

Disabled Persons' Associations in France

CATHERINE BARRAL

Centre Technique National d'Etudes et de Recherche sur les Handicaps et les Inadaptations, Paris, France

ABSTRACT *In the years following the First World War, the first associations of disabled civilians were formed, to demand the same rights and measures for professional integration as those granted to victims of war and of accidents in the workplace, and to create institutions for rehabilitation. After the Second World War, associations of parents of disabled children began to create specialized institutions for children who were impaired or failing at school. The field of disability was built on the model of rehabilitation in a type of mixed economy, with associations managing institutions and the State financing and regulating them. From the 1980s, the gradual emergence of users' associations claiming equal rights and the right to autonomy on the one hand, and the "Europeanization" of associative actors on the other, led to a reorientation of public policies.*

Introduction

The first organizations of disabled persons came into being in France shortly after the First World War. At the end of the 1940s they were followed by associations of parents of disabled children. With the emergence of users' movements in the 1980s, new forms of joint action began to appear.

By becoming poles for the construction of identity from a category of impairment, movements defending disabled persons, founders and managers of specialized institutions and services in partnership with the government, and, more recently, vectors of a social approach to disability, breaking away from the dominant rehabilitation model, these organizations played a central role in building the field of disability.

The history of the relationships of the associative movement with disabled persons and the State has been one of tension between the claim for recognition of the specificities of disabled persons and their struggle to belong to the community of citizens; mirrored for the State by tension between the republican principle of integration and equal rights, and the democratic principle of equal opportunities and of taking differences into consideration.

Depending on which of these poles of tension the associations focus upon, there is considerable variation in the nature and stakes of their commitment to disabled persons, to other associations and to public authorities.

Their position on this line of tension affects how they are organized, depending on whether they are delegated to represent disabled persons, or whether the latter represent themselves. It determines the construction of their identity, depending on their conception of disability – biophysiological (individual deficient characteristic), socio-political (discriminatory stigmatization of the difference) or systemic (result of the interaction between individuals and their environment) – and the place they hold in the field of expertise, depending on whether they take medical diagnosis as a reference or whether they fight for the recognition of individual experience as a category of expertise. Their approach to rights – sometimes communitarist, sometimes universalist – defines the nature of their claims and depends on whether they are defending category-based interests by type of impairment, or demanding access for all to common rights.

The types of action that they choose are distributed along this line of tension: segregatory, integrative, inclusive or participative, they give rise to diverse types of interaction between associations (cooperative, competitive or total opposition), to either encourage or accelerate political decisions, or else oppose them.

In a context of strong tradition of state control and republican egalitarianism, public action in relation to disability shifted throughout the century, along this same line of tension, in accordance with the axes of reference employed to organize the sector of social action, and with the pressure exerted by associations that took over from the government in the management of specialized institutions. Whilst up until the 1980s the government and managerial associations agreed on the institutional measures which were required, with a view to rehabilitation, the new forms of associative expression over the last 20 years of the century, and the pressure of international and European recommendations and directives, caused the government to re-orientate public action.

By examining the main historical stages in the construction of the field of disability, in the first part of this article we attempt to identify the associative issues, oriented towards the specificities of disabled persons, defined in terms of impairments and functional limitations to be rehabilitated by specific rights and mechanisms. Interactions between associations and public authorities are built around a partnership for the social management of disability—which is the subject of the second part of this article. The third part is devoted to the slow changes to the associative landscape in France from the 1980s, with the emergence of new forms of joint action which concentrate on people's right to self-determination. The fourth part looks at the conceptual evolution of disability and at the “Europeanization” of associative actors.

The Era of Rehabilitation and of Managerial Associations

Work-related Accidents and War Injuries: National Debt and Repair

After the French Revolution had recognized the national obligation to help the disabled, it was unclear whether or not such assistance should be public or private (Ewald 1986). In the 19th century it was mainly a question of private

charity. The types of joint action relating to this problem were those developed by a small number of disparate charities, each specializing in helping a specific category of persons (“philanthropic societies”) and societies for mutual aid between disabled persons (Montès 2000).

The major upheavals which affected French society, and other western societies, such as industrialization and the First World War, led to the emergence of joint actions of a different scope and type. They fell within a context whereby the State returned to the principle of a national obligation to help the disabled, as stated under the French Revolution. The law of 9 April 1898, introducing compensation for people injured through work-related accidents, triggered a new general philosophy of aid, with notions of risk, insurance, solidarity and joint responsibility. Society’s debt to a person injured in the workplace was not paid by a simple moral obligation to help, but by the victim’s right to compensation for the prejudice incurred, a right to repair (Ewald & Stiker 1999).

An additional and fundamental step was taken with regard to repair for victims of war (Stiker 1999). The law of 2 January 1918 asserted their rights not only to compensation (pensions), but also to professional rehabilitation. The national obligation to the wounded, within the context of exercising public power for a national interest, was now seen in terms of social obligations to reinsert people into the wheels of society, especially into and through work.

During the war years, private charities (so-called “war charities”), founded on a temporary basis to provide emergency aid to the hundreds of thousands of war victims¹, had created a great number of institutions dedicated to physical and professional rehabilitation for the injured. On the one hand, the 1918 law was a case of rationalizing and perpetuating these institutions taken on by the State. On the other hand, within the context of the war and of post-war rebuilding, professional reinsertion measures met a vital economic need – that of reintegrating the workforce that the country needed (Montès 2000).

The institutional framework – legislation and institutions – which governed the implementation of compensation and rehabilitation measures during this period, constituted the basis of the rehabilitation system on which the field of disability was to be built over the following decades.

The First Associations for Disabled Civilians: the Right to Work and to Rehabilitation

Following the rights and social measures obtained for victims of war, the 1920s and 1930s saw the creation of numerous associations of disabled civilians. Appendix 1 gives the names and abbreviations of all organizations referred to in this study.

The National Federation for Persons Injured or Disabled in Accidents in the Workplace (Fédération Nationale des Mutilés et Invalides du Travail; FNMIT) was founded in 1921, and has always (even now) been of particular importance in the associative landscape. Created in response to the indifference shown by public authorities and unions towards persons injured in the workplace, it initially concentrated on winning them the same rights to professional rehabilitation as those granted to injured soldiers (the laws of

1924 and 1930) (Montès 2000). From 1927, the federation worked on behalf of all disabled persons, however the disability may have occurred. Politically neutral and independent of the unions, its strategies, recruitment policy and modes of action defined it as a union-style association, focusing on defending rights, ensuring that common rights were put into practice, and on obtaining measures of social protection and employment for all categories of disability. In 1985 it changed its name to National Federation for Persons Injured in the Workplace and Disabled Persons (Fédération Nationale des Accidentés du Travail et des Handicapés; FNATH), and then in 2003 to National Federation for Persons Victims of Life (Fédération Nationale des Accidentés de la Vie). Its 200,000 members make it one of the largest and most powerful associations for disabled persons today.

The first groups of disabled civilians essentially brought together people with physical disabilities, mainly caused by osseous and pulmonary tuberculosis, and later on by poliomyelitis. Today's most powerful associations took root during this period, such as the French League for the Reintegration of Disabled Persons into the Workplace (Ligue pour l'Adaptation du Diminué Physique au Travail; LADAPT) in 1929, and the Association for Paralysed Persons in France (Association des Paralysés de France; APF) in 1933.

The first types of joint action involved organizing mutual aid between people with the same levels of destitution, isolation and abandonment by society due to their disabilities. The next stage was to win the same rights to rehabilitation and social integration as those which had been obtained for people injured in the workplace or at war. "All disabled civilians gradually and continuously identified with war victims" (Stiker 1999).

This first wave of associations took two forms of action: claiming the right to work and creating rehabilitation centres.

After war victims and people injured at work, these associations worked to obtain some level of economic independence for disabled people, and therefore for them to be integrated (or reintegrated) in the world of employment and to have the same rights to professional rehabilitation, by calling upon the same public spirit: national solidarity.

The second form of action was to open schools, physical rehabilitation centres, professional centres, sheltered workshops and social services similar to those that had been created, with government help, for victims of war.

But unlike the former creations, these new institutions were private, run by the associations that created them, under the tutorship of the ministries for health and employment. This particular mechanism – which still continues under the control of the ministry for health and solidarity – is one of the key aspects of the French system for managing specialized institutions and, more generally, disabled populations.

This initial period thus saw the introduction of the main concepts and reference points for public and associative action (professional rehabilitation and reinsertion) in concrete legislative form. The system for delegating a public service to associations who ran specialized institutions set the foundations for a partnership between State and associations which was to

endure through the following period, with the emergence of new associative actors: the parents of disabled children.

Construction of Identity

As they were created, associations shared common characteristics which led to a model for associative operation and for the construction of the identity of the group that they formed and of the type of impairment upon which they were focusing. The function of representation, in its different semantic forms – cognitive, statistical, political and projection into the public arena – played a key role in these processes.

The legitimisation and visibilization of the demands specific to each association were constructed on the one hand on the basis of the production of a cognitive representation of the disability upon which the association was focusing, and, on the other hand, on the basis of the singular identity of the group it represented and for which it is the spokesperson when dealing with public authorities, in order to give the scope of a public problem to the individual and social problems of its members.

The organization of forms of mutual aid, exchanges and support, based on common experience of the problems specific to a particular type of impairment, was the first objective that brought people together by type of disability or origin of disability (work-related accidents, war injuries, physical impairments of other origins, deafness, blindness, and then, later on, intellectual impairment, multiple disability, psychological problems, disabling illnesses by type of diagnosis, etc.). At the crossroads of medical, social and day-to-day life experiences, of scientific knowledge as it developed throughout the century with regard to the origins and mechanisms of various types of disability, and of specialist professional knowledge in the field of rehabilitation, a cognitive and distinct image of each type of impairment was progressively built.

Associative identities were forged on the basis of these common representations of disabilities and through the transformation of individual problems into joint causes. They took shape by their function being given concrete form in a specific legal status. The most common status in France is that of a non-profit-making association, as governed by the law of 1 July 1901, relating to the associative contract².

In the French system for developing public policies, which involves not so much parliamentary lobbying as interest groups working directly at policy-making level, the fact that the government accepts civil actors as interfaces and partners is based upon criteria of legitimacy that include the representativeness of the groups and the extent to which their demands fit in with the general interest. In order to be sure that their category-based demands are taken into account by public authorities, associations must prove their legitimacy, as representatives of both the groups they are defending and the category-based interests.

This legitimization process is linked to other forms of representation. Although the representative quality of associative spokespersons is acquired through democratic election by members, it remains insufficient to bring

politicians to examine their demands. Associations thus strive to show that in addition to their members, they also represent everyone concerned by the disability upon which their action is focused. From time to time, this necessity for numerical representativeness leads them to strategically group together to defend common interests, particularly when laws are being developed.

More often than not, this statistical representativeness is linked to a symbolic representativeness through support from well-known scientists, doctors and politicians whose fame lends credibility to associative actions and whose social capital makes it easier to obtain political support.

Parent Associations and the Institutionalization of "Maladjusted" Children

Between the two world wars, associations consolidated their position and continued to develop institutions.

During the Second World War, the Vichy government extended the principle of rehabilitation in specialized institutions not only to juvenile delinquents, but also to impaired children, by the creation in 1943 of the Conseil Technique de l'Enfance Déficiente et en Danger Moral (Technical Committee for Impaired Children and Children in Moral Danger), and encouraged the creation of private institutions. When the war ended, parents of disabled children began to mobilize, and it was in relation to the cause of children with mental problems that the first parent associations were created. Local initiatives became increasingly common and in 1960 they united to become the National Union of Associations of Parents with Maladjusted Children (Union Nationale des Associations de Parents d'Enfants Inadaptés; UNAPEI), now the most powerful association in the field of mental impairment, in terms of numbers of both institutions and personnel; and which is in charge of almost half of the specialized institutions for children and adults.

The objective of these associations was to open institutions where children who had until then been confined to hospitals or to living with their families could benefit from suitable care. Such institutions were initially planned for patients with severe mental disabilities, but they rapidly integrated other categories, favoured by an extremely broad definition of "maladjusted children" requiring special education as described in the Nomenclature and classification of maladjusted youngsters (Nomenclature et classification des jeunes inadaptés) (1943): "Maladjusted means a child, a teenager or more generally any youth under the age of 21 whose insufficient aptitudes or failings of character put him or her in lasting conflict with reality and with the expectations of those around him or her, in line with his or her age and social milieu."

As many authors have shown (Chauvière 1980, Gateaux-Mennecier, 1980, Muel-Dreyfus 1983, Pinell & Zafiroopoulos 1978, 1983, Vial 1990), several factors were part of this "invention of abnormal childhood" which contributed to the extension of the field of disability and to the expansion of associative power.

During the period of post-war national reconstruction, the wave of social measures (the most important being the creation of the French social security

system in 1945), which went hand in hand with the economic recovery, was aimed at the majority. The French government was therefore quick to recognize the utility of these parent associations, which meant that it did not have to create specific institutions to meet the educational needs of impaired children. From 1956, this recognition of the public utility of these associations led to French social security paying the running costs of the institutions, and also to a very flexible control of their creation and orientation.

With the diversification of clients, allowed by the extended definition of maladjustment, an ever-increasing number of institutions sprang up throughout France. This new institutional field was organized in a relatively independent manner, based on a psycho-medico-educational model, and where “relationship experts” (paedopsychiatrists, psychologists, special educators, soon to be followed by new specialities: psychomotricians, speech therapists, psychoanalysts), suffering from a lack of recognition in the academic field, find a field of application of their skills, thus creating a body of technical allies for associations managing institutions.

Despite the associative approach which put this form of readaptive intervention across as a necessary stage prior to an educational integration (or reintegration), institutions rarely dealt with reinsertion; indeed, they accepted a never-ending and increasing number of children with educational problems, and rejected by state schools with an insufficient number of “remedial classes”.

Little by little, parents of children with other impairments (sensorial, motor) founded their own associations and followed the same model to build specialized institutions. It was thus upon the initiative of associations, and as the children gradually grew older, that a specialized branch was created, from childhood to adulthood, leading to the proliferation in institutions for each age group (medico-pedagogical institutes for children, medico-professional institutes for teenagers, and sheltered workshops for adults).

A Public–Private Partnership “à la Française”

The model of the managerial association inaugurated between the two World Wars for the rehabilitation of adults through delegation by the public service has been generalized. Combining the roles of founders, administrators, employers and beneficiaries of the institutions, associations manage 80% of the equipment, a virtual monopoly that sanctions their partnership with the government. Yet despite their roles as managers and employers in this type of mixed economy, it is not a case of the disability sector being equally managed by associations, government and professional unions; the institutions remain under the control of the French ministry for social action and its regional and county administrations. This forces associations to diversify their modes of negotiation and their methods of applying pressure at the various national and local political and administrative levels, in order to continually consolidate the links with the government that allow them to remain in existence.

At local level, they create regional and county delegations which deal with the decentralized government administrations in charge of applying the

regulatory aspects of public policies relating to authorizations to create institutions, to the increase in the number of places and to the determination of the daily rate.

At national level, demands go through traditional parliamentary channels, but they are also the object of direct negotiations with ministries and with central administrations, prior to parliamentary debates.

The institutionalization of the relationships between associations and local or national government also takes forms which are less obvious, but extremely personal, in a distribution and exchange of skills put to the service of both the government and associations: senior civil servants and politicians (members of parliament, mayors) sitting on associations' boards of directors—civil servants by day, militants by night, and associative board members being called upon to join the upper echelons of the civil service. These forms of permanent interaction which underlie the indissociability of the politico-administrative and associative dynamics still exist. For example, the current inter-ministerial delegate for disabled persons (Patrick Gohet) was previously the executive director of the UNAPEI; the chairman of the APF (Marie-Sophie Desaulle) was recently appointed director of a regional agency for hospitalization (senior official in charge of regional health matters); Marcel Royez, chairman of the FNATH, is now in charge of social affairs for the French Ambassador in Morocco.

The Law of Orientation in Favour of Disabled Persons and the Group of 21

At the beginning of the 1970s, the preparation of a law on disabled persons was announced. It was to be the French welfare state's finishing touch to its global social action policy that had been underway since the 1960s in other social sectors. By putting onto the agenda the republican principle of integration, which it deemed to be a "national obligation", the policy aimed to reinsert or maintain persons in the most difficult situations within the national community, as part of a vast programme of planning and a tighter control by government departments (Jobert 1981). Psychiatric sectorization, undertaken in 1960, thus aimed to replace confinement in asylums by curative and preventive action in the community. In 1962, steps were taken to allow elderly people to remain at home. In 1971, a family-help system was introduced to avoid children designated as "social cases" from being placed in institutions.

With regard to disabled persons, invalids and "maladjusted children", preparatory work (and the Bloch-Lainé report (1967) in particular) for the forthcoming law planned for formal unification of the field, bringing children and adults together within the same legislative and administrative group under the generic term "disability". The task was to build a global cognitive representation of disability and to ensure coherence between successive generations of institutions and legislation that had been designed to meet the objectives of the time.

Rehabilitation within a specialized milieu thus had to be a means of integration into common areas of life (schooling, work, housing, leisure,

transport), along with financial allowances for disabled adults and parents of disabled children, and mechanisms which helped achieve educational and professional insertion (today called “positive discriminations”).

In order to achieve such a project, it was in the interest of both the government and the associations to ensure coordination between representatives of public interests, senior civil servants defending the overall philosophy of the project, and the associative representatives defending their sectorial interests, directly concerned by the implementation of this philosophy through the regulations which were to be introduced.³

In order to take on the role of consultants and partners in the drafting and implementation of this law, in 1974 the most powerful and most representative associations developed an original form of organization, with no legal status, based on a principle of inter-associative cooptation which allowed them to present a united front for proposition or opposition, transversal to the category-based interests that they defended by type of impairment, bringing together those that had been created for adults between the two World Wars (first and foremost the APF) and those created more recently for children, the two largest of which, in terms of the number of members and the number of institutions they managed) were UNAPEI and the Association for Adults and Young Disabled (Association pour Adultes et Jeunes Handicapés; APAJH). This informal group of 21 associations, known as the “Group of 21”, became the preferred interface for ministries and members of parliament responsible for preparing the law (secretary of state for social action, prime minister’s office, ministries of finance and employment and the parliamentary group in charge of the matter) (Guyot 2000).

The “law of orientation in favour of disabled persons” was passed in 1975 and would indeed appear to have been a joint effort by the government and managerial associations.

Despite the urgent need for integration that had been announced, integration remained very limited and largely subordinate to the need for rehabilitation. Managerial associations were confirmed in their partnership with the government, pursuing a social policy which was closer to the needs of population management than to the objectives of social reinsertion.

Everything led to this law being considered as “the result of a process of institutionalization” (Stiker 2000). The institutionalization of the disability sector, henceforth a specific and unified administrative entity, within a legislative and regulatory framework; the institutionalization of the status of “disabled person” which gave a person the right to benefit from services (allocations) and from orientation into a specialized milieu; finally, the institutionalization of relationships between associations and the government, with associations having the right to be part of county commissions in charge of allocations and orientations (County Commission for Special Education (Commission Départementale d’Education Spéciale) and Technical Commission for Orientation and Professional Reclassification (Commission Technique d’Orientation et de Reclassement Professionnel)). The law put the finishing touches to making this partnership an official one, allowing for the creation of an “inter-ministerial committee for the coordination of adapta-

tion and rehabilitation, aided by a national advisory board for disabled persons, with members being representatives of associations and of public and private organizations”.

The majority of the associations which were members of the Group of 21 were also members of the National Advisory Board for Disabled Persons (Comité National Consultatif des Personnes Handicapées; CNCPH)⁴. Yet not only did this group wish to remain in existence and maintain its independence after 1975, it also saw its membership level rapidly rise in subsequent years, through internal cooptation, just as when it was first created. It became the “Group of 29” and then the “Entente Committee”, and it now has 59 member associations. It acts as a sort of watchdog committee. It is independent of government bodies and acts to back or to oppose ministerial projects and decisions, via its member associations represented within the CNCPH, where they are officially appointed by the minister responsible for disabled persons. Its proposals are put forward by eight bodies (APF, APAJH, Action and Coordination Committee of Parents of Children and Adults with Multiple Disabilities (Comité d’Action et de Liaison des Parents d’Entants et d’Adultes atteints de Handicaps Associés; CLAPEAHA), National Committee for the Social Promotion of Blind and Amblyopic Persons (Comité National pour la Promotion Sociale des Aveugles et Amblyopes; CNPSAA), French Federation of Associations of Persons with Cerebral Palsy (Fédération Française des Associations d’Infirmes Moteurs Cérébraux; FFAIMC), Group for the Insertion of Physically Disabled Persons (Groupement pour l’Insertion des Handicapés Physiques; GIHP), National Union of Associations of Friends and Families of Mentally Ill Persons (Union Nationale des Associations des Amis et Familles de Malades Mentaux; UNAFAM) and UNAPEI), which represent the different categories of disability and which form a sort of unofficial management committee.

Whilst managerial associations approved of the passing of the law, opinion within the associative milieu was divided.

The Anti-Establishment Movement of Disabled Students in the 1970s

Opposition from disabled students fighting against assistance (Disabled Persons’ Committees of Opposition (Comités de Lutte des Personnes Handicapées) and Movement in Defense of Disabled Persons (Mouvement de Défense des Personnes Handicapées)), stemming from student unions and militant organizations of the far left joined together in the Disabled Persons’ Action and Coordination Group for the Repeal of the Law on Orientation (Collectif d’Action et de Coordination des Handicapés pour l’Abrogation de la loi d’Orientation; CACHALO). Although these movements were not truly speaking part of the associative milieu, this type of joint action and the subsequent analyses were deemed to be useful, partly because they were shared by some traditional disabled persons’ associations (the General Confederation for the Blind, Deaf, Severely Disabled and the Elderly (Confédération Générale des Aveugles, Sourds et Grands Handicapés et Personnes Agées), the National Federation for Ill, Disabled and Paralysed Persons (Fédération Nationale des

Malades, Handicapés et Paralysés) and, to a lesser extent, the French Union for Persons Suffering from Myopathy (Union des Myopathes de France)) and partly because they sowed the seeds for the demands for autonomy and the application of civil rights expressed by current users' associations.

Their critical analysis of the socio-political and structural causes of disability called into question the rehabilitation model, the partnership between the government and the associative establishment and the general direction of social policies governing disabled people's personal, social and professional lives. They criticized the segregationist nature of specialized institutions and demanded access to ordinary premises of everyday life and a reassessment of financial resources for people who could not work. They criticized the paternalistic attitude towards disabled persons of the managerial associations run by parents of disabled children and adults and by professionals (Turpin 1990). Some time later, certain authors were to analyse how disabled persons interiorized values of the able-bodied, the very object of their rejection (Bardeau 1986).

Defining themselves as organizations of disabled people and run by disabled people – non-disabled persons could not be elected to their decision-making bodies – they considered that their cause could only be understood and defended by people who had experienced disability and the exclusion, stigmatization and humiliation that public and associative policies of assistance impose.

Marginalized by the associative establishment and by the failure of attempts to create alliances with other social movements (Movement for Legislation on Abortion and Contraception (Mouvement pour la Légalisation de l'Avortement et de la Contraception; MLAC), Prisoners' Action Committee (Comité Action des Prisonniers; CAP), Asylum Information Group (Groupe d'Information Asile; GIA)), or with the milieu of manual workers which, on the one hand did not feel itself to be a part of this left-wing movement that had been started by the intellectual classes, and which, on the other hand – though without openly admitting it – believed that their demand for greater resources could only have a negative effect on the working class which was asking for an increase in the SMIC (minimum income), the movement ran out of momentum and then died out in the 1980s, 10 years after it had begun (Turpin 2000).

The 1980s–New Forms of Associative Action

The Claim for Autonomy and Alternatives to Institutionalization

In addition to the specialized institutions governed by the 1975 law, which continued to run without any particular changes, certain local initiatives were begun to try to find new forms of communal life as alternatives to institutions and confinement. These initiatives were based on the expectations directly expressed by those concerned – more often than not teenagers or young adults – and which eventually met those expressed by social workers, who also tended to be critical of specialized institutions and who were looking for other

forms of professional practice. The definition of a joint project, in a context where the utopia of 1968 and “power to the imagination” (one of the slogans used in the “May 68 revolution” in France) were still very much alive, led to new types of relationship between professionals and young disabled persons.

This research and experimentation, with the objective of allowing these young people to manage their own everyday lives, allowed them to get to grips with the emancipatory social roles and functions of user and consumer who could be critical of the services with which they were being provided, putting them in control of their action – a status which was socially and subjectively very different from that of “young disabled person from an IMPro” (medico-professional institute).

The pragmatic aim of creating small ad hoc associations was to give the project a legal form which would allow it to get the financing needed to see it through to conclusion.

This was the case of the “Vivre debout” (“Live standing up”) association. A small group of myopathic teenagers who were in conflict with the institution in which they were being educated, with help from a teacher who was himself disabled, founded the “Vivre debout” association in 1974. An initial self-managed home was created in 1977 for the nine young adults who had worked on the project. Two further homes were opened in 1978 and 1981, respectively welcoming 9 and 11 disabled persons who had volunteered for an experiment on self-management of their place of living. Although “Vivre debout” had no connection with the *Independent Living* movement which was at that time developing independent living centres in the United States and Canada (De Jong 1979), the initiative was nevertheless a similar type of joint action for the management of everyday life (Galli & Ravaud 2000).

The creation of the *Hand'in Cap* association in Montpellier, upon the initiative of Mireille Maller, was part of this user association movement (Maller is the author of *Handicap et autodétermination. Emergence d'un mouvement révolutionnaire*, a master's degree thesis written in 1999 at Université Montpellier III). Its aim was to set up an independent living centre (linked to the *Independent Living* movement) and home assistance for young adults severely disabled by a myopathy. In 1995 the association then founded ENIL-France (European Network on Independent Living), part of ENIL-Europe. Their demands included the refusal of disabled persons being orientated into institutions and the reassessment of financial allocations in order to allow them to live at home and to freely choose healthcare services and home help.

GIHP, originally an association for disabled students, was a special case. This association was simultaneously a group of users, a service management association and the founder of the French branch of DPI (Disabled Peoples' International). Some of its members took part in the militant movements of the 1970s and shared their criticism of the collusion between managerial associations and public authorities. But they left the area of simple contestation and rapidly decided to find concrete solutions to the problems of social insertion, creating transport services for disabled persons and auxiliary services for home-living for disabled employees – initially in Paris,

then in the provinces, whilst at the same time increasing the number of regional delegations.

An active member of DPI, GIHP attended the European forum for disabled persons and took part in French associations' liaison operations with European networks. Its main activities were to improve the distribution of information about DPI's objectives, in particular to users' associations and public authorities, and to train groups of disabled persons in *peer counselling* and *peer support*.

Another form of joint action came into being in the field of mental health with Advocacy France, an association of patients and former patients of mental healthcare services, and of care providers and volunteers in Paris and in Caen. The association has a participative and emancipatory vocation and was created with a view to providing help and mutual assistance in everyday life, mediation in day-to-day situations (renting a flat, family matters, medical matters, etc.) and support in the acquisition and exercise of civil rights⁵. It was very quick to contact Mental Health Europe (of which C. Deutsch, co-founder of Advocacy France, was to become a board member).

These innovative initiatives have several common characteristics which are food for thought. One might wonder why they are so rare. One reason for their rarity might be that they are more often than not initiated by disabled persons themselves, who are directly concerned and who will benefit from seeing the project through to fruition. But other contextual and structural factors are also involved and remain to be examined, very little research having been done on them in France.

They are also characterized by their objective, which is not to turn individual problems into a group cause, but to resolve day-to-day problems. They thus remain limited to small groups, which means that they have little visibility in the current associative landscape. But again, we might wonder about this lack of visibility, given the solutions that these initiatives provide to problems facing a far greater number of persons and given that they could easily reproduce if resources were made available.

When they exist in the same social sector, they can sometimes group together for joint operations, but they can also find themselves in competition with one another, drawing upon the same subsidy budgets granted by public authorities.

Another characteristic common to several of these initiatives is their links with European or international networks involved with the same issues. Their stories show that they find this to be an alternative to their invisibility at a national level. On the one hand these networks give them the opportunity to share common experiences and a common language, and inspire them to take further initiatives. On the other hand, regarding networks which take the form and force of social movements, the significance of their actions is amplified, taking on a broader scope and becoming part of a political discourse which transcends their local causes. Their claims and the types of action that they undertake are thus more likely to be heard and recognized at national level and to affect public policies.

Two other associations must be mentioned in this panorama of French associations. They stand out through the original nature of their objectives

and the resources they have: one at national level, the French Association against Muscular Dystrophies (Association Française contre les Myopathies; AFM); the other on the world stage, Handicap International.

Two Atypical Associations

The French Association Against Muscular Dystrophies (AFM)

In 1958, parents of myopathic children created an association with the dual objective of backing research into the causes of myopathy and into possible treatments for an illness which the medical world was ignoring at the time, and of creating medico-social institutions to look after their children's physical and motor disabilities. For 20 years the AFM's main activity was that of creating institutions, making it no different from other associations working in the field of rehabilitation. The backing it was able to provide for research remained secondary, limited to the traditional methods of collecting donations that was characteristic of the associative milieu at that time. From the 1970s, with the hopes inspired by the development of genetic research, the AFM redefined its objectives – not without conflict within its executive board – and confirmed the priority of backing research, giving itself new and original methods to achieve this objective. In 1981 it created its own scientific committee of doctors and fundamentalist researchers and pioneered a form of collaboration between scientific and medical experts, association representatives, disabled persons and their families, a joint effort combining lay and scientific knowledges of the disease. This resulted in a new model of associative negotiations between laymen and scientists, soon followed by other associations in the field of disability. In 1987, with the Telethon that it introduced in France following the example of the MDAA (Muscular Dystrophy Association of America) it revolutionized associative methods of collecting funds, though not without coming under serious criticism from the milieu, destabilised in its habits and representations.

By injecting the funds collected into research, and by working with scientists to determine the targets to fund, the association imposed itself as a true partner in research and public health policy, playing a direct role in the production process (Paterson & Barral 1994, Rabeharisoa & Callon 2000); for example, in 1990, the AFM created the Généthon, a high-performance genetics laboratory.

A member of the Entente Committee and of the CNCPH (see above), it holds an indisputable position in the associative milieu of disability, which it has never ceased to support by developing (in parallel to its scientific activity in the name of general interests) personalized services in response to individual needs and rights.

Handicap International

This association was not created by disabled persons or their families, but by professionals in the fields of social work, rehabilitation, insertion and law, and

does not see itself as an organization for disabled persons but as an aid for them, for their social insertion and rehabilitation and to defend their rights. Handicap International does little work on French territory, but rather targets developing countries to implement its philosophy of action, based on the notions of capacity building, empowerment and the defence of individual and joint rights, and its programmes of action (educational, professional, rehabilitational, etc.) over the long term, or in emergency situations where there are victims of natural or political catastrophes. Given the way it works, and its partnerships with local social players in the field of disability, it is similar to other French initiatives in the medical world, such as Médecins du Monde and Médecins Sans Frontières (French Doctors). Although it is not very involved in French associative life, it plays an important associative role at an international level. For example, it was at the origin of a worldwide campaign to remove anti-personnel mines, for which it was awarded a Nobel Peace Prize. It also helped draft the international convention on the rights of disabled persons, approved by the United Nations Assembly in December 2006.

International and European Pressure

United Nations Impetus

Up until the 1970s, the UNO's recommendations on disabled persons related mainly to the question of functional limitations and rehabilitation. From 1975, the UNO brought the issue of disabled persons' rights to the heart of its policy and of its programme of actions, with the Declaration on the Rights of Disabled Persons, followed by the proclamation of the International Year of Disabled Persons in 1981, and then by the worldwide action programme for the United Nations Decade for Disabled Persons.

The European Council and the European Parliament approved resolutions to back the United Nations policy, and the European Commission undertook a vast programme of actions to promote the economic, social and professional integration of disabled persons at European Community level (Helios, Tide, Horizon, Handynet, etc.). These programmes of support for innovative experiments and for the creation of networks were an effective means of making countries aware of the European Commission's orientations regarding disability and made it possible for local actors to develop initiatives which often struggled to gain attention and aid from public authorities (Barral 1999). French users' associations benefited from these programmes and networks for the exchange of experiences, especially in the field of mental health. The dominant associative movement nevertheless remained relatively indifferent to this European and worldwide undertaking.

The programmes of action initiated by the United Nations and the European Commission accentuated the rising force of disabled persons' movements and their interactions with European and international political bodies. Created in Canada in 1981, Disabled Peoples' International became a preferential partner of the UNO, of its agencies (the WHO in particular) and of the European Commission, regarding disability matters, progressively

followed by national movements for disabled persons to whom these programmes of European and UN actions offered a platform and the means to gain further recognition.

The rising strength of the associative movement (and its demands) throughout Europe led to the creation in 1993 of the European Parliament of Disabled People and of the European Forum for Disabled People. The institutionalization of associative groupings had the effect of empowering demands and of giving associative representatives a consultancy status among international and European bodies and, if they were not recognized as partners in social dialogue, the status of partners in civil dialogue (Barral 2000, Priestley 2007).

The Europeanization of national public policies took place through two channels: that of the “fast track” of legislation which involved restrictive measures for the member States – such as the Amsterdam Treaty (article 13), and that of the “slow track” of debate, of the circulation of ideas and the exchange of good practices between representatives of the different countries (Mohanu 2007).

This “slow-track” Europeanization played a very significant role in making the more conservative French associations aware of social approaches to disability.

Analysis in France of the structural causes of disability has become increasingly important in the field of disability research over the last 30 years, made richer by the introduction of works from English-speaking countries on social models of disability, and by debates on the revision of the *International Classification of Impairments, Disabilities and Handicaps* in the 1990s (Albrecht, Ravaud & Stiker 2001).

But managerial associations remained relatively indifferent to the analyses of the scientific community, and were little inclined to draw inspiration from the inclusive experiments being developed in other countries and the theorizing that went along with them. In its theoretical aspects (environmentalist or based upon human rights), its concrete participative applications and its political perspectives of non-discrimination, the social approach to disability nevertheless gradually penetrated the associative “fortress”, via the “slow track”, notably with regard to France’s participation in the European Forum and the debates which accompanied the review of the *International Classification of Impairments, Disabilities and Handicaps* in France, which was a vehicle for UN standards for disability.

The European Forum for Disabled Persons and the Europeanization of French Associative Actors

Characteristic of the way European institutions operate when developing community standards and programmes of action, the introduction of consultative bodies which bring together public and private partners in the sector concerned, and the search for consensus through debate between different parties, leads to a pluralist representation that excludes, at European

level, any further monopoly of representation in the form that it exists within the French field of disability.

When the European Forum for Disabled Persons was created in 1993 as a consultative body for the European Commission, and the member countries were invited to form representative national committees, the Group of 21 (which had become the Group of 29 and which now consisted of 42 associations) took it upon themselves to choose the French delegation. The French Committee for Disabled Persons on European Matters (Conseil Français des Personnes handicapées pour les questions européennes; CFHE) was made up of eight associations, six of which represented the managerial movement, members of the Group of 29's management board (APAJH, APF, CNPSA, UNAFAM, UNAPEI, National Union for the Social Insertion of Persons with Hearing Impairments (Union Nationale pour l'Insertion Sociale du Déficient Auditif; UNISDA)), a users' association, Group for the Insertion of Disabled Persons (Groupement pour l'Insertion des Personnes handicapées physiques; GIHP) and the National Federation of Victims of Life (Fédération Nationale des Accidentés de la vie; FNATH).⁶

At the time, the European Forum included 12 NGOs of European or international dimensions, and 15 member country committees each of which contained representatives for each different type of impairment. The organizations which were forum members thus represented the interests of more than 80 European associations and more than 800 local or national associations throughout the European Union. Although there was a majority of managerial associations within the French Committee (CFHE) the Forum itself was very much in favour of the new disability culture, under pressure from the DPI and users' associations, and supported by United Nations recommendations. Priority was given to demands for inclusion, equal rights, non-discrimination and the will to bring the European Commission to come up with measures which would force member countries to respect these rights. The slogan "*Nothing about us, without us*" demonstrated the determination of Forum members to be involved in all decisions that related to them and to impose the *disability perspective*, i.e. the notion that disability should be taken into consideration in all development projects.

Faced with such a variety of experiences and attitudes, French associative representatives had to learn about the European culture of consensus, the concepts and reference points of European policy: empowerment, mainstreaming, inclusion, non-discrimination, citizenship, civil rights. Back in France, as delegates, their task was to pass these reference points and arguments on to the national consultative committee for disabled persons (CNCPPH) and other groups.

In the election of Paul Boulinier, chairman of the APF, a historical managerial association, to the vice-presidency of the Forum shortly after it was created, one could see the strategic and political qualities that had been acquired through years of negotiations with the government on disability matters.

The "slow track" would seem to have borne its fruits and French associations realized that European directives would be quick to force them to reform the institutional care system if they did not take early action. Some

associations, the APF in particular, therefore came up with programmes of community-based service provision and home help, in order to be able to allow people to live at home if they so wished.

Revision of the WHO's International Classification of Impairment, Disability and Handicap

During the 1990s, work on the revision of the *International Classification of Impairment, Disability and Handicap* (CIDIH), undertaken by the WHO, and to which the French WHO collaborating centre (Centre Technique National d'Études et de Recherche sur les Handicaps et les Inadaptations; see <http://www.ctnerhi.com.fr>) had made a significant contribution, procured another method of enabling the social approach to disability to penetrate the associative milieu (along with the politico-administrative milieu in charge of disability).

Consensus conferences with associations' representatives, assessment tests for drafts that were in 2001 to become the International Classification of Functioning, Disability and Health (ICF), publications by associations and by the collaborating centre (two issues of *Handicap – Revue de Sciences Humaines et Sociales*, in 1999 and 2002), numerous local and national presentations of the new classification – all of these were opportunities to discuss the social models of disability, the systemic model underlying the conceptualization of the classification that was being prepared, their foreseeable effects on associative managerial policies and public policies, in order to enable disabled persons to enjoy social participation and exercise their civil rights.

These conceptual models destabilized the dominant representation of disability as an individual problem and associations' attachment to the previous classification (ICIDH (International classification of impairments, disabilities and handicaps)). Its conceptual breakdown (impairment, disability, handicap) reflected that of France's public and associative policies on rehabilitation and compensation, and boosted the belief of associations that their provisions for disabled persons were well-founded. The resistance from French associations was seen in the fact that the results of their assessment tests for the new classification were generally more negative than those of the other collaborating centres. On the other hand, the disabled persons representing users, and the representatives of public action in the field of social action who took part in the work, felt that despite its faults, this classification reflected an international conceptual evolution in the field of disability that France could no longer ignore.

Conclusion

It was in the aftermath of major national events that the issue of disability was taken onboard in France. The first of these – the French Revolution – made it a national obligation to help disabled persons. Following the First and Second World Wars, private initiatives were undertaken to care for disabled persons. In the 1920s, the first wave of associations created specialized institutions and fought for physically disabled persons to have the right to professional

reinsertion, following the rights that had been granted to victims of war and at work, thus making civil disability a public issue.

At the end of the 1940s, a second wave of associations created specialized institutions for children who were disabled or failing at school. Unlike the institutions from the previous era, which had been designed to equalize work opportunities, this new generation of medico-social institutions created a segregatory space on the fringes of society, in the name of the right to rehabilitation and care. Between these two generations of associations, managing specialized institutions through delegation of the public service, and the government which financed and regulated the way in which they were run, there grew a sort of mixed economy and a form of public-private partnership which was characteristic of the construction of the field of disability in France. In 1975, the law of orientation in favour of disabled persons marked the height of the rehabilitation system governing this field. It established disability as a politico-administrative category and confirmed managerial associations in their role as unquestionable partners in public policy making.

With this other national event, the May 1968 student movement, the disabled students' objection to the 1975 law put the spotlight onto the fundamental tension that existed in France on the issue of the needs of disabled persons, between the right to rehabilitation in institutional settings and the right to autonomy, self-determination and free choice of one's way of life.

The 1980s onwards saw the gradual emergence of new forms of joint action, offering alternative solutions to that of specialized centres, but remaining marginalized by the dominant associative milieu.

At the same time, at European and international levels, the demands of disabled persons for autonomy, non-discrimination and access to common rights were becoming more insistent and were receiving support from international bodies (the UN, European Council and European Commission), through recommendations and directives, through the European Forum and with such tools as the international classification of the WHO, intended to circulate a disability model that accedes to social participation and to the citizenship of persons with disabilities. French managerial associations, as well as the State, were led to a "Europeanization" of their policies, to take into account the voice of users' associations which were still scattered and to reduce the tension raised by the issue of the rights of disabled persons in other terms than that of a specific status based on the sole acknowledgement of impairment and functional limitations. This is the project for a different public policy that the French government gave itself, with the "law on equal rights and opportunities, participation and citizenship for disabled persons" of 11 February 2005, built around two notions, those of compensation and accessibility (see Winance, Ville & Ravaud 2007, in this issue).

Notes

¹ The number of wounded is estimated at 1,500,000 over a three-year period, for France.

² This law met a dual political need: that of turning the individuals into citizens by teaching them the mechanisms of representative democracy (election of boards of directors and of representatives) and by regulating civil society's participation in political debates.

- ³ The aim of this form of mediation between the politico-administrative elite and public action by civil society was to work together to give direction to public policies. It is characteristic of the French system for developing public policies in the various different areas of economic and social development (agriculture, defense, health, social action) during periods of economic growth (Jobert & Muller 1987).
- ⁴ CNCPH was to have its role and functions redefined and extended as part of major legislative reforms in 2002 and 2005. Since 2002 it has been made up of 65 members, of which 24 are family or disabled persons' associations, 17 are associations or public organizations working on behalf of disabled persons, 4 are representatives of local communities, 5 are social protection organizations, 10 are representatives of employee and employer unions and 4 are research organizations.
- ⁵ Its founders, Martine Dutoit-Sola and Claude Deutsch, are the authors of *Usagers de la psychiatrie: de la disqualification à la dignité* (Paris: Erès), 2001.
- ⁶ At the same time, another group of 10 associations was brought together by the GIHP (a member not only of the Group of 29, but also of the CFHE and the OMPH/DPI (Organisation mondiale des personnes handicapées/Disabled Peoples' International)) to make up this very same French representative committee at the European Forum: the French Group for Disabled Persons (Groupement Français des Personnes Handicapées; GFPH), comprising the New French Association for Persons with Multiple Sclerosis (Nouvelle Association Française des Scléroses en Plaques; NAFSEP), Association of Gerontology (Service d'Aide aux personnes âgées; AGEMO), National Association for the Defence of Ill, Impaired and Disabled Persons (Association nationale de défense des Malades, Invalides et Handicapés; AMI), National Association for Parents of Blind Children (Association nationale des Parents d'Enfants Aveugles; ANPEA), National Association for the Integration of Persons with Motor Deficiencies (Association Nationale pour l'Intégration des Handicapés Moteurs; ANPIHM), Association of Disabled Persons in Public Research (Association pour le Travail des Handicapés dans la Recherche Publique; ATHAREP), Croisade Des Aveugles (Crusade for Blind People), National Federation of Deaf Persons in France (Fédération Nationale des Sourds de France; FNSF), National Union of Persons with Polio in France (Union Nationale des polios de France; UNPF) and UNAPEI. Most of these 10 associations, although not managerial, were ideologically not very different from the dominant movement, and worked along the traditional lines of defending and supporting disabled persons and their families. In attempting to obtain the official status of French committee for this group of associations, GHIP/DPI and its chairman Jean-Luc Simon aimed to strengthen their identity as non-managerial and as a national mouthpiece, with the objective of carrying more weight in French debate. The GFPH's application was turned down in favour of the other candidate committee, CFHE.

References

- Albrecht, G., Ravaud, J. F. & Stiker, H. J. (2001) L'émergence des disability studies: état des lieux et perspectives (The emergence of disability studies: state of the art and perspectives, not available in English), *Sciences sociales et Santé*, 19(4), pp. 43–73.
- Bardeau, J.-M. (1986) *Voyage à travers l'infirmité: du non être valide à la construction du soi handicapé* (*Travel Through Infirmary*, not available in English) (Paris: Ed. du Scarabée).
- Barral, C. (1999) De l'influence des processus de normalisation internationaux sur les représentations du handicap (Influence of international normalization processes on the images of disability, not available in English), *Handicap – Revue de Sciences Humaines et Sociales*, 81, pp. 20–34.
- Barral, C. (2000) Les ONG de personnes handicapées et les politiques internationales: l'expertise des usagers (Disabled persons NGOs and international policies: the expertise of users, not available in English), *Prévenir*, 39, pp. 185–190.
- Bloch-Lainé, F. (1967) Report to the prime minister: *A Study of the General Problem of the Maladjustment of Disabled Persons* (Paris: La Documentation française).
- Chauvière, M. (1980) *Enfance inadaptée: l'héritage de Vichy* (*Inadapted Childhood: Vichy's legacy*, not available in English) (Paris: Ed. ouvrières).
- De Jong, G. (1979) Independent living: from social movement to an analytic paradigm, *Archives of Physical Medicine and Rehabilitation*, 60(10), pp. 435–446.
- Ewald, F. (1986) *L'Etat-Providence (The Welfare State)* (Paris: Grasset).

- Ewald, F. & Stiker H. J. (1999) Solidarité, assurance ou assistance? Entretien avec François Ewald (Solidarity, insurance or assistance? A conversation with François Ewald, not available in English), *Esprit*, Décembre, pp. 37–45.
- Galli, C. & Ravaut, J.-F. (2000) L'association Vivre debout: une histoire d'autogestion (The "Live standing up" association: a case of self-management, not available in English), in: C. Barral, F. Paterson, H.-J. Stiker, M. Chauvière (Eds) *L'institution du handicap. Le rôle des associations* (Rennes: PUR).
- Gateaux-Mennecier J. (1980) *Débilité légère: une construction idéologique (Mental Retardation: An Ideological Construction*, not available in English) (Paris: CNRS éditions).
- Guyot, P. (2000) Le rôle des grandes associations de personnes handicapées dans l'élaboration de la Loi d'Orientation de 1975 (The role of major associations of disabled persons in the development of the 1975 Orientation Law, not available in English), in: C. Barral, F. Paterson, H.-J. Stiker & M. Chauvière (Eds) *L'institution du handicap. Le rôle des associations* (Rennes: PUR).
- Jobert, B. (1981) *Le social en plan (Social Action Planning*, not available in English) (Paris: Editions Ouvrières).
- Jobert, B. & Muller, P. (1987) *L'Etat en action. Politiques publiques et corporatismes (The State in Action. Public Policies and Corporatismes*, not available in English) (Paris: PUF).
- Maller, M. (1999) *Handicap et autodétermination. Emergence d'un mouvement révolutionnaire (Disability and Empowerment. Emergence of a Revolutionary Movement*, not available in English), Mémoire de maîtrise (Université Montpellier III).
- Mohanu, V. A. (2007) L'espace européen d'action publique dans le domaine du handicap. Les dynamiques d'une institutionnalisation (The European space of public action in the field of disability. The dynamics of an institutionalization, not available in English), in: O. Baisnée & Romain Pasquier (Eds) *L'Europe telle qu'elle se fait. Européanisation et sociétés politiques nationales* (Paris: CNRS Editions).
- Montes J. F. (2000) Des mutilés de guerre aux infirmes civils: les associations durant l'entre-deux-guerres (From war injured to civil disabled persons: the associations between the two World Wars, not available in English), in: C. Barral, F. Paterson, H.-J. Stiker & M. Chauvière (Eds) *L'institution du handicap. Le rôle des associations* (Rennes: PUR).
- Muel-Dreyfus F. (1983) *Le métier d'éducateur (Special Education: A Profession*, not available in English) (Paris: Ed. de Minuit).
- Paterson, F. & Barral, C. (1994) L'association française contre les myopathies: trajectoire d'une association d'usagers et construction associative d'une maladie (The French association against muscular dystrophies: the building of a users' association and the associative construction of a disease, not available in English), *Sciences sociales et santé*, XII, 2, Juin, pp. 81–111.
- Pinell, P. & Zafropoulos, M. (1978) La médicalisation de l'échec scolaire (The medicalization of academic failure, not available in English), *Actes de la recherche en sciences sociales*, 24, Novembre, pp. 23–49.
- Pinell, P. & Zafropoulos, M. (1983) *Un siècle d'échecs scolaires (1882–1982) (A Century of Academic Failure (1882–1992)*, not available in English) (Paris: Editions Ouvrières).
- Priestley, M. (2007) In search of European disability policy: between national and global, *ALTER European Journal of Disability Research*, I, 1, November.
- Rabeharisoa, V. & Callon, M. (2000) Les associations de malades et la recherche (Associations of patients and research, not available in English), *Médecine/Sciences*, 16, pp. 945–949.
- Stiker, H.-J. (1999 [1982]) *A History of Disability* (Ann Arbor: University of Michigan Press).
- Stiker, H.-J. (2000) *Pour le débat démocratique: la question du handicap (Contribution to the Democratic Debate: The Issue of Disability*, not available in English) (Paris: Ed. du CTNERHI).
- Turpin, P. (1990) La lutte contre l'assistance pendant les années 1970 (The struggle against assistance in the seventies, not available in English), *Handicaps et Inadaptations – Les Cahiers du CTNERHI*, 50.
- Turpin, P. (2000) Les mouvements sociaux des personnes handicapées en France pendant les années 1970 (Social movements of disabled persons in France in the seventies, not available in English), in: C. Barral, F. Paterson, H.-J. Stiker & M. Chauvière (Eds) *L'institution du handicap. Le rôle des associations* (Rennes: PUR).
- Vial, M. (1990) *Les enfants anormaux à l'école. Aux origines de l'éducation spécialisée 1882–1990* (Abnormal children in school. The origins of special education 1882–1990, not available in English) (Paris: Armand Colin).

Appendix 1. Organizations referred to in this study

Name in English	Name in French	Abbreviation
Action and Coordination Committee of Parents of Children and Adults with Multiple Disabilities	Comité d'Action et de Liaison des Parents d'Enfants et d'Adultes atteints de Handicaps Associés	CLAPEAHA
Advocacy France		
Association for Adults and Young Disabled	Association pour Adultes et Jeunes Handicapés	APAJH
Association for Paralysed Persons in France	Association des Paralysés de France	APF
Association of Disabled Persons in Public Research	Association pour le Travail des Handicapés dans la Recherche Publique	ATHAREP
Association of Gerontology	Services d'aide aux personnes âgées	AGEMO
Asylum Information Group	Groupe d'Information Asile	GIA
County Commission for Special Education	Commission Départementale d'Education Spéciale	
Crusade for Blind People	Croisade Des Aveugles	
Disabled Peoples' International		DPI
Disabled Persons' Action and Coordination Group for the Repeal of the Law on Orientation	Collectif d'Action et de Coordination des Handicapés pour l'Abrogation de la loi d'Orientation	CACHALO
Disabled Persons' Committees of Opposition	Comités de Lutte des Personnes Handicapées	
European Network on Independent Living-France		ENIL-France
French Association against Muscular Dystrophies	Association Française contre les Myopathies	AFM
French Committee for Disabled Persons on European Matters	Conseil Français des personnes Handicapées pour les questions Européennes	CFHE
French Federation of Associations of Persons with Cerebral Palsy	Fédération Française des Associations d'Infirmes Moteurs Cérébraux	FFAIMC
French Group for Disabled Persons	Groupement Français des Personnes Handicapées	GFPH
French League for the Reintegration of Disabled Persons into the Workplace	Ligue pour l'Adaptation du Diminué Physique au Travail	LADAPT
French Union for Persons Suffering from Myopathy	Union des Myopathes de France.	
General Confederation for the Blind, Deaf, Severely Disabled and the Elderly	Confédération Générale des Aveugles, Sourds et Grands Handicapés et Personnes Agées	
Group for the Insertion of Physically Disabled Persons	Groupement pour l'Insertion des Handicapés Physiques	GIHP
Handicap International		
Live standing up	Vivre debout	

Appendix 1. (Continued)

Name in English	Name in French	Abbreviation
Movement for Legislation on Abortion and Contraception	Mouvement pour la Légalisation de l'Avortement et de la Contraception	MLAC
Movement in Defense of Disabled Persons	Mouvement de Défense des Personnes Handicapées	
National Advisory Board for Disabled Persons	Comité National Consultatif des Personnes Handicapées	CNCPH
National Association for Parents of Blind Children	Association Nationale des Parents d'enfants aveugles	ANPEA
National Association for the Defence of Ill, Impaired and Disabled Persons	Association Nationale de Défense des Malades, Invalides et Handicapés	AMI
National Association for the Integration of Persons with Motor Deficiencies	Association Nationale pour l'Intégration des Handicapés Moteurs	ANPIHM
National Committee for the Social Promotion of Blind and Amblyopic Persons	Comité National pour la Promotion Sociale des Aveugles et Amblyopes	CNPSAA
National Federation for Ill, Disabled and Paralyzed Persons	Fédération Nationale des Malades, Handicapés et Paralysés	
National Federation for Persons Injured in the Workplace and Disabled Persons	Fédération Nationale des Accidentés du Travail et des Handicapés	FNATH
National Federation for Persons Injured or Disabled in Accidents in the Workplace	Fédération Nationale des Mutilés et Invalides du Travail	FNMIT
National Federation for Persons Victims of Life	Fédération Nationale des Accidentés de la Vie.	
National Federation of Deaf Persons in France	Fédération Nationale des Sourds de France	FNSF
National Union for the Social Insertion of Persons with Hearing Impairments	Union Nationale pour l'Insertion Sociale du Déficiant Auditif	UNISDA
National Union of Associations of Friends and Families of Mentally Ill Persons	Union Nationale des Amis et Familles de Malades mentaux	UNAFAM
National Union of Associations of Parents with Maladjusted Children	Union Nationale des Associations de Parents d'Enfants Inadaptés	UNAPEI
National Union of Persons with Polio in France	Union Nationale des Polios de France	UNPF
New French Association for Persons with Multiple Sclerosis	Nouvelle Association Française des Scléroses en Plaques	NAFSEP
Prisoners' Action Committee	Comité Action des Prisonniers	CAP
Technical Commission for Orientation and Professional Reclassification	Commission Technique d'Orientation et de Reclassement Professionnel	
Technical Committee for Impaired Children and Children in Moral Danger	Conseil Technique de l'Enfance Déficiante et en Danger Moral	