendance) among the population (all ages) of 23,125,000 persons who declared having an impairment 97.2% live at home and 2.8% are in institutions (residential and non residential). (Source: Roussel P. (2002). La compensation des incapacités au travers de l'enquête Handicaps-Incapacités-Dépendance de l'INSEE (enquête HID 1998 – enquête HID 1999)

NB: These figures will be updated with the 2008 survey Handicap-Santé (Disability-Health). Data should be available by the end of 2009.





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Table 1. Distribution of the French population, all ages, by exclusive groups of impairments and type of dwelling (survey HID, 1998-1999)

	Population in institutions			Population at home		
	Effectifs	% on the whole population	% on the impaired population	Effectifs	% on the whole population	% on the impaired population
Motor impairment	40 800	6,2%	6,3%	3 599 300	6,3%	16,0%
Visual impairment	5 900	0,9%	0,9%	1 141 937	2,0%	5,1%
Hearing impairment	12 300	1,9%	1,9%	1 658 919	2,9%	7,4%
Speech impairment	1 700	0,3%	0,3%	326 000	0,6%	1,5%
Visceral Impairment	17 700	2,7%	2,7%	2 091 800	3,6%	9,3%
Mental impairment	117 500	17,8%	18,2%	1 645 100	2,9%	7,3%
More than 1 physical impairment	149 700	22,7%	23,2%	3 387 900	5,9%	15,1%
Physical and mental impairments	287 400	43,5%	44,4%	2 145 800	3,7%	9,5%
Other impairments	17 500	2,6%	2,1%	6 477 400	11,3%	28,8%
Total population with impairments	650 500	98,5%	100%	22 474 200	39,1%	100%
Population without impairment	9 600	1,5%		34 957 600	60,1%	
Total	660 200	100%		57 431 800	100%	

Source: INSEE-HID 98 – INSEE-HID 99 – Traitement CTNERHI 2002







Before the 2005-102 Act, the decision of the orientation of people with disabilities in institutions was taken by departmental commissions (COTOREP for Adults, CDES for children), instaured by the 1975 Act. The revision of a disabled person institutional provision occurred every year for a child, every 5 years for an adult. Most of the time these revisions were meant to renew the institutional provision for the same length of time or to re-orient the person towards another institution. With the 2005-102 Act, these 2 departmental commissions have been replaced by a single departmental office for people with disabilities (MDPH). The assessment of the person is carried out by a multidisciplinary team, who sets up a compensation plan. The compensation plan may include provision for the person in an institution. However, for children, compulsory schooling now applies, either in regular schools -permanently or part time-, or in institution provided that academic teaching is implemented (a legal requirement).

On the basis of the compensation plan, the *Commission for people with disabilities' rights and autonomy* has authority to decide the implementation of the plan and the orientation in an institution.

The decisions of the Commission are valid for no less than one year and no more than five (Article R241-31, in Décret n° 2005-1589 du 19 décembre 2005 art. 1 Journal Officiel du 20 décembre 2005). Admission and stay in an institution are also conditioned by the rules that apply to institutions regarding the user's rights and institutional quality assessment set up by the 2002-2 Act.

Legally speaking a person does not enter or remain in an institution against her/his choice (or parents' choice for a person under 18, which can be an issue). But *de facto* the lack of accessibility, the insufficient number of personal assistance services and the scarceness of resources may not allow very dependent persons living by themselves to employ personal assistants, and therefore they can find themselves with no other alternative than to enter institutions. This is the type of situation that the 2005-102 Act intends to improve with the Disability Compensation Benefit (detailed below) that should allow for more personal assistance, home adaptations and assistive devices.

Concerning persons' admission in an institution against their consent, there is the case of persons with a mental health condition considered as needing urgent psychiatric treatment and whose hospitalization can be requested by a third party (family or medical doctor) or by legal departmental chief authority (Préfet) in case 'public order is threatened'.

The Government's Research, Studies, Assessment and Statistics Department (DREES) / Direction de la recherche, des études, de l'évaluation et des statistiques) responsible for collecting, processing and displaying data on health care and social protection schemes and expenditure and related matters¹ does not provide global data comparing expenditure on residential institutions to that dedicated to support people at home or average cost per person. However the available data on public expenditure allow for a rough and non exhaustive comparison: public expenditure devoted to residential institutions for disabled adults 20 to 60 years old amount to 10,3 billion Euros in 2007 (this amount does not include the amount spent on the income provided to disabled adults (allocation for disabled adults/AAH), the complementary income provided to persons who cannot work (Garantie de resources) due to their disability, health care expenditure linked (or not) to the disability, the amounts spent on non residential institutions such as sheltered workshops).

¹The list of DREES publication « Etudes et Résultats » is available at : http://www.sante.gouv.fr/drees/etude-resultat/)



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Support at home for disabled persons 20 to 60 years old, in terms of Disability Compensation Benefits plus Compensation allocations for third party amount to 818 million Euros in 2007 (this amount does not include the amounts provided by mutual insurance companies, private insurance companies and municipalities social action schemes that take part financially to support people for living independently in the community). (A.Bourgeois & M.Duée, Compte social du handicap en 2007, Etudes et Résultats, n°677, Fev.2009).

The increasing number of national requests for proposals in the field of disability may make up this lack in the months to come, although economy oriented RFPs do not appear to be a priority.

For children and youth: according to the 2006 five-year national survey on special institutions, the number of institutions (most often non residential) had increased by 5% between 2001 and 2006: from 1,981 institutions in 2001 to 2,080 in 2006, among which 1,229 for intellectual impairment (59%) and 851 for sensory, physical impairments and multiple disabilities.

In spite of this increase, the global number of places in special institutions for children has slightly decreased (by 1%) since 2001, with 106 242 places in 2006 vs.108 235 in 2001. While the number of those dedicated to multiple disabilities has increased by 15%, consistently with the government's target-based planning.

Services: In line with the children's school inclusion policy, the number of services of special care and education at home (SESSAD) has increased by 48% during the same period. The 911 services existing in 2001, supporting 22 835 children have come to 1300 in 2006, supporting 33 836 children at home (with an increase of 11,000 places). This evolution intensifies the rising trend (of 27%) already observed between 1997 and 2001. (A.Mainguené, Etudes et Résultats, n°669, Nov.2008). A of institutions and services for children and youth available is http://www.sante.gouv.fr/drees/tabdbord/tdb-pdf/tdb7.pdf

For adults under 60: according to the same 2006 national survey on special institutions, the number of residential institutions for adults had increased by 20% since 2001. 90% of them are dedicated to persons with mental impairment and/or multiple disabilities. The 3,015 institutions of 2001 increased to 3,720 in 2006. The number of places increased by 19%, counting 99,080 places in 2001 and 118,200 in 2006. Among them, medicalised institutions for severely impaired persons count 20,000 more places than in 2001 (an increase of 19%) (A.Mainguené, <u>Etudes et Résultats, n° 641</u>, Juin 2008).

A table of institutions for adults is available at: http://www.sante.gouv.fr/drees/tabdbord/tdb-pdf/tdb6.pdf)

The creation of institutions planned for the years to come will target, for a number of them, more specifically persons suffering from autism and Alzheimer.

For the same period, the number of public services for assistance at home has doubled (SAVs, SAMSAH). *NB:These services are described below in part 4.*

Creation of services plan

The National solidarity for autonomy fund (CNSA) 2008 <u>Qualitative Assessment Report</u> presents the national policy for the development of social and medical services for disabled adults between 2005 and 2007. 87.4 million Euros (of the social security medico-social Global Expenditures Plan) plus complementary funds from Departmental administrative authorities (Conseils généraux) were dedicated to the creation of 6,400 places of nursing and medical care at home for people with disabilities (SAMSAH and SSIAD) among which 1,900 SAMSAH places for persons with mental health conditions (within the Psychiatry and Mental Health Plan).







For the period 2008-2010, the creation of 6,247 places of nursing and med.care (SAMSAH and SSIAD) among which, 2,632 in SSIADs for disabled persons; 3,915 in SAMSAHs; 24,586 places SAVS (Accompaniment to social life) is planned. (*The services and their acronyms are described next* §).

The CNSA Report provides a national map of the existing departmental equipment of such services and those budgeted to be created within two years (p.4). It shows also the unequal distribution on the national territory.

N.B. No comparative data on financial investments on services vs. institutions are available.







PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

Although still in insufficient number, and unevenly distributed through the country, the development of services is significant (see Qualitative Assessment Report mentioned in above section).

Several kinds of support can be provided at home to the disabled person – child or adult- and to the family, according to the nature of the needs (types of services lists²): educational and social support; social life accompaniment; assistance for essential activities of daily life; nursing and medical care.

For child and family: several devices have been initiated to provide children with an alternative to institutionalization, to give them access to school and to maintain them in their families:

The child (up to 20) who attends a regular school is provided at home with educational and developmental support. This type of care and support is delivered by mobile multi-disciplinary teams. Such teams are specialized in one type of impairment or the other (sensory, cognitive, physical, multiple disabilities): SSESAD, for intellectual and motor impairment; SSEFIS, for hearing impairment; SAAAIS, for visual impairment; SSAD are specialized for children (and their families) with multiple disabilities who do not attend school.

The number of these services is constantly increasing, most often linked with a special institution and functioning either as a follow-up service for a child who was formerly institutionalized or as an alternative to institutionalization (A. Mainquené, Etudes et Résultats, n° 669. Nov.2008).

Services for adults: different types of services are provided to adults at home for health care and essential activities of daily living, for personal assistance, for social activities.

<u>Nursing and medical care services</u> include: Nursing care services (<u>SSIAD</u>); Medical care (<u>SAMSAH</u>); Multi-purpose help and care services (<u>SPASAD</u>).

Personal assistance services include: life assistants services for essential daily life activities (toilet, personal care, meals... (SAV); Accompaniment to social life services (SAVS).

Disability Compensation scheme including individual budget

At the person's request (or her/his legal proxy if the person is under legal protection, or the parents if it is a child) to the local office for disabled persons (MDPH, one in each of the 100 French departments), an individual compensation plan of human and technical assistance is tailored to the person's needs, assessed by the local office multidisciplinary team. The compensation plan is then submitted to the person who reviews it and can discuss it within the next 15 days. The compensation plan includes a **Disability Compensation Benefit** (Prestation de compensation / PCH), which is an individual budget intended to contribute to the person's expenses in the four following domains:

- Human assistance
- Technical aids (permanent or temporary)
- Adaptation of dwelling, vehicle and transportation additional costs
- Animal assistance

Assistants, aids, adapted products, etc. are chosen by the person.

² http://www.cnsa.fr/article.php3?id_article=199 http://www.cnsa.fr/article.php3?id_article=194





The amount of the Disability Compensation Benefit varies according to the assessment of the nature and cost of the needs for each person and according to fixed national rates for each type of assistance and support (detailed below).

Once the individual amount of the DCB is calculated it is paid in total regardless of wages, allowances or other disability benefits the person may receive, but limited to 80% if the person has financial resources other than those. The decision to grant the compensation benefit is taken by the local *Commission for disabled persons' rights and autonomy* (one commission in each of the 100 departmental offices for disabled persons), who pays for it (out of the national non-contributory fund (i.e.taxes) distributed to departments by the National fund of solidarity for autonomy/CNSA) and controls its effective use (expenses receipts to be provided by the person).

The eligibility criteria for the benefit are the following:

- Age: The Disability Compensation Benefit is paid to adults between 20 to 60. Since 2008, it is paid to children under 20 when a complement to the Disabled Child Education Allowance (Allocation d'éducation pour enfant handicapé/ AEEH) is needed.
 Over 60, adults are paid the Individualized Allowance for loss of autonomy (Allocation personnalisée d'autonomie/ APA) which amount depends on the level of needs for activities of daily living.
- <u>Nationality</u>: people with disabilities living in France, who are not French citizens, straight with the law and with a residence permit (not mandatory for EU and EFTA members) are eligible to this benefit.
- <u>Disability</u>: Unlike most other disability benefits, the allocation of the Disability Compensation Benefit is not based only on the assessment of the gravity of the impairment, but also on the actual performance of essential activities of daily life. Are eligible persons who suffer from an impairment of one or more physical, sensory, cognitive or mental function and who face total difficulty to perform one activity of daily life, or a serious difficulty to perform at least two of a list of 19 activities divided into four domains, in line with the WHO's *International Classification of Functioning, Disability and Health* (WHO, 2001): Mobility; Self-care; Communication; General tasks and demands and Interpersonal interactions and relationships.

The assessment of the global situation and needs of the person, as well as the level of difficulty to perform daily living activities (focused on the intrinsic functional level of the person regardless of the use of technical aids) is carried out by the multidisciplinary team of the local office for disabled persons (MDPH), with a multidimensional assessment guide (GEVA/Guide d'évaluation multidimensionnelle) based on the WHO's International Classification of Functioning, disability and health. This 40 p. guide is composed of 8 parts (social, economic and family situation; dwelling; educational background; professional background; health; psychological aspects; functional capacities; aids).

The Disability Compensation Benefit is intended to replace progressively the 'Compensation allowance for assistance by a third party'. For the time being disabled persons can still choose the one of these two compensation systems that suits them better. It is worth mentioning that the Compensation allowance for assistance by a 3rd party is also a form of individual budget and not submitted to control. It was granted on the basis of incapacity rating (i.e. degree of gravity of the impairment and not the functional state). The Compensation allowance for assistance by a third party amounts from 404.32 € to 808.65 €/month.

Between December 2007 and December 2008, the number of persons who have been paid on account of the Disability Compensation Benefit has doubled (28 600 in 2007; 58,200 in 2008). This increase is partly due to the number of persons who have given up the Compensation allowance for assistance by a 3rd party and chose the Compensation Benefit in 2008 instead.







The average DCB monthly amount per person was 1,010 Euros in 2008. (<u>Debout C. & Lo S-H, Etudes</u> et Résultats, n°690, Mai 2009).

Disability Compensation Benefit rates for personal assistance (2008 rates). The DCB is a national scheme and the rates apply for the whole country.

The rates depend on the type of assistant chosen by the disabled person: direct employment: €11.57 per hour; service provider: €12.73 per hour; family member: €3.36 per hour (50% of guaranteed minimum wage) or €5.03 per hour (75% of guaranteed minimum wage if the family member has to cease from professional activity).

The Disability Compensation Benefit is not an income but is intended to contribute to the expenses for human assistance for essential activities of living, defined and rated as follows:

Essential activities of living, assessed in terms of amounts of time of human assistance needed, are divided into three main groups: **self care** (washing, dressing, eating, toileting); **mobility** in the home (transferring, walking, walking up and down stairs, operating a wheel chair) up to 5 hours/day and outdoor mobility to carry out activities related to the disability and requiring the presence of the person with disability up to 30 hours/year; **participation in social life** (outdoor mobility and communication for leisure, culture, organizations, etc.) up to 30 hours/month.

Unlike the Individual allowance for loss of autonomy (APA) (for people over 60), domestic help (shopping, preparing meals, housekeeping, washing and ironing, etc.) is not covered by the Disability Compensation Benefit, but it can be provided by a local scheme of social aid (that exists in the 100 administrative departments of the country) within a limit of 30 hours/month.

The Disability Compensation Benefit rates for family members are €3.36 per hour (50% of guaranteed minimum wage) or €5.03 per hour (75 % of guaranteed minimum wage if the family member has to cease from professional activity). The financial compensation for a family member should not exceed €865.05/month (i.e. 85% of minimum guaranteed wage /SMIC) net on the basis of 35h/week (national rate for family employments). It can be raised by 20% (€1,038.06/month) if the family member does not work in order to take care of a disabled person; or if the disabled person requires total help for all essential activities of daily living (personal care, moving around, social participation) and a constant or quasi-constant presence due to a health care or help for activities of daily living.

Family carers are paid directly by the disabled member of the family who receives the Compensation Benefit. The disabled person can choose to employ someone else instead of a family member. No study is available yet on the issue of possible conflicts of interest between the disabled person and the family.

In the framework of the reform of special institutions (2002-2 Act), people with disabilities living at home can be provided short-term stays in institutions to relieve family carers temporarily.

2002-2 Act (reforming social and medico-social action) sets rules of assessment and quality that apply to institutions as well as to services at home (Art. 12, Art L311-8).

The National Agency for assessment and quality of social and medico-social institutions (<u>ANESM</u>) is responsible for: validating, developing or updating procedures, norms and recommendations of professional good practice and assessment within institutions and services; and, accrediting external bodies for the assessment of the activities and quality provided by social and medicosocial institutions and services.







Quality assessment requires an internal assessment by the service or institution (on the basis of a national referential guide), and an external one by authorized bodies, whose list is provided by ANESM.







4.1: PERSONAL ASSISTANCE SERVICES

(for independent living that are controlled and directed by disabled people themselves)

The Disability Compensation Benefit is intended for all life situations (at home, at work, in education and training). At work the number of hours of assistance for a professional activity or for an elective function cannot exceed 156 hours/year. The Dis.Comp. Benefit can be used for personal adaptive equipment.

A student in college, university or other education or training setting in France can use the DCB to pay personal assistants. The situation of disabled students has recently been revised. The DCB students are entitled to amounts to an average of 1300 Euros a month regardless of their parents' income and of other disability benefit or resources they may be entitled to.

The text of the law is not clear as whether a disabled student who wants to study abroad can still receive the DCB, but it seems that this case can be negotiated with local authorities delivering the DCB.

Support is provided by disabled people's NGOs and by private for-profit providers:

Disabled persons NGOs: This type of support is often provided by the same managerial organizations of disabled persons that run special institutions who now diversify their range of activities and expand their capacity to meet the needs of people with disabilities , such as APF (Association of French paralyzed persons), <u>ADEP</u> (Association of polios), <u>GIHP</u> (Group for the insertion of the physically impaired).

Private profit-making service providers: The development of the independent living policy in France, with the implementation of Act 2005-102 and the allocation of Disability Compensation Benefits boosts the market of services. The number of private service providers (such as <u>Edadom</u> or <u>OPHS</u> among others) is therefore increasing.

P.Roussel's study on 'compensation of activity limitations' in the population of the 1998-1999 national disability survey (HID) shows that 25% women and 17% men require human assistance (see table 3 below). The data will be updated with the 2008 national Disability-Health survey (Handicap-Santé), which data should be available by the end of 2009. 58,200 persons received DCB in 2008 but no data is available yet on the type of assistance they used it for, or on who provided personal assistance (family member or other person). The 2008 disability survey should provide updated data on this.

Nursing care services (SSIAD) are paid by Social Security

Medical care (SAMSAH) is paid by Social Security

Essential daily life activities services (SAV) paid directly by the person with the Disability Compensation Benefit

Social life assistance services (SAVS) paid by the General Council (local authority)

The system is currently in a phase of transition and adaptation. Adjustments are to be made to rationalize the different sources of funding.

This period of transition shows also evidence that adjustments need to take into account the services effectively provided, their cost that varies according to the service provider and the amounts allocated with the Disability Compensation Benefit.

The types of support and number of hours entitlement are described above. Human assistance can be paid up to 24 hours/day.







In principle, the law applies to all citizens eligible to the benefits wherever in the country and in overseas French departments provided that they reside permanently in France (or in overseas French departments). In case people have to travel or stay abroad, they are still entitled to the Disab.Compens. Benefit as long as they do not stay away from France more than 3 months a year. Should their stay abroad last longer 'for education, learning a foreign language or vocational training', the text of the law is unclear whether the DCB is still paid to them in total or not. (Schweitzer L. & De Broca A. (eds.) (2008). Code du handicap 2009 - Logement, emploi, santé, éducation, compensation, accessibilité, ressources, Paris, Dalloz, p.66-67).

The law states that 'The State warrants equal treatment for people with disabilities (...)', but *de facto* support services are unequally distributed over the country, and people may not find the same type of support wherever they go, whatever their compensation plan and benefit include. The assessment of these inequalities is in progress.

The person can choose the service providers she/he wishes, but within the limits of the amount of money allocated that is based on national rates (see rates above). The expenses can be controlled afterwards by the local office for people with disabilities (expenses receipts may be requested).

As a general rule, there is no exclusion. The Disability Compensation Benefit is provided to any citizen who is entitled to it according to the eligibility criteria described above. People under legal protection have to refer to their legal guardian. As said above, the individualized compensation (support) plan is developed with the person by the multidisciplinary team of the local office for disabled persons and the decision to allocate the Benefit is taken by the local Commission of people with disabilities' rights and autonomy.







4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

(to increase independence and accessibility in daily life)

The Disability Compensation Benefit application procedure is described above: individualized compensation plan developed with the person by the multidisciplinary team of the local office for disabled persons and decision of allocating the Benefit taken by the Commission of people with disabilities' rights and autonomy.

The rates for assistive equipment and adaptations apply to persons living at home or in institutions). A fixed list of 20 types of aids are funded by social security within limits. Should the price of a technical aid exceed the social security limit, the Disability Compensation Benefit can complete the expense up to $\in 3,960$ for a period of three years.

At home: the Disability Compensation Benefit includes funding for home adaptations. A list of the refundable assistive devices (LPPR) is available at the local offices for people with disabilities, or by the technical aids providers and on internet.

At work: technical aids and adaptations at work are provided to the person, as required from the employer who receives funding from the local offices of the Management Agency of the disabled persons' integration in employment fund (AGEFIPH) for that purpose. This public help covers 50% of technical aids and adaptations of the working station. The Disability Compensation Benefit will not pay for those but can be used for further adaptations specifically needed by the person.

In education and training, including university or college: the Compensation Benefit can fund needed assistive devices other than those provided by the school or the institution.

There are a great number of private technical aids providers that advertise their products on internet and in showrooms. There are also a number of counseling services providing help for adequate choice of technical aids and home adaptations such as: <a href="https://example.com/hac-number-numbe

Counseling centers (free or with charge) can provide advice for the two phases of home adaptations (assessment and production) Such as <u>FENCICAT</u> that provides free individualised advice for funding, for choice of product, sometimes with an occupational therapist, displays products in showrooms and data bases; <u>PACTARIM</u>, <u>ALGI</u> (Association for homes accessible and adapted to all). For production, a national network of craftsmen and small building enterprises (<u>CAPEB</u>), advertise campaigns to raise awareness of the growing market of technical aids and home adaptations for aging and dependent persons.

Official lists of refundable products and provisions are available from <u>LPPR</u> and <u>LPP</u>. The National Fund for Solidarity and Autonomy (CNSA) provides a website dedicated to <u>technical</u> aids. Technical aids market and costs watch.

The study carried out by P.Roussel on the <u>compensation of activity limitations</u>, in the population (all ages) of the 1998-1999 national disability survey, shows that 25 % women and 22% men use a technical aid and that 5.5% women and 3.4% men use home adaptation (Table 2). The estimates of the use of a technical aid by the population in institutions are over 66%, (a figure to consider with caution though due to the small number of respondents) (Table 3).







Table 2. Proportions of users of assistive devices or home adaptations among disabled persons living at home, by sex and age

	Use of home adaptation		Use of a technical aid (including prosthesese)		Use of human aid	
	Men	Women	Men	Women	Men	Women
0-19 years	0,6%	0,2%	6,0%	3,2%	7,9%	12,2%
20-39 years	0,7%	1,2%	8,7%	11,5%	9,5%	6,2%
40-59 years	2,2%	3,2%	26,4%	17,4%	13,0%	17,1%
60-79 years	6,6%	8,7%	30,5%	35,1%	24,2%	32,7%
80 years and over	11,7%	17,5%	60,6%	71,1%	56,2%	76,1%
Total	3.4%	5.5%	21.7%	24.9%	16.8%	25.0%

Source: INSEE-HID 99 – Traitement CTNERHI 2002

Tableau 3. Use of technical aids in institution by type of impairment

	Effectifs	Proportion
Motor impairment	30 600	75,1%
Visual impairment	3 400	57,5%
Hearing impairment	8 000	65,5%
Speech impairment	1 000	36,6%
Visceral impairment	11 000	61,7%
Intellectual impairment	13 000	11,1%
More than 1 physical impairment	135 000	89,9%
Physical and intellectual impairments	224 000	77,9%
Other impairments	4 000	25,1%
Total	429 300	66.4%

Source: INSEE-HID 98 – Traitement CTNERHI 2002

Funding for this kind of support comes from a variety of sources:

National fund of solidarity for autonomy (CNSA)

Local administrative authority (Conseil général)

Social security (CPAM)

Mutual funds of agriculture (MSA)

Other mutual funds

Municipalities

Family Insurance Fund (CAF)

Management agency for employment integration of people with disabilities (AGEFIPH)







The Compensation Benefit rates for personal assistance and support services are described above in the relevant sections.

Rate for other technical aids: maximum €3,960 for a three year period

Adaptation of home: maximum €10,000 for a 10 year period Adapted vehicle: maximum €5,000 for a 5 year period Additional transportation costs: between €5,000 and 12,000for a five year period Animal assistance: €3,000 for five years (50 €/month)

All French departments have a compensation fund, which is an assistance fund available for expenses not covered by legal aids.

The geographical scope is the same as concerning personal assistance: the benefit is granted to any citizen entitled to it, wherever the person lives or moves to in France and in overseas departments. But the availability of services is unequally distributed over the country and the person may not find the device (or find better device) she/he needs.

The person can choose the assistive equipment and home adaptation she/he wishes within the limits of the amount of money she/he is granted according to the rates related to the Compensation Benefit. The benefit can be granted on estimates of the expenses but receipts are required.

Same answer as for personal assistance. As a general rule, there is no exclusion on grounds of legal capacity. The Disability Compensation Benefit is provided to any citizen who is entitled to it according to the eligibility criteria described above. However, people under legal protection have to refer to their legal guardian.







PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE

Among DPOs, the National Advisory Council of people with disabilities is unquestionably the main partner of the government for disability policy design and planning, as official legal body. They were largely involved in the development of the current policy and the accessibility and compensation scheme promoting independent living. Somewhat paradoxically the most influential DPOs in the Council are the 'managerial' ones (although not-for-profit), those who run the institutional equipment (as mentioned above in Part 2).

Most DPOs are impairment-centered and as such have all developed an internal solidarity among their members and with non-members with the same impairment. They all provide counseling and information, more or less formalized depending on their importance and resources (permanent offices, websites, local delegations, group support, etc.).

The main national organizations that have created the national equipment of special institutions, today expand their activity in the field of services (APF, ADEP, AFM, ...).

<u>GIHP</u> since its creation in the 1950s has claimed the right to independent living and has long set up services for that purpose (adapted transportation and apartments).

Advocacy created in the late 1980s, by users and ex-users of psychiatric services and volunteers, has initiated an original form of practice centered on the development of « citizen spaces » providing peer-support, peer-counseling and a mediation scheme when problems occur with social or medical surroundings (family, neighbours, doctors, apartment owners, ...). (Dutoit M. L'advocacy en France. Un mode de participation active des usagers en santé mentale, 2008).

In Advocacy's image, the CNSA (National solidarity fund for autonomy) promotes and funds 'groups for mutual help' (GEM) peer-support groups of persons with mental health conditions, since 2007.

Among good practice, initiatives of independent living mutual/cooperative forms of dwellings are flourishing here and there, reported in Roussel P. & Sanchez J. (2008). <u>Habitat regroupé et situations de handicap.</u>

The *Independent Living Movement*, its history, claims, modes of functioning and group practices are still hardly known in France among people with disabilities, except for a few like GIHP (see above) who became the French representative of DPI, or for some individuals like <u>Mireille Maller</u> and her brother Gerard, who leant on I. L. plea and experience to fight against the institutional system and to create *Hand in Cap/ Mouvement pour une vie indépendante*, in Montpellier.







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