

Report on the social inclusion and social protection of disabled people in European countries

Country: France

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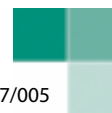
Background:

The [Academic Network of European Disability experts](#) (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network will support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.

This country report has been prepared as input for the *Thematic report on the implementation of EU Social Inclusion and Social Protection Strategies in European countries with reference to equality for disabled people*.

The purpose of the report ([Terms of Reference](#)) is to review national implementation of the open method of coordination in Social inclusion and social protection, and in particular the National Strategic Reports of member states from a disability equality perspective, and to provide the Commission with useful evidence in supporting disability policy mainstreaming.

The first version of the report was published in 2008. This is the second version of the report updated with information available up to November 2009.



Summary of changes since 2008

Housing and homelessness:

The French response to the question of the EU questionnaire on homelessness and housing exclusion that mentions disability states that our public policy aiming at homeless persons is basically universalist and egalitarian, meaning that there is no priority for any specific group. However there is a housing provision ([maisons relais](#) / social residence) for persons who cannot afford or access an ordinary home for social reasons or because of a mental health condition.

There is no data on homeless disabled persons since they are not distinguished from homeless persons.

New strategies and actions for the inclusion of disabled people:

There have been no new strategies and actions for the inclusion of disabled people, since the 2005-102 Act based on global accessibility and compensation, described in our 2009 Independent Living report. 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.

New changes in incomes, benefits and pensions:

Other than the reform of the allowance for disabled adults (AAH), there have been no changes on the issue of income, benefits and pensions since our 2008 social inclusion, social protection report. Relevant developments are listed below.

- Première conférence nationale du handicap- June 10, 2008 (First national conference on disability) <http://www.gouvernement.fr/gouvernement/la-conference-nationale-du-handicap-du-10-juin-2008>
Among other topics, the President presented the reform of the Allowance for disabled adults. This reform is described in our 2009 Employment update report since its main aim is to optimise access, maintenance or return to work.
- Rapport du gouvernement au parlement relatif au bilan et aux orientations de la politique du handicap (Government report to parliament on the outcome and orientations of disability policy)
- This government report concerns the implementation of disability policy framed by the 2005-102 Act, with specific reference to the income and benefits policy that raised critical reactions from disabled persons' organisations.
 - In particular the chapter entitled: «The government wishes to continue the development of the implementation of the right to compensation (Le gouvernement souhaite poursuivre le développement de la mise en œuvre du droit à la compensation)» (p.34)
 - And chapter: « National solidarity guarantees minimum resources for disabled persons (La solidarité nationale garantit des ressources minimum pour les personnes handicapées)» (pp.105-111).
- National advisory council of disabled persons. January 27, 2009 Comments of the commission « Compensation and living resources » on the Government report to the parliament on the outcome and orientations of disability policy. (Conseil national consultatif des personnes handicapées.
Note thématique du 27 janvier 2009 de la commission « compensation et moyens d'existence » sur le rapport du Gouvernement au parlement relatif au bilan et aux orientations de la politique du handicap) <http://www.cnpsaa.fr/spip.php?article31>.
Critical comments on the shortcomings of the implementation of the 2005-102 Act concerning the chapter on compensation.

- Pour la garantie d'un revenu d'existence pour les personnes en situation de handicap (avril 2007) (For a guaranteed living income for disabled persons) <http://www.apf.asso.fr/documents/actualites/CNCPHcommission3Rapportressources.pdf>
Disabled persons organisations' plea for a raise of the disability allowance (AAH) to the level of the guaranteed minimum wage (living income).
- Loi handicap: pour suivre la réforme (Disability law: monitoring the reform). 2007 Senate Report <http://extranet.senat.fr/rap/r06-359/r06-359.html>

With regard to the issue of living incomes (<http://extranet.senat.fr/rap/r06-359/r06-35913.html>) it was expected that the creation of the Disability Compensation Benefit (DCB) (Act 2005-102) would alleviate extra costs due to a disability. If this is shown to be true for severely disabled persons, it is not, or less important for persons who need less help and who manage with the assistance of their families and rely on the Allowance for compensation by a third party (ACTP/ a form of individual budget) that is not submitted to control and most often used for different kinds of daily expenses other than paying the family member. The possibility of choice that disabled persons still have between the ACTP and the DCB is meant to disappear in the years to come, in favor of the DCB only. It is against this forthcoming reduction of choice that the issue of raising the allocation of disabled adults (AAH) up to the SMIC level has been raised by organizations of disabled persons. At the national conference on disability (June 2008), the government announced that the AAH would be raised by 25% progressively between now and 2012, which is still lower than the SMIC and calculated independently from the possible raise of the SMIC during these years. One of government's concerns is to discourage disabled persons from relying on an allowance that would be the equivalent of a salary, rather than seeking work or returning to work.

Other sources of information related to the monitoring of poverty policy

- [ONPES](#) (Office national de la pauvreté et de l'exclusion sociale / National observatory on poverty and social exclusion)
 - Instrument panel for monitoring the aim of lowering poverty by one third in five years (Tableau de bord pour le suivi de l'objectif de baisse d'un tiers de la pauvreté sur cinq ans), April 2009, ONPES.
(http://www.onpes.gouv.fr/IMG/pdf/Tableau_de_bord_suivi_pauvrete_complet_220409-2.pdf)
The monitoring instrument comprises 11 objectives and 18 main indicators. Disabled persons are principally included in objective 1: To fight against monetary poverty and inequalities. Indicator: poverty rate at threshold of 60% of median wage (E U indicator).

This objective is aimed principally at persons benefitting from social minima allowances. The allowance for disabled adults (AAH) is one of five social minima.

- Report of the National Observatory on Poverty and Social Exclusion-2007-2008 (available in English) http://www.onpes.gouv.fr/IMG/pdf/rapport_en_anglais.pdf
p.31-70: Stability of monetary poverty and corrosion of the relative financial situation of the poorest.

"Constant progression in the number of recipients of the allowance for disabled adults

The progression of the number of AHH recipients is constant and regular, at about 3% a year: between 1999 and 2006, their number rose from 693,000 to 804,000 in all of France. This evolution is not particularly reactive to fluctuations of the economic context. It is the result of both the growth of entries into the scheme and the low rates of departure from it, mainly due to the particular difficulties of professional reintegration of this type of public.⁶⁷

On 21 December 2006, seven out of ten AAH beneficiaries had a disability rate greater than or equal to 80%. Six out of ten have no other income than social benefits.

About half of new AAH recipients were previously recipients of another social minimum allowance, the RMI in particular. For example, out of 5% of those entering the AAH scheme in 2004, nearly 2% benefitted from the API the previous year, and nearly 47% were RMI beneficiaries.⁶⁸ For a large part of them, this previous situation was transitional to when the validation of their disability by the COTOREP became effective and they were able to become AAH recipients. Another explanation has to do with increased sensitivity to certain pathologies amongst social-minima beneficiaries, given their difficult living conditions. Finally, what also needs to be taken into account is disabled children benefitting from the special-education allowance switching at age 20 to the AAH scheme.” (p.72)

- *France, portrait social-Edition 2007, Indicateurs d'inégalités sociales*
http://www.insee.fr/fr/ffc/docs_ffc/ref/fporsoc07d.pdf

New changes in long-term care and support:

The policy concerning this issue is framed by the 2002-2 and 2005-102 Acts, as described in our Independent Living report. The implementation of these two acts is in progress. It implies a significant diversification of long-term care and support modalities (residential or assistance services at home). At the national conference on disability (June 2008) the government confirmed the creation of 50 000 new places in institutions or in community and home services planned until 2012.

Implications of the economic crisis:

To date, no data are available to assess the implications of the economic crisis. There should be data in one or two years on homelessness, but probably not on homeless disabled persons since they are not identified specifically among the homeless population.

Introduction. General Information.

Significant facts in 2008-2009.

First, we would like to point out some general information:

In January 2009, the government provided a “Report to the parliament on the outcome and orientations of disability policy”.

(<http://www.ladocumentationfrancaise.fr/rapports-publics/094000070/index.shtml>).

This report has been at the centre of a debate, first within the National Advisory Council of Disabled Persons (CNCPPH), then at the parliament. Parliament debates can be found at:

<http://www.assemblee-nationale.fr/13/cri/2008-2009/20090256.asp>

In this report, the government underlines:

- An increase of financial effort of the State for disability.
According to the report, GDP costs dedicated by the nation to disability increased from 1.75% in 2000 to 1.91% in 2006 (5.2% growth per year)
- An increase in the number of persons receiving the Disability Compensation Benefit (DCB).
In 2008 the number of DCB beneficiaries was six times higher than in 2006 (8900 persons in December 2006 vs. 58 000 in June 2008). The average monthly amount received was 1000 Euros, which is twice as much as the amount that disabled persons could expect before the creation of the DCB.
- An increase in the number of disabled children in mainstream education.
Currently 17 000 children attend regular schools.
- An increase in the Allowance for disabled adults (AAH).
By 2012 the AAH will be increased by 25% and the calculation rules for drawing concurrently the AAH and a salary for disabled persons who work have been improved.



All these issues have been discussed with the parties concerned.

In March 2009, the National Observatory on training, research and innovation in relation to disability (Observatoire National sur la Formation, la Recherche et l'Innovation sur le Handicap, ONFRIH) provided its first report on its three domains: 1/research and innovation, 2/ training, 3/ prevention.

http://www.travail-solidarite.gouv.fr/IMG/pdf/Rapport_ONFRIH_2008.pdf

The Observatory reports current progress in the development of disability studies in France. Some national institutions such as the CNSA (National Solidarity Fund for Autonomy), DREES (Direction of Research, Studies, Evaluation and Statistics) or IRESP (Research Institute of Public Health) support disability studies through grants for studies specifically dedicated to disability. However the ONFRIH also reports that disability is not one of national research priorities, and that research on disability remains dispersed and isolated. Researchers often work alone in research centres that are not focused on disability and there are often few links between them.

Since September 2009, French governance of disability policy has been undergoing in depth modifications. Following pressure from the National Advisory Council of Disabled Persons (Conseil national consultatif des personnes handicapées / CNCPH), a cross-ministry committee on disability was created. This Committee, which replaces a former cross-ministry delegation has been placed under the authority of the Prime Minister and is responsible for defining, coordinating and assessing disability policies. This Committee intends to strengthen the consistency of cross-ministerial and intersectional disability policy. For this purpose it will include all ministers in charge of a section of disability policy and the needs of disabled persons; therefore potentially all ministers.



PART ONE: SOCIAL INCLUSION PLANS (GENERAL)

See the report on the national strategies plan sent in autumn 2009.

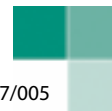
1.1 Please describe how and where disabled people are included in your country's published plans for social inclusion and protection?

1.2 In reality, what major actions has your country taken and what are the positive or negative effects on disabled people? (policy or practical examples)

1.3 What is the most recent research about disabled people's equality and social inclusion in your country?

General source of reference (in English)

http://www.adecri.org/images/stories/the_french_social_protection_system.pdf



PART TWO: INCOMES, PENSIONS AND BENEFITS

2.1 Research publications (key points)

In France, scientific research on the level of poverty and income or pensions/benefits of disabled people is quite scarce. Therefore it is difficult to gather precise information on the level of income of disabled people. The main difficulty is the diversity of situations among disabled people. Depending on the cause of disability and whether they have worked or not, disabled people are entitled to different benefits / income / pensions. In terms of basic benefits, other financial aids are added depending on incapacity level, the family situation and so on. Finally, calculation of the amount of the benefit often depends on the income of other persons living with the disabled person. The relationship between disability and poverty in France is therefore difficult to grasp.

However, following the implementation of the new disability frame law (Act 2005-102), an extensive debate has taken place between the government and organisations of disabled persons, about the issue of income. The key points of this debate are as follows:

- The 2005 law in itself is considered to have avoided the issue of income.
- The CNCPH (Comité National Consultatif des Personnes handicapées – National advisory committee of disabled persons) decided to work on this issue in 2006 and produced a report in April 2007.
<http://www.apf.asso.fr/documents/actualites/CNCPHcommission3Rapportressources.pdf>

This report highlights that disabled people willing to work have difficulties accessing training and employment. It emphasises the low level of income of all disabled people and the necessity of distinguishing income and financial aids provided to compensate additional costs of disability. It also raises the question of discrimination between the different pensions or benefits. Finally the report puts forward some recommendations to provide decent incomes to disabled persons:

- Observing different levels of resources, it recommends creating a unique life income equal to the guaranteed minimum wage.
- Observing that the amount paid to the disabled person living in an institution is too low, an increase of 30% of the guaranteed minimum wage is recommended.
- Observing that disabled people who work have sometimes a lower income than when they do not work, it recommends a better system where wages and pensions/benefits are drawn concurrently.

In March 2008 93 organisations of disabled persons and patients, who argued that their incomes were under the poverty level, formed a collective movement (entitled “Ni pauvres, ni soumis” / neither poor nor submissive) to put their claim forward.

(Web site: http://www.nipauvrenisoumis.org/a_pacte_inter_associatif/).

At the end of 2008, the debate was focused on the issue of the relationship between work and disability. The government decided to transform the system of benefit allocation, mainly the Allowance for disabled adults (Allocation Adulte Handicapé – AAH). Currently, the eligibility criteria are mainly based on incapacity level (see below); in the future the government intends to define eligibility criteria on the basis of “employability” and “non-employability”. See for example, the President’s speech at the National Conference on disability, June 2008:

http://www.elysee.fr/documents/index.php?mode=cview&press_id=1486&cat_id=7&lang=fr

In 2009, the government continued to increase the AAH (Allowance for disabled adults). Since September 2009, it has been raised by 2.2% (which brings the monthly amount to 681.63 Euros) and overall by 10% since 2007, (i.e. over 60 Euros per month).

By 2012, the AAH should be increased by 25%.

Additionally, the condition for allocation of the AAH introduced by Act 2005-102, according to which the disabled person must have been unemployed for at least one year (for persons with an incapacity rate below 80%) has been removed. The government also continued exploring the notion of employability and the specifications of an instrument to assess the overall capacity of persons claiming the AAH and their possibility of accessing employment, taking into consideration their capacity and their environment.

Regarding the issue of resources, the Commission 3 of the CNCPH (National advisory committee of disabled persons) in charge of employment issues, made several criticisms of the Government's report on disability policy (mentioned above), for example:

- The commission considered that the Government did not tackle all aspects of the resource issue. Namely that it did not examine the issue of invalidity and industrial injury pensions, or the problem of the resources of persons working in sheltered settings. The commission considers that the question of the harmonization of resources for all disabled persons, whatever the social protection scheme, still remains to be dealt with.
- The 2010 national budget plan (Loi de finances 2009) states that there is systematic examination of the capacity to work of every new Disabled adult allowance (AAH) claimant and of those requesting a renewal of the allowance. Commission 3 of the National Advisory Council of Disabled Persons (CNCPH) disputes whether this examination is systematic.
- While the government affirms clearly its will to implement measures intended to encourage disabled persons to work and to facilitate their professional integration, a number of measures do not support this, such as the reduction to 6 months from 13 or 24 months the concurrent drawing of a salary and the AAH.
- Commission 3 also discusses the impact of other measures, such as that concerning standard deduction: after concurrently drawing AAH and salary, for 6 months, the person may keep a partial AAH, because of a standard deduction of 80% below 0.4 of minimum wage (SMIC) and of 40% above.

Apart from the above general information mentioned above, some data concerning particular categories of disabled persons are available. For example, studies have been carried out on populations receiving social benefit from the non-contributory scheme (social minima), among which are beneficiaries of the Allowance for disabled adults.

Below are some references and a summary of Senator Valérie Létard's report on social minima. We wish to insist here that there is a lack of scientific research on disability, income and poverty.

- (2004) « La situation des personnes handicapées. Un enjeu de société », ADSP – Actualité et dossier en santé publique, n°49
<http://www.hcsp.fr/explore.cgi/adsp?ae=adsp&clef=91&menu=111282>
- « Minima sociaux : mieux concilier équité et reprise d'activité », (2005), Rapport d'information n° 334 (2004-2005) de Mme Valérie LÉTARD, fait au nom de la commission des affaires sociales, déposé le 11 mai 2005 devant le Sénat.
<http://www.senat.fr/rap/r04-334/r04-3341.pdf>

Summary: An information report dedicated to social minima, by Senator Valérie Létard on behalf of the Senate Commission of social affairs was presented May 18, 2005.

This report entitled “Social minima : reconciling equity with return to work” underlines the great complexity of the current scheme, the diversity of eligibility criteria to one of the 9 social minima (Minimum insertion income (RMI), Insertion allowance (Allocation d’insertion), Solidarity specific allowance (Allocation spécifique solidarité), Lone parent allowance (Allocation parent isolé), Disabled Adult Allowance (AAH), Invalidity additional allowance (Allocation supplémentaire d’invalidité), Old age additional allowance (Allocation supplémentaire vieillesse), Allowance equivalent pension (Allocation équivalent retraite), Widowhood allowance (Allocation veuvage), as well as the opaqueness of their calculation rules.

The report suggests thorough tidying up of the scheme to harmonise the various eligibility criteria, to erase threshold effects likely to provoke a severe loss of resources when returning to work (such as the loss of related advantages: housing aid, medical coverage, local aids,...) and to implement measures assisting return to work.

The report suggests setting up a working group on these topics to improve knowledge of them and to develop a proposal for legislation.

(Source:<http://www.vie-publique.fr/actualite/alaune/minima-sociaux-propositions-du-senat.html>)

- (2008), Le Rapport de l’Observatoire National de la Pauvreté et de l’Exclusion sociale, 2007-2008, La Documentation Française.
<http://lesrapports.ladocumentationfrancaise.fr/BRP/084000261/0000.pdf>
- Conseil supérieur de l’emploi, des revenus et des coûts (1997), « Minima sociaux : entre protection et insertion », La documentation française, Paris, 221 pages. (Social minima: between protection and integration)
<http://www.ladocumentationfrancaise.fr/rapports-publics/024000309/index.shtml>

Summary: In 1995, over 3.3 million people benefited from the different social minima and the total amount of allowances was over 80 billion francs. This report draws on the work of relevant government bodies, institutions (INSEE, Ministry of Labor and Solidarity, CNAF, UNEDIC) and research teams. The document presents the characteristics of the various minima, their beneficiaries and their resources. Through comparison with examples from other countries, the report highlights the specificities of the French system. But above all, it analyses the complexity of the mechanisms, it points out the inconsistencies between these different minima and other social policies and examines their relationship with employment and unemployment.

- Belleville Anne (2004), Insertion sociale et conditions de vie des bénéficiaires de minima sociaux, DREES, Etudes et Résultats, n°300. (Social integration and living conditions of social minima beneficiaries)
<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er300.pdf>

At the end of 2001, over 6% of the metropolitan population received 1 of the 4 following social minima: Minimum insertion income (RMI), Lone parent allowance (API), Disabled adult allowance (AAH), Solidarity specific allowance (ASS). To get a better knowledge of the living conditions of their beneficiaries and of their perception of their situation, a survey was carried out beginning of 2003 among 5000 beneficiaries of RMI, ASS, AAH or API. Comparison of the situations of the various categories of beneficiaries shows significant differences. First of all beneficiaries of AAH have more often specific characteristics: often unemployed with serious health conditions, they differ from the other categories of beneficiaries who all seek, more or less quickly, to return to the labor market.

Thus, half of the beneficiaries of ASS, API and RMI were looking for a job at the time of the survey, and around fourth quarter were employed. Among the surveyed beneficiaries (not including AAH), over 80% had their own dwelling, predominantly in social housing. Their homes are generally equipped with basic sanitary appliances.

It was rather their small size and timeworn accommodation that they complained about. The level of dissatisfaction depended on the type of social minimum. The API beneficiaries are the most dissatisfied.

All studies examining social conditions in regard to health status show that social minima beneficiaries' health state is far worse than that of the general population, at comparable ages and gender. Apart from the beneficiaries of AAH, the beneficiaries of RMI were more likely to have at least one disease and to report poor health. Even if they were often in touch with friends or family, many social minima beneficiaries felt isolated and excluded: almost 1 RMI beneficiary in 4 reported this compared with 1 in 7 beneficiaries of the 3 other social minima.

- BROUARD Cécile, DUTHEIL Nathalie, GILBERT Pascale, MICHAUDONA Hélène, VANOVERMEIR Solveig, TISSERAND Pierrette, VASLIN Catherine, MAUDINET Marc, PIQUET Annick, SANCHEZ Jesus (2004), « Le handicap en chiffres », Mire, Dress, CTNERHI.
<http://www.sante.gouv.fr/drees/handicap/handicap.pdf>
- CHANUT Jean-Marie, MICHAUDON Hélène (2004), L'AAH, un minimum social destiné aux adultes handicapés, Etudes et Résultats n° 344. DREES.
<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er344.pdf>

The Allowance for disabled adult (AAH) is a social minimum intended for adults 20 years old and over. Until 2005 the allowance was allocated by the departmental commissions of orientation and vocational rehabilitation (Cotorep) on the basis of medical criteria (incapacity rate) and the capacity to work. In December 2003, 770 000 persons benefitted from the AAH, corresponding to an average annual increase of 2.8% since 1988. More men than women benefit from the AAH, but the average age of women is higher.

Three quarters of the beneficiaries live by themselves, without children and are often unqualified. A third of them live with their family or friends. Mental health conditions and intellectual disabilities are an important cause of AAH allocation and are significantly more frequent among these beneficiaries than among those with a disability acknowledged by Social Security as having a disease or an injury. The growth in the number of AAH beneficiaries between 1988 and 2003 is mainly due to the acknowledgement of an incapacity rate of between 50% and 79% by the departmental commissions of orientation and vocational rehabilitation (Cotorep). These rates went up by an average of 5.4% between 1995 and 2003 and are expected to keep rising if the legislation remains unchanged.

The number of AAH beneficiaries per 1000 inhabitants varies a lot from one department to the other. The differences appear to be due to geographical differences regarding the prevalence of disability, the economic situation of departments and the level of unemployment. The role of the unemployment rate is particularly significant for incapacity rates between 50% and 79%, and an acknowledged incapacity to find a job.

- Demoly Elvire (2008), Les demandeurs de l'AAH. Une population souvent éloignée du marché du travail, Etudes et Résultats n° 640. (AAH claimants. A population excluded from competitive employment)
<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er640.pdf>

The AAH (Allowance for disabled adult) is a social minimum intended to provide financial aid to disabled persons with low resources. Between July 2005 and June 2006, 330 000 persons received response to their AAH claim in metropolitan France and 7 out of 10 obtained it. AAH claimants are aged 45 on average and the main disability for a majority of them is motor or intellectual. Over a fourth of them have been disabled since childhood, and most often due to intellectual disabilities.

Only one AAH claimant out of 10 works in the competitive market, generally as a worker or employee. Where disability occurred in childhood, persons are more likely to work in specialised institutions (sheltered work / ESAT) than in mainstream work and their education has often been disrupted. AAH claimants have very seldom had a continuous professional activity. Half of those who do not work any longer have lost their job for health conditions. $\frac{3}{4}$ of AAH claimants are outside competitive employment.

- DUTREIL (Christian), TROUVE (Claire), (1996), « Rapport concernant les aides financières spécifiques versées aux personnes handicapées et leurs effets sur l'insertion en milieu ordinaire de travail » (Report about specific financial aids to disabled persons and their effects on integration in competitive employment), Inspection générale des affaires sociales, IGAS, Paris, FRA.

The main aim of this report is to analyze all the aids allocated to disabled persons likely to work in competitive employment and to determine whether these devices have an impact, and to what extent, on finding a job or returning to work. The first task was to establish a catalogue of the financial aids (which are numerous, based on different logics and various calculation modes, concurrent schemes and ceilings). The authors then analyzed the most frequent situations and attempted to draw general trends, recognising that the finance is not the only element that the disabled person takes into consideration when deciding to work or not.

Source : http://www.ctnerhi.com/fr/ctnerhi/pagint/centre_doc/base_donnees/saphir.htm

- GUEDJ (Nicole), CRENEAU-JABAUD (Béatrice), (2006), "Ressources et handicap : guide des droits des personnes handicapées" (Financial resources and disability : guidebook on the rights of people with disabilities), Paris, Editions Claude Fitoussi, 370 pages.

Summary: This book deals with the rights of disabled persons regarding resources, property, and legal status in relation with national solidarity ; with family solidarity in addition to national solidarity in terms of tax reductions, matrimonial regime, properties, life insurance, securing resources, ...; with litigations regarding acknowledgment of disability, social aid, insurance, harm compensation, right to dignity and autonomy... The book gives information on aids that are available from the State, and new devices included in the 2005-102 Act. Available at: éditions Claude Fitoussi, 74 Boulevard de Reuilly 75012 Paris, Tél : 01 43 07 57 79, Fax : 01 43 42 17 09).

Source : http://www.ctnerhi.com/fr/ctnerhi/pagint/centre_doc/base_donnees/saphir.htm

- IGF (Inspection Générale des Finances), IGAS (Inspection Générale des Affaires Sociales) CLAVREUL (Gilles), BASTERI (Anne-Michelle), AUVIGNE (François), PICARD (Sylvain), MAIGNE (Gautier) (2006), « Rapport - sur l'allocation aux adultes handicapés : mission d'audit de modernisation ». (Report on disabled adult allowance), Paris, IGF – IGAS. Téléchargeable à l'adresse : <http://www.bdsp.ehesp.fr/Base/Scripts/ShowA.bs?bqRef=341048>

This document was written after the issuing of the 2005-102 Act, i.e. the frame law of the new disability policy.

Summary: The aim of the mission was to assess the state of management of the AAH by the Departmental commissions of orientation and professional reinsertion (COTOREP), to establish a diagnosis and recommendations for the management of the allowance within the new institutional scheme.

The findings are a matter of concern: low quality of service, due to the time limits and a lack of rigor in analyzing and dealing with cases (infrequent multidisciplinary consultations, medical consultations, etc.), leading to numerous errors of judgment, inadequate management leading to heterogeneous procedures and an absence of consistent strategy on vocational integration of beneficiaries.

The new management scheme should improve the quality of service but brings risks such as porosity of the RMI-AAH devices, growth of disparities between departments, discrepancy between allocation of the allowance and vocational integration policies.

Recommendations: The State should define a strategy for the AAH by improving procedures (setting objectives for service quality in the conventions between CNSA (National Solidarity Fund for Autonomy) and MDPH (Local/departmental office for disabled persons), and equipment) and by defining a professional integration approach for all beneficiaries of the AAH according to their employability. This requires strengthening of management aims including definition of the role of each actor in the process (project management by DGAS (Ministerial direction of social action), involvement of DGEFP (Ministerial direction of employment and vocational training), creation of a strategic committee, project management by CNSA (National Solidarity fund for autonomy) included in the COG (Convention of objectives and management with the State). This should be backed up by a more efficient information system, including medical aspects and a casting vote should be given to the State representatives within the CDAPH (commissions for the rights and autonomy of disabled persons) concerning decisions related to AAH. The improvements should reduce departmental (local) disparities, ensure better knowledge of the people concerned and their professional life stories, and strengthen professional insertion and transitions from AAH to employment.

- Muriel Nicolas, Marie-José Robert, (2007-2008), Les bénéficiaires de l'allocation aux adultes handicapés, in « Les Travaux de l'Observatoire », cahier 2, pp 145-157.
http://www.travail-solidarite.gouv.fr/IMG/pdf/Nicolas_2.pdf
- Roussel, P., Velche, D. (1997). « Caractéristiques des titulaires d'allocation aux adultes handicapés au titre de l'article 35-2 de la loi de 1975 : étude de 716 questionnaires ». CTNERHI, décembre 1997, 165 p.
- Roussel, P., Velche, D. (2000). « Une population hétérogène : les bénéficiaires de l'AAH ayant un taux d'incapacité inférieur à 80% ». *Handicap – Revue de sciences humaines et sociales*, 87, 35-53.
- VELCHE (Dominique) (2000), « L'emploi des personnes handicapées : accompagner la transition vers un nouveau modèle ? » (Employment of persons with disabilities: accompanying the transition toward a new model?), *Handicap, revue de sciences humaines et sociales*, 88, pp. 43-69.

Summary: Economic changes and the evolution of the representation of disability challenge the current compensation mechanisms. These are limited and counterproductive regarding professional integration. Disabled persons' protection schemes conflict with the non-discrimination principle. These schemes appear economically and socially counterproductive.

One must recall that the system criticised was originally meant to be a response to the social disadvantages experienced because of disabilities or exclusionary attitudes. The principle of equal opportunities bears in itself the risk of increasing inequalities, but that of equalisation of opportunities brings in interesting perspectives. However there is a risk that integration of the most « employable » persons pushes the others back toward the field of dependency.

Source : http://www.ctnerhi.com/fr/ctnerhi/pagint/centre_doc/base_donnees/saphir.htm

- Velche, D (2004), Emploi et/ou allocations : les tendances actuelles dans l'Union européenne, ADSP – Actualité et dossier en santé publique, n°49, pp55-57.
<http://www.hcsp.fr/hcspi/docspdf/adsp/adsp-49/ad495557.pdf>

2.2 Type and level of benefits (key points and examples)

The pension and benefit for disabled people.

In France, there are different pensions and benefits for disabled people depending mostly on the origin of the disability (its cause and context of onset). Depending on the cause, the person will get either a benefit from Social Security (logic of insurance) or a benefit from national solidarity (non contributory scheme).

The main difference is that benefitting from Social Security implies that the person has worked and contributed to social security. If the person has not worked and so has not contributed to Social Insurance, he/she will benefit from National Solidarity.

1. Benefits from Social Insurance. Contributory scheme.

1.1. Military invalidity benefit:

This is financed by the State. It is paid to people having become disabled during war or military service. The amount of the pension depends on the incapacity level and the salary grading of military and civil employees of the State.

<http://www.droit.org/code/index-CPENSIML.html>

http://www.defense.gouv.fr/sga/votre_espace/monde_combattant/pensions_et_retraites/pension_militaire_d_invalidite/pensions_militaires_d_invalidite

1.2. Industrial injuries and occupational diseases benefit (rente d'accident du travail)

People disabled following an injury that occurred as a result of or in connection with work or who suffer from an occupational disease (listed in Book IV of Social Security Code (Code de la sécurité sociale)) might get a work injury pension from Social Insurance. This is a compulsory insurance scheme financed by contributions from employers with benefits in kind and earnings-related cash benefits (indemnities or pensions).

(http://ec.europa.eu/employment_social/missoc/2007/tables_part_3_en.pdf, page 72)

The amount of benefit is calculated in relation to the annual basic earnings of the person and to their incapacity level. This incapacity level is defined after a medical assessment by the state health insurance office.

It also depends on the duration of sick leave.

In 2005, 950 000 persons received an industrial injury or occupational disease benefit.

(<http://www.risquesprofessionnels.ameli.fr/media/chiffres-cles-2005.pdf>)

For more information:

http://www.risquesprofessionnels.ameli.fr/fr/accueil_home/accueil_accueil_home_1.php

<http://vosdroits.service-public.fr/F2928.xhtml>

1.3. Invalidation benefit

Invalidation benefit is paid by Social Security. It is allocated to workers under 60, who as a result of a disease or an impairment, can no longer (in any occupation whatsoever) earn more than one third of the normal earnings of a worker in the same category with the same training and in the same region.

At the age of 60, this payment is replaced by an old-age pension.

The amount of benefit is calculated in relation to the average annual salary during the 10 best insurance years (or, when applicable for a shorter period) and the incapacity level.

The contributor must be economically active at the time of the disease. There are three categories of benefit:

- Group 1 (medically still able to work): 30% of the average annual earnings for the best 10 years of insurance prior to interruption of work (or, when applicable, a shorter period).
- Group 2 (medically unable to work): 50% of the average annual earnings for the best 10 years of insurance prior to interruption of work (or, when applicable, a shorter period).
- Group 3 (those requiring help from another person): Group 2 pension + 40% supplement.

Conditionally, the invalidity benefit might be put together with the AAH ("Allowance for disabled adults") (non-contributory scheme)

In 2007, 585 000 persons received the invalidity benefit.

http://www.securite-sociale.fr/comprendre/dossiers/comptes/2008/ccss200806_fic_09-9.pdf

<http://vosdroits.service-public.fr/N14943.xhtml?&n=Sant%C3%A9&l=N17&n=S%C3%A9curit%C3%A9%20sociale&l=N416&n=S%C3%A9curit%C3%A9%20sociale%20:%20r%C3%A9gime%20g%C3%A9n%C3%A9ral&l=N424>

1.4. Supplement for assistance by a third party (majoration pour tierce personne)

This is paid by Social Security and given to people who have worked, who have contributed to Social Security and who are affiliated to a social security scheme. It is a supplement to the employment injury benefit, to the invalidity benefit (third group) and to old-age benefit (for medical incapacity), in order to pay for the assistance of a third party. The amount is equal to 40% of the second group of invalidity pension.

2. Benefit from the non-contributory scheme.

2.1. The Allowance for disabled adults (AAH – Allocation Adulte handicapé)

The AAH is a non-contributory social minimum: a subsidiary benefit, paid conditionally from national taxes.

This allowance is given to persons aged between 20 and 60 who are permanently at least 80% disabled or acknowledged, on account of their disability, as being unable to secure employment, and whose resources do not exceed a certain ceiling.

The benefit can be topped up with complementary resources (Garantie de ressources des personnes handicapées) for disabled persons who cannot work (recognised as having a work capacity of less than 5%), or a supplement for autonomous life (Majoration pour vie autonome) for disabled persons who can work, in order to guarantee a minimum income. In both cases, the person must have independent housing.

http://ec.europa.eu/employment_social/missoc/2007/tables_part_3_en.pdf

The amount of allowance may be up to € 621.27 per month. The amount of complementary resources (Garantie de ressources des personnes handicapées) is € 179.31 and the supplement for autonomous life (Majoration pour vie autonome) is € 103.63.

In 2006, 803 806 persons benefitted from the AAH. Of these, 124 698 received the supplement for autonomous life (MVA), and 49 527 the complementary resources (GRPH).

(<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er619.pdf>)

Constant progression in the number of recipients of the allowance for disabled adults.

Progression in the number of AAH beneficiaries is constant and steady at about 3% a year: between 1999 and 2006, their number rose from 693 000 to 804 000 for all of France. This evolution is not particularly reactive to economic fluctuations. It is the result of both an increase in new entrants to the scheme and the low rates of departure from it, mainly due to particular difficulties with professional reintegration.

On December 31, 2006, 7 out of 10 AAH beneficiaries had a disability rate greater than or equal to 80%. 6 out of 10 had no income other than social benefits. About half of the new AAH recipients benefitted previously from another social minimum allowance, namely the RMI (minimum insertion income). For example, out of 5% of AAH new beneficiaries in 2004, nearly 2% benefitted from the Lone Parent Allowance (API) in the previous year and nearly 47% benefitted from RMI.

For a large number of them, these other allowances were transitional to when the validation of their disability by Cotorep became effective and they were able to become AAH recipients. Another explanation has to do with increased sensitivity to certain ill-health amongst social minima beneficiaries due to their difficult living conditions. Finally what also needs to be taken into account is the population of disabled children reaching the age of 20 who switch from the special education allowance to the AAH scheme.

(2008), Le Rapport de l'Observatoire Nationale de la Pauvreté et de l'Exclusion sociale, 2007-2008, La Documentation Française, p. 70.

(<http://lesrapports.ladocumentationfrancaise.fr/BRP/084000261/0000.pdf>)

More detailed information to be found at :

(<http://www.officiel-handicap.com/index.php?sub=chapitre&lin=13>) (this link is the most relevant for information on benefits)

(<http://www.handicap.gouv.fr/>)

(<http://vosdroits.service-public.fr/particuliers/N12.xhtml>)

Statistics:

(<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er619.pdf>)

2.3 Policy and practice (summary)

As mentioned above, there is currently in France a strong debate on the issue of a living income for disabled persons. Raising the level of income has been one of the main demands of disabled persons' organisations. However, the 2005 law (Act 2005-102) has not tackled the problem and the income of disabled persons has become an important political issue. As mentioned above, the two main priorities of disabled persons' organisations are the homogenisation of the different benefit schemes and an increase of the income level up to the guaranteed minimum wage (subject to taxes). However, the government has set up other priorities, mainly the issue of employment of disabled persons and the development of incentives to work. Possibilities to draw simultaneously a salary and a benefit have been extended, so that people who work get more money than when they do not. The government also intends to implement a benefit scheme based on the capacity to work.



For that purpose the current scale used to determine the incapacity level should be revised. This project promises to be controversial. This is the situation in October 2009.

PART THREE: CARE AND SUPPORT

3.1 Recent research publications (key points)

As stated above, scientific research on disability is still quite poor and publications on the topic of care and support for disabled person in France are rather scarce. Some data can be found in the grey literature.

- Some statistical data may be obtained through surveys carried out by the DREES (Central Department of research, studies, assessment and statistics) and the DRASS (Regional direction of social action). They provide some information on the number of institutions and services (reported in the next section of this report):
 - <http://www.sante.gouv.fr/drees/statiss/default.htm>
 - <http://www.sante.gouv.fr/drees/statiss/frames/fr22.htm>
 - Dossier solidarité et santé, n°2, avril et juin 2006, études diverses.
<http://www.sante.gouv.fr/drees/dossier-solsa/pdf/dossier200401.pdf>
- In 2004 the CTNERHI (National Centre of studies and research on disabilities and social maladjustments) provided a synthesis report¹ (quoted above) on data concerning care and support:
 - In 2001, social provisions for disabilities, incapacities and work injuries were equal to 25.6 billion Euros, that is 6.1% of total Social Security expenditure. Data on total expenditures related specifically to care and support for disabled persons could not be found.
 - 1.1 million persons (out of 22.5 millions declaring at least one impairment) living at home reported having difficulties accessing their homes². 600 000 persons (declaring at least one impairment) reported that they never left their homes. The interesting fact is that the majority of the persons declaring at least one impairment attributed their difficulties with accessing their homes to their state of health and not to the lack of accessibility. It also showed that home adaptations are insufficient.³
 - Concerning human assistance, in 1999, 2 million adults aged 20 to 59 years old and living at home were getting an invalidity benefit or had an incapacity level acknowledged by an administrative body. 40% of them reported getting regular help as a result of their health condition. The care givers (an average of 2 for one disabled person) often are members of the family. Housework and shopping are the two activities for which disabled adults most often need help.

See also :

Dutheil, N. Les aidants des adultes handicapés, Etudes et résultats, DREES, N°186, août 2002. (Caregivers of disabled adults)

<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er186.pdf>

According to the 1998-2000 national disability survey (HID / Handicaps-incapacités-dépendance) carried out by INSEE, 2 million adults aged 20 to 59 and living at home were officially acknowledged a level of disability. 40% of them received human assistance due to their health condition. 62% of those received help from one or more non professional caregiver, 25% from professionals and family members and 13% from professional caregivers only.

¹ BROUARD Cécile, DUTHEIL Nathalie, GILBERT Pascale, MICHAUDON Hélène, VANOVERMEIR Solveig, TISSERAND Pierrette, VASLIN Catherine, MAUDINET Marc, PIQUET Annick, SANCHEZ Jesus (2004), «Le handicap en chiffres», Mire, Dress, CTNERHI.

<http://www.sante.gouv.fr/drees/handicap/handicap.pdf>

² Most of those persons are persons older than 60 years.

³ See also: Razaki C., Le logement des personnes âgées et/ou handicapées à partir de l'enquête Handicaps, incapacités, dépendance, statistiques commentées pour l'Agence Nationale pour L'Amélioration de L'Habitat, CTNERHI, novembre 2001.

Caregivers were most often family members. Assistance is provided first for house chores (70%) and shopping (65%). Family non professional caregivers are husbands and wives or parents. In more than half the cases, the family caregiver is a woman of average age 47. Parents are most often women of average age 63.

Parents declare more often than husbands and wives that care giving hinders their freedom to go out and that it has negative consequences on their well-being. Moral burden and anxiety are the main consequences associated with the caregiver's role.

- Concerning technical aids, almost 5.7 million persons (all ages) living at home use at least one technical aid (adapted furniture included). Needs for technical aid are less often met at home than in institutions. See pages 54 of "Handicap en chiffres" for more details.

The CNSA (Caisse Nationale de Solidarité pour l'Autonomie – National Solidarity Fund for Autonomy (non contributory scheme)) created in 2005, issued a request for proposals in 2007 on the issue of care and support to disabled persons

(http://www.cnsa.fr/IMG/doc/APR_07_conjoint_HAS-CNSA.doc)

entitled: « Evaluation et amélioration de la prise en charge globale des personnes en perte d'autonomie », « Evaluation and improvement of overall support for persons losing autonomy ». The studies provided information about disabled persons' access to care and highlighted the difficulties disabled persons meet in getting basic health care such as dental care, or gynaecological care (only 20% of disabled women seem to get gynaecological care instead of 80% to 90 % of the general population) (due to inaccessibility, lack of appropriate devices...)⁴.

A public hearing took place in October 2008, organized by the HAS (Health Authority) and the CNSA to get an overview on this matter. The participants' presentations and the summary of the two days are available at:

http://www.has-sante.fr/portail/jcms/c_674890/audition-publique-acces-aux-soins-des-personnes-en-situation-de-handicap-du-22-au-23-octobre-2008

http://www.has-sante.fr/portail/upload/docs/application/pdf/2008-10/dp_ap_pour_web_16-10-08.pdf

It provides detailed information about access to health care for disabled persons. Content of the hearing and a summary of the first presentation is provided below

Content:

Éléments de cadrage / Framing data

Données statistiques sur la consommation de soins

Statistical data on health care consumption

Accès aux soins courants/ Access to usual health care

Problématique en médecine générale/ Issues with general practice

Trisomie 21 et accès aux soins / Down syndrom and access to health care

Surdit , accessibilit  linguistique et soins/ Deafness, linguistic accessibility and care

Difficult s du parcours ambulatoire/Difficulties in ambulatory care

Accès aux soins d'urgence et aux consultations sp cialis es

Access to emergency and specialized care

Handicap et accueil aux urgences/ Disability and emergency units

Handicap et consultations sp cialis es/ Disability and specialised units

Accès aux soins bucco-dentaires / Access to dental care

⁴ Chauvin, Pierre et Parizot, Isabelle (eds) (2005) « Sant  et exp riences des soins ; de l'individu   l'environnement social » co dit  par l'Inserm et Vuibert, collection Questions en sant  publique. Et Chauvin, Pierre et Parizot, Isabelle (eds) (2005) « Sant  et recours aux soins des populations vuln rables », Editions Inserm, 325 pages.

Accès aux consultations spécialisées (suite)

Accès aux soins gynécologiques/ Access to gynecological care

Accès aux soins ophtalmologiques/ Access to ophtalmic care

Accès aux soins psychiatriques / Access to psychiatric care

Vie en institution et accompagnement pour l'accès aux soins

Life in special institutions and access to health care

Institutions et projets de soins / Institutions and care planning

Vie en institutions médico-sociales et accès aux soins

SAMSAH et accès aux soins / Personnel assistant service and access to care

Vie en institution et réseaux de soins

Life in institution and care networks

Établissements et réseaux de soins / Institutions and care networks

Accès aux soins et autisme / Autism and access to care

Aspects organisationnels, juridiques, sociaux et économiques

Organisational, judicial, social and economic aspects

Articulation sanitaire-social / Linking health and social care

Droit et information du patient / Patient's rights and information

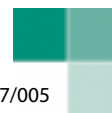
Aspects juridiques de la prise en charge financière / Judicial Aspects of financial provision

Approche européenne / European approach

Consommation et accès aux soins des handicapés : éléments de contexte, données chiffrées, déterminants. (Health care access and consumption of disabled persons) Catherine SERMET, Directrice-adjointe, IRDES, Paris.

Like in other developed countries, there are in France broad social inequalities regarding health and access to care, concerning most particularly some vulnerable groups, such as disabled persons. The more care needs they have the more disadvantaged they are. This work takes stock of the global level of health care consumption of disabled persons under 60 and enquires on access limitations and their determinants. It leans on two general population surveys available in France: Health and social protection 2004 Survey and 2002-2003 Health Decennial Survey (Enquête Santé et Protection Sociale de l'Institut de recherche et de documentation en économie de la santé (IRDES) and Enquête Décennale Santé de l'Institut national de statistique et des études économiques (INSEE)).

Since there is no variable defining precisely the population with a disability (for instance an allowance for disabled adult or child), the authors had to use proxies of the notion of disability that is: on one hand having a limitation of daily life activities due to a health problem or to a disability for at least the last 6 months and on the other hand a motor impairment of upper and lower limbs: walking 500 meters, walking up and down stairs, bending down, opening a tap or carrying 5 kgs. Persons declaring activity limitations need more often care and have higher average expenses than persons without limitations. As an average per year, they see a doctor 12 times, vs. 5.8 times for persons without limitations. Expenses for medical care, drugs and hospital amount a total of 3 860 Euros for persons with limitations vs. 888 Euros for persons without limitations. The expenses for GP's care is twice as high, specialist's care 2.6 higher, drugs 5.9 higher and hospital 6 times higher. These discrepancies between the two populations remain after taking into account age, gender and social situation differences. Secondly, the authors questioned the reason for inequalities in accessing care for these persons with equivalent needs. First without taking into account the social situation. Persons declaring motor problems have difficulties accessing 3 of the 5 selected types of care: mammography (OR=0.747), cervical smear (OR=0.6) and ophthalmological visits (OR=0.694). On the other hand, access to GPs' or pediatricians' consultations in case of acute affection of upper respiratory system (OR=0.962) does not seem to be a problem, nor dentists' consultations. After taking into account the social situation, only access to cervical smear remains limited for women with a motor impairment.



Therefore the differences of access observed for mammography and ophthalmology are probably linked with the less favorable social situation of disabled persons. The reasons for this limited access to health care are numerous and they have been described in other studies.

Among them giving up health care for financial reasons could explain why the incidence of disability on access to care decreases or disappears once social variables are adjusted. Globally 26.7% of persons with activity limitations for 6 months at least had to give up health care of all kinds for financial reasons. Persons without limitations are only 14.3% in that case. Dental care is the most frequent care that is given up (26.7% of persons with limitations vs. 14% of those without limitations).

In 2000, Pr. M. Fardeau provided a synthesis and analysis of the French care and support system, compared to other countries. His report is interesting for understanding the system as it was before the new frame law of 2005, and for understanding some of the difficulties in implementing the new policy.

Fardeau M; Avril S; Bon C; Kerroumi B; Lang G, (2000), « Comme vous, comme nous tout simplement. Sur une analyse comparative et prospective du système français de prise en charge des personnes handicapées », Rapport au Ministre de l'emploi et de la solidarité, 126 p. (« Simply like you, like us. Comparative and prospective analysis of the French system of provisions for disabled persons », Report to the Ministry of Labour and Solidarity).

<http://www.myobase.org/Record.htm?idlist=19&record=19122339124919405119>

In 2006, the ENA (National school of governance) produced a synthesis report on services and institutions that provide care and support to disabled children, at home or in special institutions.

The pioneer role that disabled persons' organizations have played historically has led them to manage most special institutions, that is 90% to date, employing 78 000 professionals.

In each of the 100 French departments, one to three organizations (ADAPEI, APAJH, PEP, ...) run between 1 to 20 medico-social institutions in the field of disability and employ an average of 300 persons. A hundred of large associations of regional or inter regional size run over a hundred institutions each and provide work to 1500 to 3000 employees. Their budget is quite substantial, whether they are local or nationwide: in the Island of La Réunion, the largest one manages an annual budget of over 100 million Euros; the budget of APAJH rises up to half a billion Euros.

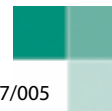
The report shows that a lot of disabled children are not provided a place in an institution, in an institution close to their families, or are not accepted in school. It highlights inequalities between children depending on the department responsible where they live and their social origin. Finally, it provides a synthesis of the changes brought about by the 2005 law.

ENA, « Groupe n° 5 : LA PRISE EN CHARGE DES ENFANTS HANDICAPES EN France », 2006

<http://www.ena.fr/index.php?page=ressources/rapports/enfance/handicapes>

Summary

The ENA task group analyzed the shortcomings of the system of provisions for disabled children and the perspectives of reform opened by the 2005-102 Act of Feb.11 2005. The implementation of this ambitious law requires facing numerous challenges so that its principles find a concrete expression.



State of facts

In spite of significant funding, the disability policy for children shows a number of shortcomings. National social effort in favor of about 270 000 disabled children is quite significant: 6.6 billion Euros in 2006, provided by Social security for 79%, the State for 12% and the Departments for 9%. However the current system of provision does not meet the children's needs.

A lot of disabled children do not get an education adapted to their needs, because of an insufficient number of places and their uneven distribution in the country (1300 children called « children without solution » are not provided for at all) and because orientations do not take into account the specific needs of each child. This situation explains for one part the orientation of around 3000 French children to Belgian institutions.

Special institutions system and regular schooling system are still deeply compartmentalized which is conflicting with the principle of mainstream education for disabled children stated by the founding 1975 law.

Health care provision remains unsuitable for disabled children: screening often belated, access to health care far more difficult for them than for other children.

These shortcomings are partially linked with the public steering scheme: the domains of activities are entangled; actors' coordination is too weak. Besides, the lack of reliable knowledge of the institutional needs and resources leads to a non optimal distribution of available resources.

Act 2005-102 of Feb. 11 2005 bears an ambitious reform. It re-affirms the right to mainstream education and its implementation has started. Each disabled child or youth must systematically register in a regular school. This registration however does not mean schooling. The creation in 2006 of local offices of disabled persons (MDPH) makes access to rights simpler. Disability compensation is improved and the Disability compensation benefit (personal budget) is allocated to children as well since 2008.

The creation of the CNSA (National solidarity fund for autonomy) and of new planning instruments to manage the supply in terms of places in special institutions: the PRIAC (Interdepartmental disability and loss of autonomy programs) are meant to strengthen and streamline the steering of the field.

– Challenges and solutions

The law backs up its objectives with legal and institutional devices, but it does not provide at the same level necessary developments regarding the evolution of practices as well as the financial implications that its implementation requires. Therefore a number of obstacles must be overcome to prevent the improvement of the provisions from being delayed any longer.

- Improving healthcare provision

In this domain, marginal in the law, it is crucial to improve access to health care through contracts over several years between the Ministry of health and medical regional authorities (ARH), through prevention including the definition of protocols and institutions certification by the Central Health Authority. Coordination mechanisms between health and medico-social sectors must be set up to avoid ruptures in the children's health and social course.

Finally, development of research and training should contribute to improve knowledge in the field of child's disability and the dissemination of this knowledge.

- Improving child disability compensation

The orientation and compensation device is likely to be weakened due to the staffs' recruitment modalities.

The MDPH (local offices for disabled persons) have to be rapidly provided with the human resources they need to fulfil their mission. During the transition phase previous to the implementation of the individualized compensation device (that requires a precise assessment of needs), the allowances must ensure at the minimum, the level of compensation provided by the former SVA (Sites for an autonomous life).

- Succeeding in mainstreaming all children

The opening of regular schools to disabled children implies structural evolutions that are necessarily progressive. The less disabled children should join regular schools which implies massive transfers. Mainstreaming implies also to generalize partnerships and exchanges between schools and medico-social institutions. A complementarity scheme between sectors ought to replace the medico-social channel scheme to allow flexibility and inclusion.

The task group has identified the main implications of these evolutions on the number of places in school and in institutions, for the next 5 to 10 years. Over 35 000 sensory or motor disabled children and around 25 000 children with mild mental disability are likely to join regular schools.

Redeployments of funds released by the suppression of places in medico-social institutions should allow to meet needs that are currently insufficiently covered (mental health conditions, multiple disabilities: over 10 000 places should be created); it should also allow to increase assistance to disabled children in school. Quantitatively this means recruiting 6 000 AVS (school life assistants), creating 30 000 places of special education mobile assistance, and qualitatively this means vocational training of the AVS and training of all the bodies of the educational community.

- Mobilizing all the concerned actors and modifying the gaze on disability

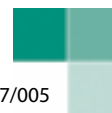
Planning should be renovated. A better knowledge of the needs requires carrying out detailed studies in each department. The coordination of the medico-social, health and education sectors ought to be intensified.

The improvement of the system regulation implies, in terms of quality, to strengthen the controls (external by the DDASS (Departmental social and health authority; internal by the federations of disabled persons organizations) in terms of budget, to converge towards performance standards in order to reduce the current cost gaps. Three tracks are suggested for the management of the funds of the ONDAM MS (Objectif national de dépenses de l'assurance maladie pour les établissements médico-sociaux) to be more transparent and more efficient: to extend the field of competence of the financial jurisdictions to controlling private managers; to ensure a better follow up of the funds of the LFSS (loi de financement de la sécurité sociale); to experiment a decentralized management of the ONDAM MS with voluntary departments.

3.2 Types of care and support (key points and examples)

Concerning care and support, the new law (voted in 2005) has brought about some important changes. The main one is the creation of the right to compensation for the consequences of the disability (droit à compensation des conséquences du handicap) made effective through the disability compensation benefit (prestation de compensation du handicap /PCH). Described in 2009 Independent Living Report for ANED.

See http://www.handicap.gouv.fr/article.php?id_article=49.



Each disabled person may get compensation for his/her needs as defined by the law⁵.

The compensation benefit may be paid as a sum of money or in kind. It may cover costs related to need for technical aids, for human aid, for animal aid, costs related to housing or car adaptations, or to specific or special need. Criteria for eligibility are defined as follows: the person who has an absolute difficulty in doing one defined activity⁶ or a serious difficulty with doing two defined activities, and whose difficulties are permanent or expected to last more than 1 year, can get compensation benefit. This compensation right implies the development of an individualised life plan: the personalised compensation plan. This plan defines the compensation needs in relation to the needs and the wishes of the disabled person as described in his/her life project. By law, the right to compensation depends on the formulation of a life project. This plan is put together by a multidisciplinary team in collaboration with the disabled person (and his/her family) and assesses the different dimensions of his/her situation. This new disposition leads to individualisation (personalisation) of the policy. Firstly, as mentioned, it is based on the life project written by the person, and secondly, it is supposed to take into account the specificity of the situation of each disabled person.

This new right and benefit is managed by the new “Maison Départementale des Personnes handicapées”. To date, as the system has only recently been implemented, it is difficult to evaluate if and how it has changed the living conditions of disabled persons in France. In June 2007, 19 200 persons had received the new compensation benefit. There were 12 200 recipients in March 2007 and 6 900 in December 2006. Costs for the winter term of 2007 were equal to 71.3 million Euros (41.8 million Euros for the autumn term and 43.8 million Euros for the whole year 2006). (ESPAGNOL Philippe (2007), « L'allocation personnalisée d'autonomie et la prestation de compensation du handicap au 30 juin 2007 », Etudes et résultats, n° 615, DRESS, <http://www.sante.gouv.fr/drees/etude-resultat/>).

The number of beneficiaries has continued to grow and there were 58 000 in June 2008. The amount of the benefit was about 1000 Euros a month, which is twice the level of the previous benefit.

At a recent National Disability Conference (June 2008) a number of problems were raised: unmet need for assistance at home and for parenting; and financial costs for legal protection are not covered by the compensation benefit (as mentioned in the recommendations of the technical group on the right to compensation).

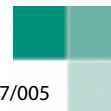
Following this conference, the government has started a reflection and consultation to solve these problems. But to date, no concrete measure has been taken.

⁵ Art. L. 114-1-1 du code des familles et de l'action sociale. « - La personne handicapée a droit à la compensation des conséquences de son handicap quels que soient l'origine et la nature de sa déficience, son âge ou son mode de vie.

« Cette compensation consiste à répondre à ses besoins, qu'il s'agisse de l'accueil de la petite enfance, de la scolarité, de l'enseignement, de l'éducation, de l'insertion professionnelle, des aménagements du domicile ou du cadre de travail nécessaires au plein exercice de sa citoyenneté et de sa capacité d'autonomie, du développement ou de l'aménagement de l'offre de service, permettant notamment à l'entourage de la personne handicapée de bénéficier de temps de répit, du développement de groupes d'entraide mutuelle ou de places en établissements spécialisés, des aides de toute nature à la personne ou aux institutions pour vivre en milieu ordinaire ou adapté, ou encore en matière d'accès aux procédures et aux institutions spécifiques au handicap ou aux moyens et prestations accompagnant la mise en œuvre de la protection juridique régie par le titre XI du livre 1er du code civil. Ces réponses adaptées prennent en compte l'accueil et l'accompagnement nécessaires aux personnes handicapées qui ne peuvent exprimer seules leurs besoins.

« Les besoins de compensation sont inscrits dans un plan élaboré en considération des besoins et des aspirations de la personne handicapée tels qu'ils sont exprimés dans son projet de vie, formulé par la personne elle-même ou, à défaut, avec ou pour elle par son représentant légal lorsqu'elle ne peut exprimer son avis. »

⁶ The defined activities are: mobility (to stand, to transfer oneself, to walk, to move, to grasp), personal care (to wash oneself, to go to the toilet, to dress oneself, to eat), communication (to talk, to hear, to see, to use communication devices), general tasks, relations with others (orientation in time and space, to manage own security, to control his/her behaviour when relating to others).



Furthermore, a new problem has arisen concerning implementation of the disability compensation benefit for children. Since April 2008, the DCB has also been available to children. However, it appears to be less favourable for children than for adults.

The 2005 law also anticipated the extension of the disability compensation benefit to persons over 60 years old. The aim was to create a 5th risk unifying the compensation of dependence and disability, whatever the age of the person. However, no action has as yet been taken.

Concerning the provision of care and support, there is a great diversity of services available although they are insufficient in number (described in the 2009 ANED Independent Living Report). What we can say is that there are no independent living centres in France such as there are in the UK or US. The French system is strongly structured around the distinction between care provided in institutions and care provided at home. Services are different for adults and for children.

It is important to note that the French system presents the following specificity: disabled persons' associations are managing most of the services and institutions for disabled persons. This results from French history⁷ and arrangements with the Social Security Scheme.

Concerning institutions (see http://www.cnsa.fr/article.php3?id_article=201, for more information) there are institutions for children (up to 20 years old) and for adults (over 20 years old and up to 60 years old at time of admission).

- MAINGUENÉ Alice (2008), « Les établissements pour adultes handicapés : des capacités d'accueil en hausse - Résultats provisoires de l'enquête ES 2006 », Etudes et Résultats, n°641, DREES. (Institutions for disabled adults : Results of the 2006 Survey on institutions) <http://www.sante.gouv.fr/drees/etude-resultat/>

According to the 2006 survey « Social and medico-social institutions », the number of institutions for disabled adults has increased by 20% between 2001 and 2006.

The number of places in sheltered work institutions and services has also increased by 13% and by 19% for residential institutions. This increase goes up to 35% for places in residential institutions specialized for very dependent mentally impaired persons and by 45% for medical institutions for the same population. In total over 200 000 disabled adults were in special institutions by Dec.31 2006. About 30 000 of them worked during the day in a sheltered workshop (ESAT) and lived in a residential institution the rest of the time. Men are always more numerous in all categories of institutions (60% in ESAT, 56% in the other institutions). The average age keeps going up, as well as the time spent in a same institution (in average over 10 years). During 2006, discharges amounted to 6% of the institutionalized population. Half of the persons who had left an institution were oriented to another medico-social institution.

However, to date, the insufficient number of places for disabled persons in institutions⁸ is a matter of concern. Mainguené (2008) gives the following data: 200 000 disabled persons were living in institutions on the 31st of December 2006. However, many disabled people have to go to Belgium to find a place. This problem was previously raised in 2005 by the IGAS report (Salzberg, Bastianelli, Saintignon, 2005)

⁷ WINANCE M., VILLE I., RAVAUD JF. (2007), "Disability Policies in France: Changes and Tensions between the Category-based, Universalist and Personalized Approaches". *Scandinavian Journal of Disability Research*, vol.9, n°3-4, pp 160-181.

Barral, C. (2007), "Disabled Person's Associations in France". *Scandinavian Journal of Disability Research*, vol.9, n°3-4, pp 160-181.

⁸ For details, see :

http://www.cnsa.fr/IMG/xls/Panoram_ESMS_annexe_donnees_cles_offre_de_services_adultes.xls and

http://www.cnsa.fr/IMG/xls/Panoram_ESMS_annexe_donnees_cles_offre_de_services_enfants.xls

SALZBERG Liliane, BASTIANELLI Jean-Paul, SAINTIGNON Pierre de, (2005), « Les placements à l'étranger des personnes handicapées françaises », Inspection générale des affaires sociales, Paris ; Inspection générale des affaires sociales ; 158 pages.
<http://lesrapports.ladocumentationfrancaise.fr/BRP/064000542/0000.pdf>

In March 2005, the Secretary of State in charge of disabled people ordered a mission to understand and assess the problems raised by the orientations of children to special institutions in Belgium and Switzerland and to set up a precise state of facts (context, administrative, legal and financial issues, characteristics of the populations oriented) with special attention paid to autistic children.

This issue was recently raised again by the CNCPH (National Advisory Committee of the disabled persons). At a recent National Conference on Disability, the President announced the creation of 50 000 places within the next 5 years. Implementation of this has started.

Concerning services providing care and support at home, it is much more difficult to give an overview. There are different types of services for adults and for children. For children, special education services are organised in relation with the disability. Their number has considerably increased in the last few years: in 1985, there were 5000 SESSAD, in 2005, 26300.

(See LE DUFF Rachelle et RAYNAUD Philippe (2007), Les services d'éducation spéciale et de soins à domicile (SESSAD): publics et modalités d'intervention, Etudes et résultat, n°574, DRESS. <http://www.sante.gouv.fr/drees/etude-resultat/> and the ENA report, 2006).

Mobile special education services:

These services (instigated by the Dec. 10, 1970 Decree)

are independent or attached to a special education institution. They operate in the living spaces of children or youth, most often at home or in school. They contribute to mainstreaming and to prevent the orientation of children to special education institutions. They currently provide for about 30 000 children and they are specialized by type of disability. The more numerous are the SESSAD (Services of special education and care at home) dedicated to intellectual, motor and behavioral disabilities.

SSAD (Service of care and assistance at home) provide for multiple disabilities ; SSEFIS (Service of family education and mainstreaming support) are specialised for severely hearing impaired children above 3 years old.

SAAAIS (Service of assistance to acquisition of autonomy and mainstreaming) for visually impaired children (p. 8, ENA, « Groupe n° 5 :LA PRISE EN CHARGE DES ENFANTS HANDICAPES EN France », 2006 at : <http://www.ena.fr/index.php?page=ressources/rapports/enfance/handicapes> »)

A recent study focused on the issue of parents' satisfaction about the support and care given to their children. (Lo Seak-Hy (2007), L'appréciation des parents sur la prise en charge de leur enfant handicapé, Etudes et résultats, n°565, Dress. <http://www.sante.gouv.fr/drees/etude-resultat/>). The results show that the parents' satisfaction depends on individual and familial characteristics of the children and on the kind of support (support at home, at school or in a special institution).

In June 2009, a problem has arisen concerning school assistants for children in mainstream education. Their contracts were limited to 6 years and the government did not renew them. Therefore many children have lost their assistants. The government has tried to negotiate a solution with associations, but to date no solution has been found.

The CNSA has carried out a service census (see references in note 4).

Disabled persons may use the services of private professionals. In the last few years (in the context of new policy), a specific concern has been raised around severely disabled people living at home, who experience great difficulties financing and finding the human help they need to live independently. For these people, the new law brought about substantial change as it gave them the possibility of financing the human assistance they need through the new compensation right (previously the number of hours that could be paid for was limited). However, it is difficult to evaluate the practical consequences, and severely disabled persons still have difficulties getting the assistance they need.



PART FOUR: SUMMARY INFORMATION

4.1 Conclusions and recommendations (summary)

- Conclusions of the task forces of the National conference on disability.
- CNCPH comments on the Government Report to the Parliament on disability policy.

4.2 One example of best practice (brief details)

4.3 References