

ANNEX VIII : FRANCE

Dr Bernard Azéma, CREAI Languedoc Roussillon, Montpellier France

1. BACKGROUND

Legacy and pioneers

Since the Middle Ages, the first history of people with intellectual disability (ID) is a legacy of compassion, support, charity and also fear, relegation or ostracism (Braddock & Parish, 2001). In 1656 the “Hôpital Général”, a charitable hospital, was established in Paris. Inside its walls were gathered the human symbol of poverty, of inability to work, of disability and of prostitution. The Hôpital and Hospices models spread in France. The Enlightenment and the French Revolution introduced a profound change of thinking, contributing to change in the care and treatment of people with disability.

In the nineteenth century, for the French pioneers like Itard (1801) with Victor the wild boy of Aveyron, Séguin (1846) or Bourneville, the education, social and health care for people with intellectual disability (ID) are associated. (Gateaux-Mennecier J., 2003). Pinel (1800; 1809) or his pupil Esquirol (1838) did not share these understanding and were less optimistic. They considered that the “idiots” were uneducable and must stay in hospitals.

Bourneville set up firstly an “Asile-Ecole” (an Asylum-School) and then an “Institut Médico-Pédagogique” (a medical and educational institution for children with ID) near Paris, in Vitry sur Seine in 1893 (Chapireau et al., 1997). He proposed to disseminate this idea through the state and to establish special annex classrooms for children with mental retardation (intellectual disability) in the ordinary schools. He died just before the creation by the French Parliament of the “Classes de perfectionnement” (Table 1).

Table 1: Development of the French Acts on disability and disabled people: a chronology

1882: Compulsory Education Act (Loi d’obligation scolaire)
1907 : Alfred Binet and Théodore Simon proposed the IQ test to distinguish the “anormaux d’école” (mentally handicapped child destined for school) and the “anormaux d’hospices” (mentally handicapped child destined to live in a hospitals)
1909: “Classes de perfectionnement”, first classes for children with mental retardation (destined for school)
1923-1924: Rehabilitation and access to employment for the mutilated ex service-man of the war
1945: Set up of the Social Insurance for all the employees, first step to the universal social insurance (Ordonnance n°45-2454 Réorganisation de la Sécurité Sociale) All the employees and their family members can access to private care and cure facilities without charges.
1948: Medical homes for the children with intellectual disability (Circulaire du 27 janvier 1948)
1949: The Cordonnier Act (August the 2 nd) benefits, access to vocational training and employment for the disabled persons: blind, mutilated, impaired.

1957 : “Loi n° 57-1223 sur le reclassement professionnel des travailleurs handicapés”
The Sheltered Workshops are also dedicated for people with intellectual disability. In this Act appears the first legal quotation of the word “handicap” in France.

1956-1970: The Annexes XXIV, different types of institution for children with special needs, are created: Instituts Médico-Educatifs (IME), Instituts Médico-Professionnels (IMPro), Instituts de Rééducation-(IR). These institutions are specialised. They are dedicated either to children with intellectual or motor, or sensory impairments or personality disorders with challenging behaviour (IR). They match medical and socio-educational approaches.

1964: Creation of the Centre National and the Centres Régionaux pour l’Enfance et l’Adolescence Inadaptée, national and regional agency for research, training, information, policies and service provision in special needs and socially maladjusted persons.

1969: The Bloch-Lainé Report, an exhaustive and historical report to the Prime Minister about disabled persons.

1975: Two great Acts of solidarity, Loi n°75-534 d’Orientation en faveur des personnes handicapées and Loi n°75-535 relative aux institutions sociales et médicosociales. These two Acts changed completely the landscape, the political and social approach of disability in France. They reinforced a positive discrimination for the disabled persons, giving benefits and income, stimulating and organising the service provision. The national policies are separated in two different areas: on one hand the policies and planning for health (hospitals, health professionals...) and on the other hand the social aid and the management of the care for disabled people. The disability pattern of the handicap and disability is medical.

1982-1983: Circulaires sur l’intégration scolaire des enfants et adolescents handicapés.
These “Circulaires” involve the mainstreaming for the children with intellectual disability.

1983: First Decentralization Acts. The shifting of a degree of administrative power from Paris to regional bodies has been a key aspect of French domestic policy. This policy led -over the hundred of “départements”- to the creation of the 26 administrative regions which are overseen by regional councils. The national level manages employment and training of disabled persons, the French départements with their councils (Conseil Général) manage lodging. Moreover the adults with severe and multiple impairments are managed both by National, local and social insurance level.

1987: Creation of the AGEFIPH, this Governmental Organization aims to involve employment in the free market for people with disability.

1991: Reinforcement of the service provision for people with severe disability: Maisons d’Accueil Spécialisé- MAS, Foyers médicalisés : home with health care.

1993: A decree describing the scale, the different thresholds of disability in an official guidebook: “Décret n°93-1216 du 4 novembre 1993, relatif au Guide-Barème applicable pour l’attribution de diverses prestations aux personnes handicapées”

1996: “Plan Autisme”. A policy specially dedicated to the persons with autism and pervasive developmental disorders in France.

2002: A total shift of the laws with the “Loi n°2002-2 rénovant l’action sociale et médico-sociale & Loi n°2002-73 de modernisation sociale”. They introduce new policies, new rules, reinforcement of the service user rights and self-advocacy, participation of the service users at the service organization and empowerment, evaluation commitments of the quality.

2002: New planning for the people with autism and pervasive developmental disorders and for people with severe disability.

2004: Establishment of the “Haute Autorité de Lutte contre les Discriminations et pour l’Egalité, HALDE”. The HALDE is a governmental authority. Its aims are to provide for all the citizens an equal access to society and to fight against discrimination. About 15% of the requests at the HALDE involved health or disability.

2004: An Act set up a solidarity day, a new tax: “Loi n° 2004-626 du 30 juin 2004 relative à la solidarité pour l’autonomie des personnes âgées et handicapées”. Each employee will give the amount of one working day to finance the new needs of disabled and dependent old people. The “Caisse Nationale de Solidarité pour l’Autonomie (CNSA)” administers this new tax. As a technical Agency, the CNSA has also to develop an expertise about the quality of the services provided (project methodology, guidelines, technical help to the national and local organizations, evaluation...)

2005: The achievement of the legal shift is done with the ”Loi n°2005-102 pour l’égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées” (Equalization of the Rights, the Chances, the Participation and the Citizenship Act). This Act is a big step to the mainstreaming. The disability pattern is now social in accordance with the International Classification of Functioning, Disability and Health-ICF of the WHO (2001). The disability pattern of the handicap and disability is social.

- People with disability get a ”compensation” right, with benefits and special allowances, universal and access to whole society, a true and a by-Act guarantee of citizenship..
- The solidarity day tax finances the Dependence Risk Insurance for disabled and dependent old people
- Creation of the “Maison Départementale des Personnes Handicapées” : the Local Council, the Committees, the technical and social staffs dedicated to assess the rights in disability and the financial providers are in the same organism.
- The same committee for everybody (children and adults), the Rights and Autonomy Committee (“Commission des Droits et de l’Autonomie”)
- The whole children are registered in the local primary or secondary school: the ordinary schooling is the main solution, the special needs institutions are by default.

2. HISTORICAL CONTEXT OF SERVICE DEVELOPMENT

The management of the facilities is devolved to NGOs

Since the Second World War the state authority entrusted the NGOs with the mission to develop service provision for persons with intellectual disabilities (ID), and to manage facilities for disabled people (Azéma, 1999a; Azéma, 1999b; Barreyre, 2000; Zribi, Rebmeister & Kieken, 2000). There has been intense lobbying to develop facilities. The advocates sought and achieved funds and policies. The nineteen seventies and eighties were periods of an intense development of the services. The NGO assumed the management and provided services to people with ID.

UNAPEI- Union Nationale des Amis et Parents des Enfants Inadaptés is a federation of 750 organizations parents and friends of people with a mental handicap. This federation is a very influential advocate in the intellectual disability field. It gathers together 60.000 families, 75.000 carers and takes care of 180.000 persons with intellectual disabilities. UNAPEI manages 2.700 facilities.

APAJH-Association de Parents pour les Adultes et les Jeunes Handicapés is another great national NGO. It advocates for the mentally disabled people. This federation gathers 87 local organizations, claims 25.000 members and 13.850 carers, cares for around 25.000 disabled persons. APAJH administers 587 facilities with state funds for about 468 millions euros.

People with autism or developmental disorders are advocated by two main organizations: Sésame-Autisme and Autisme-France. Sésame-Autisme (created in 1963) gathers 40 local associations, manages 56 facilities and cares 1.000 people with autism with 1.000 carers. Autisme-France was created in 1989 and supports an educational approach of autism. This organization, affiliated with Autism-Europe is very active in the European lobbying to involve the inclusion of people with autism.

People with Down syndrome are represented by the federation FAIT 21, member of the European Down Syndrome Association. The national federation gathers the local organizations named “Groupement pour l’Insertion des Trisomiques 21 – GEIST 21”. GEIST exists in most French areas. The FAIT 21 provides services dedicated to schooling, social support and inclusion in the community.

People with severe, multiple and profound disabilities, “in French Polyhandicap”, have a political and technical support in some little organizations: CESAP or HANDAS (a part of the big organization for the people with motor impairment and Cerebral Palsy, «Association des Paralysés de France – APF”)

Finally a galaxy of small organizations advocates for rare diseases (Fragile-X syndrome, Prader-Willi syndrome, Tuberous sclerosis, Williams-Beuren syndrome, Angelman syndrome etc...) Most of them are gathered in a Rare Disease Alliance (“Alliance Maladies Rares”) with others federations (159 NGOs). Their actions are to spread knowledge, to support and fund research or to defend people with rare diseases in France and in Europe (Eurordis). In some instances, they are service providers.

Service provision, policies and policy makers

So the public policies to the benefit of people with intellectual disability have been put in the hands of the advocates with intellectual disabilities. They administer service provision. They are controlled by the local delegate of the national Authorities, the “Directions Départementales des

Affaires Sanitaires et Sociales – DDASS”. The DDASS are responsible for implementing in each “département” (a county-size district) the health, the “social-health” and social policies, as defined by the State. Their activities must be co-ordinated with those of the “Directions Régionales des Affaires Sanitaires et Sociales – DRASS” as well as with those of local authorities (“départements”, “communes”; more or less the equivalent of counties and boroughs in the French administrative geography, but with different responsibilities) (Palier, vol.1, p.109). The DDASS are decentralized bodies of the Social Affairs Ministry. There are 95 DDASS in mainland France, 8 in overseas territories and départements .

The social and medico-social institutions (“Etablissements sociaux et médico-sociaux “) can be public or private and are either residential or non-residential. They provide both for children and adults with physical or intellectual disability a diverse range of services: sheltered workshop, specialised or care homes, long-stay centres, day care and social support services. (Palier, p.118)

Currently the service providers for disabled people are administered and funded by multiple councils and authorities: the DDASS and DRASS, the Département authority (Conseil Général) and the Social Insurance. So the disability service landscape is very complex. Institutions or services can be funded by one or two financial resources. To plan the services for the people with ID and their representatives, it is necessary to associate multiple partners and multiple financial resources. The Conseil Général have a central role today, because of the management and partial funding of the Maison Départementale des Personnes Handicapées-MDPH. This MDPH should become an important area to promote the experience of citizenship for persons with disabilities, who are now very powerful in the MDPH council.

3. THE DEFINITION OF INTELLECTUAL DISABILITY

The legal and administrative definition of disability

“A handicap is defined, within the meaning of the present Act, as any limitation of activity or restriction of participation in the life in society undergone in its environment by a person because of a substantial, durable or definitive deterioration of one, or more physical, sensory, mental, cognitive or psychic functions, of a polyhandicap or an invalidating disorder of health. ” (The Equality of the Rights, the Chances, the Participation and the Citizenship of the Disabled Persons Act, February 11th 2005)

It is the first legal definition of handicap or disability in France. Until this legal definition, the French Act only said that in individual... “is handicapped who is recognized like that by the legal committee”. The categorization of people with disabilities is a central topic. Its consequences are ethical, political and financial (Barreyre, 2000).

This new definition of the February 11th 2005 Act is drawn out of the International Classification of Functioning, Disability and Health (ICF-WHO, 2001).

Previously France adopted the ICDIH 1-WHO (1980). The first translation in French was done in 1988 (OMS-INSERM-CTNERHI, 1988; CTNERHI, 1989)

The other classification used in the national databases of Public Health System is the ICD-10th. In mental health research it is usual to find researches using the DSM-IV TR of the American Psychiatric Association. But there is some reluctance in the opinion of the clinical practitioners about the unconditional use of the DSM IV.

French childhood classification: the CFTMEA

The French Child and Adolescent Classification of Mental Disorders (Classification Française des Troubles Mentaux de l'Enfant et de l'Adolescent – CFTMEA) proposed by Misès & Quémada (1994, 2002) is supported by the French Federation of Psychiatry. The classification is used and largely spread in child psychiatry. The connections with the ICD-10th of the WHO are established in a correspondence table.

In the CFTMEA the naming of intellectual disability is “déficience mentale” (mental disability) and the different levels of IQ chosen are: 50-69, 35-49, 20-34 and less than 20. In the CFTMEA coding there are two entries: the IQ level and another categorization which introduce typology of intellectual disability.

- The CFTMEA considers the existence or not of a challenging behaviour and of mental disorders associated with the ID: “déficience harmonique” or “dysharmonique” (harmonious or unharmonious intellectual disability). This proposal exists in the ICD-10th in the 4th code F7x.0 (no challenging behaviour); F7x.1(challenging behaviour); F7x.8 (others challenging behaviour)
- The existence of multiple disorders like sensory and motor disabilities. This typology is named “polyhandicap”. The “polyhandicap” is a French concept which emphasizes the severe, profound and multiple disabilities. It associates a severe or profound intellectual disability with severe motor impairments and sometimes others impairments or illnesses like sensory, metabolic etc. (Ponsot, 1995; Zucman, 1998)

The legal and administrative definition of intellectual disability

In France the administrative categorization of the population with disabilities uses frequently the concept of “**Handicap Mental**” in official statistics. This concept combines on one hand people with intellectual disability and on the other hand some people with mental disorders and cognitive impairments. So the field and the boundaries of the Handicap Mental concept are not exactly adjusted with intellectual disabilities (ID). The former categorization is sometimes used by professionals in papers or reports.

Nevertheless the definition of **intellectual disability** chosen by the French researcher in adulthood is the one of W.H.O. (I.C.D. 10 and I.C.F.). The AAMR definition (AAMR 2002) is not well known. Sometimes in scientific research the DSM-4 is used by the researchers to code the clinical characteristics of the patients enlisted in the surveys.

However, in the administrative form disability and the guidelines the recommendations are to use both **the I.Q.** and an **adaptive behaviour assessment** to give a diagnostic of ID.

The specific and important needs of people with “polyhandicap” are recognized by the new Act (Dutheil, 2005).

4. LEGAL RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITY

a. Eligibility

***Since the Disabled People Act of 1975**, there were **two disability committees**:

- The disabled children (age 0 to 20): the **“Commission Départementale d’Education Spéciale-CDES”** administered both by the local representative of the National Authority of Health and Social Affairs and the Education Department.
- The disabled adults (from age 20 to 60): the **“Commission Technique d’Orientation et de Reclassement Professionnel – COTOREP”** administered both by the national authority of health and social affairs and the Employment Ministry.
- From age 60 the disabled persons are integrated in the old people rights.

The first International Classification of Impairment, Disability and Handicap - ICIDIH proposed by Phil Wood was used in France since the first French translation in 1988. The ICIDIH inspired the Guide-Bareme (1993) used to define eligibility to services and benefits for disabled persons.

The official guidebook of disability -**“the Guide-Barème”**- appears in 1993. It introduced a revolution in the allocation process of the attendance allowance. The Guide-Barème aims at more equity and to reduce inequalities in the allocation process. The Guide-Barème recommendations are to use not only the IQ but also adaptive behaviour data to define the eligibility.

For people with ID the Guide-Barème setting distinguishes different levels of legal handicap for adults with ID:

- Less than 50%, if the person is carrying cognitive impairments with a good adaptive behaviour, and without human support.
- Between 50 and 75 % if the person has skills in daily life but needs support. It is the case in mild ID.
- Higher than or equal to 80 %, if the person has special needs in daily life, is able to get employment in a sheltered workshop or in free market with support. It is the case in moderate ID.
- Higher than 90 %, if the person needs a permanent help, is unable to work, to speak, to be autonomous.
- The presence of other disorders like epilepsy, mental health disorders, sensory impairments etc... could lead to a higher rate.

For the people with Down syndrome the allowance rate is equal or higher than 80 %.

***From the beginning of 2006, and the “Equalization of the Rights, the Chances, the Participation and the Citizenship Act”**, the process turns totally.

The new Act changes the procedures. The **« Commission des Droits et de l’Autonomie »** Rights and Autonomy Committee becomes the only one committee. All ages are on the range of this committee. New procedures are involving: Compensation Plan, new mechanisms in the allowance providing. Otherwise, the empowerment of the disabled people is reinforced in the local authority: **“Maison Départementale des Personnes Handicapées”**.

So, times are changing quickly and a transition phase is now beginning in France. The legal trends are more and more inclusive for the disabled people and the people with ID. Much hope rises up

in the community of disabled people and the advocates. The test of time will make the decision because this politics is ambitious but expensive.

The Act creates a Compensation Benefit for Disability (“Plan de Compensation du Handicap”) which includes assistances and support, given according to the needs and the Life Project (“Projet de Vie”) without financial resources condition.

The **Project of Life** is the contribution of the disabled person and/or his legal representative to define his own needs, wishes and aspirations. It should be written in a confidential document. The person is free not to do it. The staff of the Departmental House of Handicap can, if the person wishes it, bring a help to the formulation of the needs and the project of life.

Independently of the Compensation Benefit, the Act:

- Improves the resources of the disabled people who perceive an **Adult Disability Allowance** (“Allocation Adultes Handicapés-AAH”);
- Reinforces the existing assistances to reduce obstacles and improve participation in the community;
- Provides services and facilities.

b. Education, disability specific service provision, etc

The Rights and Autonomy Committee provides different rights to the persons with ID: social security benefits and free of charge access to health care system, special allowances, specific service provision, tax exemption, disability card, advices.

c. Revocation of the rights

The rights can be revoked by the Rights and Autonomy Committee.

PREVALENCES OF ID

De Kervasdoué et al. (2002) issued an exhaustive survey on health databases in France. It is a National Council in statistics and information retrieval (CNIS) report. The report aims to describe the French statistical landscape, to identify the main health topics in public policies, to define the shape of the desirable data and to stress the health inequities. De Kervasdoué et al. recommend collecting disability data according to the International Classification of Functioning, Disability and Health (WHO, 2001).

Registers and ad hoc Surveys

The prevalence studies of ID are rare and almost **involved in childhood** (Cans et al., 1999 & 2003) Data about disability in France can be gathered by registers or by ad hoc surveys. There are registers in childhood in two French “départements”: in Isère (main city Grenoble) created in 1991 and in Haute-Garonne (main city Toulouse) recently created in 1999.

Some ad hoc surveys in childhood were conducted by the INSERM Unit 149, during the years 1985-86 and 1989 in 14 French “départements” (Rumeau-Rouquette et al., 1992) and in 1992-1993 in 3 “départements” (Rumeau-Rouquette et al., 1997)

The National Statistics, INSEE, with others partners launched a huge nationwide survey: the **Handicaps, Incapacités, Dépendance (HID) survey** (Mormiche, 2000; Goillot & Mormiche,

2001 & 2002; Ville & Ravaud, 2003) It is a national declaratory survey. The whole French population were interviewed in two successive waves at home, in the institutions (for people with disabilities or for the elderly), in the hospitals, the jails etc. (homeless persons were also involved). The data collected are considerable and the works are still in progress.

In the HID survey, data are reported by gender, by institution types, by disability, 10 years by 10 years from 0 to 60 in institution for disabled people and after 60 in institution for the elderly (Table 2). The intellectual and “mental” disabilities are gathered together. The others disabilities are motor, hearing, visual, speech, “metabolic and visceral”.

Table 2: Handicaps, Incapacités, Dépendance (HID) Survey

People with I.D. in the community	Intellectual or Mental Disability	Intellectual or Mental + Motor Disability	French Population
	Percent	Percent	
0-19 years	4 %	1 < %	14 770 000
20-39 years	2 %	1 %	16 170 000
40-59 years	3 %	2 %	14 910 000
+ 60 years	2 %	6%	11 570 000
Total	3 %	2 %	57 410 000

A further breakdown of persons surveyed in the HID living in institutions and in the community appears in Table 3.

Table 3: People with intellectual disabilities in the community (Source HID) -

	PWID in the community		PWID in educational and residential institutions, in day services and in psychiatric hospitals		Community and Institutions
	Number	Percentage Community	Number	Percent Institutions	Total
ID mild, moderate, severe and profound	150.000	0.3 %	24.200	3.7 %	0.3 %
ID non specified	50.000	0.1 %	68.000	10.4 %	0.2 %
Total	200.000	-	92.000	-	292.000

Assessment of People with Intellectual Disabilities in HID 1998 &1999

(Source Ville & Ravaud, 2003: p.116)

Ville and Ravaud (2003) found in their own research a ratio of 0.5 % of people with ID in the HID sampling. These prevalence data are lower than other international surveys.

Table 4: Facilities and service users in France (all disabilities)

	Type of facility	Facilities (number in 2001)	Users (number in 2001)
Sheltered Workshop	“Ateliers Protégés	468	16.651
	“Centres d’Aide par le Travail”	1.419	96.651
Residential facilities: educational, care homes...	“Foyers d’Hébergement”	1.294	38.244*
	“Foyers Occupationnels”	1.083	34.142
	“Foyers Accueil Médicalisé”	278	9.044
	“Maison d’Accueil Spécialisées”	360	14.037
	Total	4.903	208.769

Table 4 presents figures for the population of people with disabilities, not only intellectual disability, in facilities and services in France (See reference page 2:

<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er308.pdf>)

Facilities for people with disabilities in France in 2001

(Source DREES – Vanovermeir, 2004)

People who access to a sheltered workshop can live either in a residential home, like a Foyer d’Hébergement, or at their own home or in family (Table 4). So it is not 208.769 persons who use facilities, but only around 170.000 (Vanovermeir, 2004). Prevalence rates according to level of intellectual disability within each type of facility are presented in Table 5.

Table 5: Percentage of people with intellectual disabilities in facilities in France in 2001

(Source DREES – Vanovermeir, 2004)

		Persons (number in 2001)	Percentage of PWID in the facility			
			Mild ID %	Moderate ID %	Severe and profound ID %	Severe, profound and multiple disabilities %
Sheltered Workshop	“Ateliers Protégés	16.651	81	18	0	0
	“Centres d’Aide par le Travail”	96.651	37	51	11	0
Residential facilities: educational, medicalized home...	“Foyers d’Hébergement”	38.244	31	55	13	0
	“Foyers Occupationnels”	34.142	31	55	13	2
	“Foyers Accueil Médicalisé”	9.044	5	3	63	11
	“Maison d’Accueil Spécialisées”	14.037	1	12	86	29

A small number of disabled people are living in a foster home: 5.800 in 1997 (Aliaga & Woitrain, 1999). No data on those with intellectual disabilities are available.

A specific issue of the HID survey is dedicated to people living at home with significant impairments in the activities of daily living, around 216.000 persons from age 20 to 59. Forty percent are living with an ID (15 % only ID and 25 % ID and other disabilities). The disability score, the needs in care, the types of carers, social inclusion are described (Raynaud & Weber, 2005).

Databases and sources on prevalence

In 2002, the National Report on Public Health, the Haut Comité de Santé Publique (High Committee of Public Health) has not quoted the topic of ID, as a public health problem (HCSP, 2003).

Otherwise France has chosen a set of health indicators after a considerable report of a working party, the “Groupe Technique National de Définition des Objectifs de Santé Publique-GTND0, (Abenhaim & Le Gales, 2004). The report has selected as health indicators the topic of “Disabilities and Handicaps” and Epilepsy.

Epilepsy: The quotation of ID in epilepsy is evocated (p.410) but the authors are disappointed by the lack of statistics, relevant surveys on the cognitive development and on the quality of life for instance. (Abenhaim & Le Gales, 2004, p. 409-413)

In 1999, the number of deaths by epilepsy was 1.164. Epilepsy led to 35.000 DALY's (disability adjusted life years) lost in France. In 2000, 75.000 hospitalisations in France were the consequences of epilepsy. During the same period 66.000 hospitalisations were justified by mood disorders or nervous breakdown (data of the DREES-BESP report on PMSI Hospital Activity. So the HCSP report has taken epilepsy as one of the indicators of national public health management. The objective is to reduce and prevent the impairments (especially cognitive impairments in childhood) associated with epilepsy. The HCSP report proposed to reduce the impact of epilepsy in childhood and adulthood. Epilepsy indicators (incidence and prevalence) were chosen as one the 100 topics of the Public Health Policy Act (august 9th 2004).

Medical databases

The **Programme de Médicalisation des Systèmes d'Information- PMSI**, Medical Information System Program-MISP is used in France to translate facts of hospital activity into synthesised medical terms. The MISP is fitted from the Robert Fetter (Yale University) experience of Diagnosis Related Groups-DRG (in French, Groupes Homogènes de Malades-GHM). Major Diagnosis Categories are groups of DRGs each covering all functional system diseases. Each stay of over 24 hours is classified in an MDC according to its main diagnosis.

The PMSI database is made up of information furnished by the public and private hospitals. The PMSI data make possible to characterize medically, all anonymous discharges of the establishments. In order to describe the pathology, the ICD-10 (WHO) is used with a major diagnosis and associated diagnosis.

In fact, medical databases cannot provide information on the health system use by people with ID because ID is not habitually quoted by the practitioners. Only some diagnoses like Down syndrome are sometimes quoted.

Social Insurance databases

The free of charge medical access is given for a certain list of medical disorders. The mental disorders like autism, the intellectual disability, Down syndrome, severe genetic disorders can receive this. These types of disorders are called Affections Longue Durée-ALD (long time disorders). ALD data base are accessible (Haut Conseil pour l'avenir de l'assurance maladie, 2005) ; Caisse Nationale d'Assurance Maladie des Travailleurs Salariés, 2006).

Disability databases

The main data collection is produced by the Direction de la Recherche, des Études, de l'Évaluation et des Statistiques – DREES (Directorate of Research, Surveys, Evaluation and Statistics of the French Ministry of Health and Social Affairs). The childhood data are issued from the child Committee in special needs, Commission Départementale d'Éducation Spéciale – CDES. Data on ID are not yet available but a profound reform of data collecting is launched with a new data collection, the OPALES system. For the adults, no data on ID are available from the Committee, the COTOREP. (Colin et al., 1999)

The main source of data is the service provider's survey of the French administration: Enquête ES. These surveys are not permanent and are spread in time. It is an exhaustive declaratory survey. The first ES Survey was launched in 1982. Data on disabilities and ID, on manpower, on facilities are available. The last exhaustive issue was published by the DREES in 2000 (Woitrain). Partial data are published regularly on specific topics like people with autism (Barreyre et al., 2005) waiting lists (Barreyre & Peintre, 2005) facilities (Trémoureaux & Woitrain, 2000; Vanovermeir, 2004 & 2005) severe, profound and multiple disabilities (Dutheil, 2005)

The waiting list of adults with ID staying in childhood facilities because of the lack of places in adult facilities is available (Barreyre & Peintre, 2005). The number of those on the waiting list was around 4.000 in 2001, of whom 63.4 % were persons with ID. The difficulties are more important for those who have a lower level of ID.

At the regional level data are produced occasionally by agencies or offices operating in health or social areas: the Regional Authority like DRASS liaised with the DREES, the CREAIs or the ORSs.. These data are produced to plan services and to shape public policies.

Finally, statistics on employment of people with disabilities are issued by the National Agency AGEFIPH (2005) but PWID are not easily found in the report.

DATABASES ON LIFE EXPECTANCY OF PERSONS WITH INTELLECTUAL DISABILITY

There are no data available in France on life expectancy among persons with intellectual disabilities.

SERVICE PROVISION

1. CRITERION FOR ELIGIBILITY FOR INTELLECTUAL DISABILITY SERVICES

The Committees employ currently the Guide-Barème to categorize the level of disability and the rights eligibility. The new guideline is in an experimental stage to set the Compensation Plan. The same Committees (Commission des Droits et de l'Autonomie)

rule on the service provision. The request is first examined by an independent and multidisciplinary staff member, who makes recommendations to the Committees.

The authority with responsibility for funding (State administration, local authority, Social insurance) watches over the service provision and participates in the committees with professionals, experts, services user delegates, advocates and elected representatives. The service user delegates are powerful in the newly established committee.

But, the eligibility for the disability service strongly depends on the local service provision. Theoretically the decision of the ad hoc committee is available on the national territory. Practically, there is a wide geographical variation in service provision for adults with ID. For instance, the Parisian region is poor in facilities for adults with ID. The reasons are historical, financial (land and building costs) and sociological. Some regions of France are more equipped (Azéma, 1999a & 1999b)

2. TYPES OF SERVICE PROVISION FOR ADULTS WITH INTELLECTUAL DISABILITY

a. Educational and Residential services: residential care, residential home...

Sandier et al. (2004) issued on behalf of the European Observatory on Health Systems and Policies an evaluation study on the delivery of health care, health system plan and financing health in France.

Disability is measured in terms of a disability rate which takes into account the degree of difficulty with daily living. The specific committee evaluates the rate of incapacity and determine the right to benefits according with the Guide-Bareme. The committees also have the authority to refer the disabled person to a specialized institution.

These institutions provide treatment, special education and vocational training to children affected by ID. The costs are financed by the health insurance system. Different types of institution cater for disabled adults with different levels of functional autonomy. They are split into different types according to the severity of the deficiencies and the needs for care.

Residential centres are linked to sheltered workshops (Centres d'Aide par le Travail – CAT and Ateliers Protégés) and take in people who are slightly disabled.

Occupational centres (Foyers Occupationnels) take care of disabled adults who are not able to work.

Institutions for the most heavily dependent persons, the Maisons d'Accueil Spécialisé-MAS, residential care, are financed entirely by the health insurance funds, while in other institutions like Foyers d'Accueil Médicalisé-FAM, medicalized homes, there is a double source of funding: the health care part is paid for by the health insurance fund and the costs of residential care are charged to the patient or to the local authority (Département).

“An incapacity rating of over 80%, or for some conditions over 50%, confers the right to cash allowances that are paid out by the family allowance funds: a special education allowance for children and an allowance for disabled adults. Finally, a compensation allowance, paid out by the general councils, finances the wages of people employed by disabled people or their families” (Sandier et al., 2004).

b. Day services

The persons with ID can get services at home (own or familial residences, small residential facility). Different types of service could be provided:

- a social help by carers : Service d'Accompagnement à la Vie Sociale-SAVS
- a support to manage the living conditions at home : Service d'Aide à Domicile-SAD
- a multidisciplinary follow-up: nurses, practitioners, paramedics: Service d'Accompagnement Médico-Social pour Adultes Handicapés-SAMSAH
- A nurse support at home: Service de Soins Infirmiers à Domicile-SSIAD

SOURCES OF INCOME

Benefits and allowances

The Rights

* The main income support provisions for people unable to work due to disability in France is the **Allocation pour l'Adulte Handicapé-AAH**, which is a social assistance measure. Adults with ID may claim AAH, which requires an assessment from the ad hoc committee, the COTOREP and now the "Commission des Droits et de l'Autonomie" as well as a means test.

The person must be assessed as 80%+ disabled by the committee, or as 50-79% disabled and unable to get a job on account of his or her disability (Brunel University, 2002)

This benefit depends on incomes of the persons. The amount of the AAH is 610.28 euros per month (since January 2006). This amount is reduced if the person is living in a hospital, a jail or a Maison d'Accueil Spécialisé. It is then a third: 183.08 euros per month.

* Disabled people have the right to get a lodging benefit: **Allocation Logement à caractère Social-ALS**. This benefit depends on incomes of the persons. The amount is variable and depends on the geographical area, on the type of housing and on the lodging cost.

Disabled people can get a new benefit since the shift of the French Laws: the **Prestation de Compensation à Domicile**. This Compensation Allowance is defined according to the Personal Compensation Plan by the Committee (Commission des Droits et de l'Autonomie).

The Compensation Allowance aims to finance:

- **Human helpers** (professional or family carers) in order to enable living at home independently or to work in the community. The gross salary is between 11.02 and 13.92 euros per hours for a professional. For a carer, member of the family, the compensation is between 3.10 and 4.64 euros per hours with a maximum per month of 798 euros. .
- **Technical help**, equipment (amount 3.960 euros maximum per three years)
- **Equipment of the house** (amount 10.000 euros maximum per ten years)
- **Equipments of the vehicle** (amount 5.000 euros maximum per five years)
- **Animal help** for blind people (amount 3.000 euros maximum per five years)
- **Special allowances**: 100 euros per month and/or 1.800 euros per three years.

These amounts were defined in January 2006.

The optional help or benefit

People with disabilities can get - like the elderly - some facultative benefits or help depending of the Social Authority of the Cities (CCAS). In fact, some cities provide services like meal delivery at home or housework.

National minimum wage as reference

The minimum wage in France is called the **Salaire Minimum de Croissance**, called also SMIC. The amount of gross salary per hour is 8,03 euros and per month 1217,88 euros (February 2006)

HEALTH SERVICES AND UTILISATION

1. HEALTH SERVICES OFFERED TO PWID

People with intellectual disabilities (PWID) can receive mental, medical or dental care either by the public and private hospitals or in a practitioner office. They have to choose one practitioner who coordinates the treatments and the follow up.

However, some residential facilities (the MAS and the FAM) and some services at home (SSIAD and SAMSAH) provide care and treatment with a medical and paramedical staff. PWID who are eligible could get medical care and hospitalization free of charge.

a. Physical health

There are no specific services in physical health especially dedicated to PWID.

The main body of health provision to PWID is genetics with the development in France of Resources Centres in Rare Diseases (for instance Prader-Willi, FragileX syndrome). Some university hospitals or foundations (like Lejeune Foundation) offer a medical follow-up in Down syndrome.

Generally, PWID use health services in the middle of the general population. This situation is not optimal because there are difficulties in gaining access to good and timely care. Usually hospitals and clinics must provide an easy access to people with disability. It is a commitment to get the accreditation label. Some medical equipment offers easier access.

b. Mental health

The general population

Since the end of the Second World War, mental health policy in France is based on a movement towards de-institutionalization. The country has been divided into geographical areas (secteurs) serving the population living in that area. On average, an adult zone covers 67 000 inhabitants. A multi-disciplinary team in each zone must provide preventive care, treatment, follow-up care and rehabilitation for people suffering from psychiatric disorders.

Each psychiatric secteur is linked to a hospital which treats psychiatric patients of that area. In each zone, a Centre (Consultation Médico-Psychologique) provides consultations and mental health care. Facilities outside the hospital focus on domestic issues, rehabilitation and social support. Nevertheless, there are great geographical variations of resources between the different mental health teams.

Private hospitals accept patients with psychiatric disorders on the same basis as public hospitals. A large number of psychological disorders are dealt with on an outpatient basis by private general practitioners, psychiatrists or psychologists (Sandier et al., 2004).

People with ID

People with intellectual disabilities can get free access to public or private medical resources. In some facilities, the care homes (MAS and FAM) or the home services (SSIAD and SAMSAH), psychologists and sometimes psychiatrists are practicing in the staff.

In the others facilities, PWID have to use medical resources in the community.

c. Dental health

The dental care is an emerging trend in France. Some scarce networks are evolving with collaboration between Teaching Dental Clinics, dentists in the community and hospitals. However huge progress must be done in this area. Hennequin and the Clermont-Ferrand University of Dental Health is a pioneer (Hennequin et al., 2004).

2. RESEARCH ON THE HEALTH OF ADULTS WITH ID

a. Main researchers

In general, disability studies are rare in France. The French medical literature is poor in this type of concern (Ravaud, 2004; Ravaud & Ville, 2005). There are few departments in this area in the Universities and the Teaching Hospitals. The research is mainly dedicated to sociological or psychological approaches. The researchers are gathered in a network: the “Institut Fédératif de Recherche sur le Handicap- IFRH 25” a Federative Institute of Research on Disability. They share a strategy of scientific developments; they operate in concert with teams, research units or laboratories from various Administrations or Offices - public-funded Research, Universities, Higher Education structures, Hospital Centers, Research Organizations (supported by Associations or Foundations) - which conduct researches in similar scientific domains or subjects. The topic of intellectual disability is not well represented in the research areas of the IFRH 25.

Another body of research is the genetic approach of ID which is well documented, particularly by the ORPHANET structure and the Rare Diseases network or by Foundations like Lejeune Foundation or NGOs such as FAIT 21.

The main topic on adults with ID is the topic of aging, an issue of central concern to the policy makers, the professionals and the advocates.

b. Collection of selected topics in ID

A great part of the papers involves mental disorders like **Mental health** (Anguis et al., 2003; Casadebaig et al., 2004; Chapiro, 2003 & 2004; INSERM, 2003 & 2004 b) **or autism and pervasive developmental disorders** (Aussilloux Iet al., 2004; Aussilloux & Livoir-Petersen, 1994; Aussilloux & Baghdadli, 2005; Azéma, 1994 & 1999a; Azéma et al., 2006; Baghdadli et al., 2002, 2003 & 2005; Barthélemy, et al., 1997; Friedel, undated ; Gayda et al., 2002; Lapuyade et al., 2000; Misès & Grand, 1999; Rogé, 1989; Sauvage & Lenoir, 2005)

Another research area is devoted to **Down syndrome** (Allison et al., 2000; Benzadon, 2002; Chagnon, 2002; De Fréminville & Nivelon, 2002; Guilbot et al., 2000; Hennequin et al., 1999 &

2000; Lécuyer, 1988a, 1988b, 1996; Réthoré. 1995, 1998 ; Satgé & Sasco, 2002; Satgé et al., 1997a, 1997b, 1998a, 1998b, 2001, 2002, 2003)

Severe, multiple and profound disabilities (Polyhandicap) gather a considerable body of researches (Beyer-Zilliox et al., 2002; Cans et al., 1999; Dutheil, 2005; Ponsot, 1995; Printz, 1997; Puisais-Hee & Saulus, 1993; Raynaud & Weber, 2005; Richard et al., 2005 ; Rumeau-Rouquette et al., 1991 ; Salbreux et al., 1979 ; Salbreux & Savy, 1993 ; Svensen, 2004 ; Zribi, 1993; Zucman, 1998)

Aging with ID is a growing trend with wide coverage in scientific papers and the administrative reports. (Azéma & Martinez, 2003 & 2005; Breitenbach, 1993, 1997, 1999, 2000; Breitenbach et al., 1998; Chagnon, 2002; Gabbai, 1990, 1992, 1993, 1998a & 1998b; Guilbot et al., 2000; Hommet, 2000; Hugonot-Diener & Hugonot, 1991; Lécuyer, 1988a, 1988b, 1996; Lefebvre, 2000; Leroux et al., 1993; Liberman, 1987; Pellerin et al., 2000; Menecier et al., 1998; Michaudon, 2002; Printz, 1997; Réthoré. 1995, 1998 ; Zribi & Sarfaty, 1990 & 2003)

Dementia in ID is poorly addressed, except by a few pioneer investigators (Breitenbach et al., 1998; Gabbai, 1998b; Visser, 1997).

The life expectancy calculation is well developed for the general population with the EuroReves network leadership (Cambois & Robine, 1994; Robine et al., 1992; Robine, 1997; Robine et al., 1998, 2003) but life expectancy in ID is poorly known (Azéma & Martinez, 2003 & 2005; Benzadon, 2002; Gabbai, 1990, 1992 & 1993). Data on population projections are available in some areas.(Marabet, 2002; Marty, 1999)

Sterilization, sexuality and AIDS prevention are the main topics on sexual health. The ethical question of sterilization, the management by staff facilities, the rights to have pregnancy, the daily support of parenting with ID are the main topics (Diederich, 1998; Diederich & Greacen, 1996 & 2002; Giami, 1999; Giami & Lavigne, 1993; Vaginay, 2002 & 2004)

Working conditions and employment studies have been completed: (Blanc, 1995; Blanc & Stiker, 1998; Hugonot-Diener & Hugonot, 1991; Leroux et al., 1993; Marissal & Robin, 2006; Moallem, 2001; Velche, 2000)

Oral and dental health is only emerging as a topic of study: (Allison & Hennequin, 2000; Allison et al., 2000; Faulks & Hennequin, 2000 ; Ginisty, 1998 ; Hennequin & Allison, 2000; Hennequin et al., 1999, 2000a, 2000b & 2004)

Activity and sport practice: Marcellini & Banens (2003) issued an important report on physical activity and sport practice by disabled persons (including people with ID) This topic is well explored in the Sport University (Bui-Xuan et al. 2000 ; Marcellini & Banens, 2003 ; Ninot & Maïano, 2000)

Cancer in ID is an emergent topic with the new longevity of PWID (Benard et al., 2003; Satgé & Sasco, 2002; Satgé et al., 1997a, 1997b, 1998a, 1998b, 2001, 2003a & 2003b, 2004a & 2004b, 2006).

3. FOLLOW-UP OF PWID AND GENERAL POPULATION

a. Epilepsy: prevalence

The most recent prevalence survey in France quoted by Abenhaim & Le Gales (2004) is 9 per 1.000 in adults (>16 years). Authors report on prevalence higher if the drug prescriptions are

taken in count: 10.4 per 1.000. So, depending of the epilepsy definition, there are between 300.000 and 600.000 French people who have epilepsy.

b. Blood pressure screening

A regional survey in Languedoc Roussillon took place, using a health questionnaire. The target population comprised adults with autism and pervasive developmental disorders (Azéma et al., 2006).

c. Blood cholestérol screening: no data.

d. Breast screening, cervical screening:

Satgé and Sasco (2002) have prepared recommendations about the population with Down syndrome.

e. Testicular cancer screening: no data.

f. Health promotion screening

i. Medication use

Baghdadli et al.(2002) stated their concern on the use of psychotropic drugs in people with autism and pervasive developmental disorders

ii. Oral hygiene:

Hennequin or De Fréminville & Nivelon (2002) with the French Federation in Down syndrome are involved in campaigns and dental health promotion.

iii. Contraception: no data

TRAINING FOR HEALTH PROFESSIONALS...and CARERS

Information about intellectual disability is not widely disseminated among health professionals (Richard et al 2005). Azéma et al., conducted interviews on this topic with the Medical and Dentistry Academic Association Secretariat, the AUFEMO to collect information on training courses providing in France. Professionals training schools in Social Work, Therapists etc., were included.

Undergraduate training

Regarding the specific undergraduate training, there are few topics about the intellectual disability in the training of nurses, psychologists, practitioners, dentists and paramedics

- Nurses training: 4 modules about psychiatrics disorders with 1 module (45 hours) about mental disability and 2 modules in humanities with 1 module about handicap.
- Psychologist training: Eight professional Masters (fifth years) treat about the intellectual and mental disability. In a Professional Master, there are approximately 460 hours of theory training and 450 hours of practice.

- University of Aix-en-Provence: Master 2 "Psychologie clinique et psychopathologie"

Master 2 "Psychologie des perturbations cognitives

- University of Amiens: Master 2 "Psychologie de la personne déficiente" (DPF)

- University of Clermont-Ferrand II: Master 2 "Troubles cognitifs et socio-cognitifs, inadaptations et exclusions"
 - University of Lyon II: Master 2 "Psychologie clinique de la santé, du vieillissement et du handicap"
 - University of Montpellier III: Master 2 "Développement, Education, Handicap"
 - University of Rouen: Master 2 "Psychologie of handicaps et de la prévention chez l'enfant"
 - University of Strasbourg ULP : Master 2 "Psychologie du développement : Enfance et déficience"
- GP training courses: In the training of psychiatry, child psychiatry and paediatrics (sixth years), in each one there are modules of 2 hours about mental disability and 2 hours about autism.
 - Dentist training: during the sixth year, there is a module (10 hours) about oral and dental health of people with an intellectual disability.
 - Training of Professionnels of sport and fitness: One professional Master (fifth years) : « Interventions et gestion en Activités physique adaptées »
 - Occupational Therapists: these professionals receive some hours during their training on the psychiatric approach of occupational therapy.
 - Carers such as social workers, the “Educatuers Spécialisés” or “Moniteurs Educatuers” receive limited training courses on ID but none specifically on health. The topic of autism or pervasive developmental disorders is better addressed. The short duration training courses for “Aides Médico-Psychologiques” give limited information on care in ID.

The postgraduate training in ID

Postgraduate training is a right for everybody during the professional activity and a legal requirement for the GP and medical specialists.

The postgraduate training of practitioners is not centrally organised. Training is available from the Universities, the Medical Unions, and other associations. Currently, the topic of health among those with ID is not offered to health practitioners. The Provence Alpes Cote d'Azur Regional Association of private practitioners (URML) do however provide more general documentation about Disability. (Available at <http://www.urml-paca.org/repertoire/accueil.html>)

Azéma et al also examined training course proposals from two of the main postgraduate training course organisers. The two organisers which have responsibility for providing publicly funded training courses are UNIFAF (13.000 public and NGO facilities and 590.000 employees in health and social facilities) and ANFH (2265 public facilities and 680.000 employees). Training regarding the health of people with ID is very rare and mostly dedicated to mental health, psychiatry and autism.

At the university level, there are few “Diplomes Universitaires-DU” or Diplomes InterUniversitaires-DIU”, University Degrees (UD) and professional learning.

- University degree: duration of UD is 1 or 2 scholar years. They are accessible for the health professional, carers, psychologist, therapist, nurses, etc.

In France, few UD concerns the training about people with an intellectual disability. The main topic concerns autism and psychiatric disorders among children, adolescents and adults. There are no specific UD about the people with an intellectual disability only.

- University of Bordeaux : DIU Autisme
- University of Clermont-Ferrand : DU « Handicap psychique de l'enfant, de l'adolescent et de l'adulte »
- University of Grenoble: DU "Autisme et psychose"
- University of Montpellier : DIU Autisme
- University of Nancy: DU "Psychopathologie de l'enfant atteint d'un handicap ou d'une maladie chronique
- University of Paris VI :
 - DU "La psychose, le polyhandicap de l'enfant et la famille"
 - DU "Psychopathologie des processus cognitifs chez l'enfant et l'adolescent"
 - DU "Accompagnement des personnes atteintes de maladie génétique et de leur famille"
 - - University of Strasbourg : DU " Autisme et trouble apparentés"
 - - University of Toulouse: DU "Formation à l'intervention pluridisciplinaire dans l'autisme" DU "Approfondissement sur l'autisme et autres troubles de développement" DIU "Autisme"
- Knowledge about Down syndrome: this training concern the medical and social professional
 - -University of Bordeaux :
 - University of Clermont-Ferrand :

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LOI n° 2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées.

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LOI n° 2005-102 du 11 février 2005 and the decrees.

http://www.handicap.gouv.fr/article.php3?id_article=97

USEFUL WEBSITES

AFRT: Association Française pour la Recherche sur la Trisomie 21. Down syndrome researcher network.

<http://www.univ-paris7.fr/AFRT/>

AGEFIPH: a Governmental Organization involving employment in the free market for people with disability.

<http://www.agefiph.asso.fr/>

ALLIANCE MALADIES RARES: the portal of the Rare Diseases Federation

<http://www.alliance-maladies-rares.org/>

ANCREAI: Federation and network of the CREAI (Regional Agency for the People with Disability and Social Affairs)

<http://ancreai.org/>

APAJH: Federation of organisations for disabled people

http://www.apajh.org/apajh/site_internet/accueil.178.html

APF: (Association des Paralysés de France), French association of the motor disabled persons.

<http://www.moteurline.apf.asso.fr/>

AUTISME France: Federation of Organizations of parents for people with autism spectrum disorders.

<http://autisme.france.free.fr/>

CCNE: National Consultative Ethics Committee for Health and Life Sciences

<http://www.ccne-ethique.fr/english/start.htm>

CESAP : “Comité des Soins aux Polyhandicapés” Multiple, severe and profound disabilities

<http://www.cesap.asso.fr/>

CNAM: Chaire Handicap, Travail et Société. University Department specialized in post-graduate training in disability study.

<http://www.cnam.fr/handicap/>

CNSA: Caisse Nationale de Solidarité pour l'Autonomie

<http://www.cnsa.fr/>

CTNERHI: research centre in disability with a documentation department.

<http://www.ctnerhi.com.fr/ctnerhi/pagint/ctnerhi/missionne.php>

DREES - Direction de la Recherche, des Études, de l'Évaluation et des Statistiques: Directorate of Research, Surveys, Evaluation and Statistics of the French Ministry of Health and Social Affairs.

<http://www.sante.gouv.fr/>

EPILEPSIE FRANCE: portal of advocate in epilepsy.

<http://www.bfe.asso.fr/index.php>

EURORDIS: European portal for Rare Diseases in six European languages

<http://www.eurordis.org/>

EURO-RÊVES NETWORK: life expectancy indicators

<http://www.reves.net/> & <http://www.hs.le.ac.uk/cgi-bin/reves/euroreves.cgi>

FAIT 21: Federation of NGO advocate in Down syndrome

<http://www.fait21.org/>

FNORS: (Fédération Nationale des Observatoires Régionaux de la Santé) National Federation of Regional Health Surveillance Centres

<http://www.fnors.org/>

French Ministry of Health and Solidarity

<http://www.sante.fr/>

Groupe de Réflexion sur la Trisomie 21 et les pathologies associées : Down syndrome researcher network. <http://www.univ-paris7.fr/GRT21/>

HALDE : (Haute Autorité de Lutte contre les Discriminations et pour l'Egalité) High Committee for Equalization and against Discriminations.

<http://www.halde.fr/>

Haute Autorité de Santé: High Committee in Health and medicine (Evaluation, Accreditation, Guidelines)

<http://www.anaes.fr/anaes/anaesparametrage.nsf/Page?ReadForm&Section=/anaes/anaesparametrage.nsf/accueilpresentation?readform&Default=y&>

Haut Comité de Santé Publique: High Committee of Public Health

<http://www.hcsp.ensp.fr/hcspi/explore.cgi/accueil?ac=accueil>

IRDES: (Institut de Recherche et Documentation en Economie de la Santé) Institute for research and information in health economics

<http://www.irdes.fr/english/home.htm>

INPES National Institute for Prevention and Health Education

<http://www.inpes.sante.fr/index.asp?page=INPES/quisommesnous.htm>

INSEE: (Institut National de la Statistique et des Etudes Economiques) National Institute for Statistics and Economic Studies. http://www.insee.fr/en/home/home_page.asp

INSERM: Inserm is the only French public organization entirely dedicated to biological, medical and public health research.

<http://www.inserm.fr/en/>

Institut Fédératif de Recherche sur le Handicap: Federative Institute of Research on Disability – Disability Network.

<http://ifr-handicap.inserm.fr/handiwebeng/preview.html>

Jérôme Lejeune Foundation: dedicated to study intelligence genetic diseases.

<http://www.fondationlejeune.org/eng/Default.asp>

LEGIFRANCE: the French Laws and Codes.

<http://195.83.177.9/code/index.phtml?lang=uk>

ORPHANET: a database dedicated to information on rare diseases and orphan drugs

<http://www.orpha.net/consor/cgi-bin/home.php?Lng=GB>

Secrétariat d'Etat aux Personnes Handicapées: State Secretariat for People with Disability

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

SESAME AUTISME: Federation of organizations of parents for people with autism spectrum disorders.

<http://www.sesame-autisme.com/site/index.php?page=accueil>

UNAPEI: Federation of organisations for parents and friends of mentally disabled persons

<http://www.unapei.org/about.mhtml>

CAT UNAPEI: Sheltered Workshop network for mentally disabled persons of the UNAPEI

<http://www.cat-unapei.org/index.php>