

**TO MR REGIS BRILLAT,
EXECUTIVE SECRETARY OF THE EUROPEAN SOCIAL CHARTER**

COLLECTIVE COMPLAINT

Seeking a finding that France has not satisfactorily implemented Articles 15 and 17 of Part II and Article E of Part V of the Revised European Social Charter of 3 May 1996, which came into force on 1 July 1999, and

Submitted to the European Committee of Social Rights, in accordance with the procedure laid down in the Additional Protocol to the European Social Charter of 9 November 1995, by:

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I. ADMISSIBILITY OF AUTISM-EUROPE'S COLLECTIVE COMPLAINT

As explained below, Autism-Europe's collective complaint meets the admissibility requirements laid down in Articles 3 and 4 of the Additional Protocol to the European Social Charter of 9 November 1995.² Autism-Europe (i) has the right to submit a collective complaint, (ii) its complaint deals with provisions of the Revised European Social Charter of 3 May 1996³ and (iii) the purpose of the association's work is such that the association is outstandingly qualified to report the inadequacy of educational provision for the autistic in France.

1.1 AUTISM-EUROPE'S RIGHT TO SUBMIT A COLLECTIVE COMPLAINT

Autism-Europe has consultative status with the Council of Europe and is on the list of international non-governmental organisations authorised to lodge collective complaints.⁴

1.2 PURPOSE OF AUTISM-EUROPE'S COLLECTIVE COMPLAINT

Autism-Europe's collective complaint, in attacking the inadequacies of educational provision for the autistic in France, seeks a finding by the European Committee of Social Rights that France is not satisfactorily implementing Article 15(1)(Part II) of the Social Charter, which provision has to be read together with Article 17 (1)(a)(Part II) and Article E(Part V).

The provisions which France has accepted⁵ are:

Article 15(1)(Part II) of the Social Charter (hereafter referred to as "Article 15"):

"With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular: to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private ..."

² Hereafter referred to as "the Additional Protocol". It should be stated that supervision of compliance with undertakings given under the Revised European Social Charter is governed by the provisions of the Protocol where the country in question has ratified it.

³ Hereafter referred to as the "Social Charter".

⁴ **Appendix 2.** This appendix also includes the statutes and lists the members of Autism-Europe's administrative council.

⁵ France has declared itself (Article A of Part III) bound by all the articles in Part II of the Social Charter - see list of declarations to Treaty No.163.

Article 17(1)(Part II) of the Social Charter (hereafter referred to as “Article 17”):

“With a view to ensuring the effective exercise of the right of children and young persons to grow up in an environment which encourages the full development of their personality and of their physical and mental capacities, the Parties undertake, either directly or in co-operation with public and private organisations, to take all appropriate and necessary measures designed: to ensure that children and young persons, taking account of the rights and duties of their parents, have the care, the assistance, the education and the training they need, in particular by providing for the establishment or maintenance of institutions and services sufficient and adequate for this purpose ...”

Article E(Part V) of the Social Charter (hereafter referred to as “Article E”):

“The enjoyment of the rights set forth in this Charter shall be secured without discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national extraction or social origin, health, association with a national minority, birth or other status.”

1.3 AUTISM-EUROPE’S QUALIFICATIONS TO SUBMIT THE PRESENT COLLECTIVE COMPLAINT

Autism-Europe is qualified, within the meaning of Article 3 of the Additional Protocol, to submit a collective complaint concerned with educational provision for autistic people in France.

Under Article 2 of Autism-Europe’s statutes, the association’s purpose is “*to improve life for everyone affected by autism*”⁶. Article 2 also states that, to achieve that aim, the association has a duty in particular to:

- promote autistic people’s dignity and rights in the spirit of international conventions and declarations and of the charter adopted in declaration form by the European Parliament on 9 May 1996⁷, which is concerned in particular with the right to adequate education;
- exercise vigilance so as to prevent all neglect of or negligence towards the autistic;
- appropriately promote the care, education, guidance, training and wellbeing of children, young persons and adults with autism.

⁶ The characteristics of autism are specified in the international diagnostic and classification systems (DSM IV (*Diagnostic and Statistical Manual of Mental Disorders - USA*) and ICD 10 (International Classification of Diseases - WHO) and we reproduce them in **Appendix 3**, which also includes a description of autism prepared in May 2000 under the auspices of the Autism-Europe administrative council.

⁷ Appendix 4.

II. SUBSTANTIVE ISSUES: HONOURING BY FRANCE OF ITS UNDERTAKINGS

Article I of Part V of the Social Charter specifies how undertakings which a state gives are to be implemented: *“Without prejudice to the methods of implementation foreseen in these articles the relevant provisions of Articles 1 to 31 of Part II of this Charter shall be implemented by a. laws or regulations ... d. other appropriate means.”* It should be noted that the explanatory report to the Social Charter states that the words “shall be” mean that the method chosen must be effective.⁸

Under these provisions there is a requirement on France to implement the undertakings which it gave under Articles 15 and 17 of the Social Charter

- i. not only through laws or regulations
- ii. but also by “other appropriate means”, involving a duty - in the actual words of the articles concerned - on France:
 - to take the necessary measures to provide persons with disabilities with education as part of general schemes or through specialised bodies, so as to ensure their effective exercise of the right to independence, social integration and participation in the life of the community (Article 15);
 - and, so as to ensure that people with disabilities have the education and the training they need, to establish or maintain institutions and services sufficient and adequate for this purpose (Article 17).

It should be noted that the explanatory report to the Social Charter states that Article 15 *“not only provides the possibility, but to a large extent obliges Parties to adopt positive measures for the disabled”*⁹.

In order to assess the state of affairs in France, as regards both the law and implementing measures, it is important to understand Article 15 of the Social Charter in the light of Committee of Ministers Recommendation (92)6 and the appendix to it¹⁰. The appendix states in particular that¹¹:

- *“All people with disabilities, regardless of the nature or degree of their disability, have the right to appropriate free education adapted to meet their needs and wishes.”*
- *“Taking into account the principle of early intervention, it is in the child’s interest:*

⁸ Explanatory report to the Social Charter, para.139.

⁹ Ibid, para.64.

¹⁰ Ibid. Recommendation No.R (92)6 of the Committee of Ministers to member states on a coherent policy for people with disabilities (adopted on 9 April 1992), see in particular section V of the appendix (Education).

¹¹ Appendix to Recommendation No.R (92)6, paras. 1.1, 1.5, 1.6, 2.1, 3.2, 3.4 and 5.1.

- *to begin medico-educational measures at pre-school age, especially where they are intended to make it easier for the child to obtain a school education at a later stage;*
- *to attend school or pre-school classes from a very early age.”*
- *“... education should be provided in an ordinary environment together with their peer groups wherever possible and whenever the necessary assistance, support and fostering for young people with disabilities can be given there; to meet their specific needs, the supply to children with disabilities of special therapeutic, technical and educational aids should be ensured ...”*
- *“To enable the largest possible number of children with disabilities to attend a mainstream school, the following requirements must be satisfied:*
- *medico-therapeutic and psychological services;*
- *adapted class size in which the main teacher should be assisted, if necessary, by other adequately qualified staff;*
- *...*
- *counselling, implementation and action concepts which take account of the kind of disability concerned.”*
- *“Special schools and vocational training school should be:*
- *set up in sufficient number;*
- *equipped with the necessary collective and individual technical support;*
- *staffed by teachers with adequate special teaching qualifications;*
- *installed as resource centres for mainstream schools and*
- *linked with mainstream schools to increase co-operation.”*
- *“Special teaching should continue for as long as the person with a disability profits by it.”*
- *“Particular attention should be paid to the role of adult education, especially in so far as people with mental disabilities are concerned. Adult education should provide the maximum range of opportunities for people with disabilities, including training in basic skills and specialised education.”*

As will be clear from the explanations which follow, although the law and regulations in France are partly consistent with the undertakings given under Articles 15 and 17 of the Social Charter, France is failing to implement its commitments appropriately in the manner set out in Committee of Ministers Recommendation (92)6.

2.1 THE LAW AND REGULATIONS

For the reader's information we shall recapitulate on the main law and regulations dealing with educational provision for people with disabilities, some of whose provisions are specifically concerned with autism sufferers.

On 30 June 1975 Parliament enacted a framework law setting out provision for people with disabilities¹². This was followed in 1989 by a further framework law on education which reaffirmed the right of people with disabilities to education.¹³ On 30 June 1975 Parliament also enacted a law on social and medico-social institutions.¹⁴ This was amended *inter alia* by a law of 11 December 1996 making adapted provision for autism sufferers.¹⁵ The social and medico-social provision governed by the last two of these pieces of legislation has recently been reorganised, in legislation of 2 January 2002.¹⁶ All this legislation has been codified in the Code of Social Action and the Education Code.¹⁷

2.1.1 Provisions in principle consistent with France's undertakings

In our view, the following provisions satisfy France's undertakings under Articles 15 and 17 of the Social Charter and are therefore neither open to criticism nor the subject of Autism-Europe's collective complaint.

Nonetheless, Autism-Europe's collective complaint takes on particular gravity where, despite a legislative and regulatory context capable of meeting the right of people

¹² Law No.75-534 of 30 June 1975 laying down framework provision for people with disabilities, Official Gazette, 1 July 1975, p.6596, www.legifrance.com, in consolidated form.

¹³ Law No.89-486 of 10 July 1989 laying down framework provision on education, Official Gazette, 14 July 1989, p.8860, www.legifrance.com, in consolidated form.

¹⁴ Law No.75-535 of 30 June 1975 on social and medico-social institutions, Official Gazette, 1 July 1975, p.6604, www.legifrance.com, in consolidated form.

¹⁵ Law No.96-1076 of 11 December 1996, amending Law No.75-535 of 30 June 1975 on social and medico-social institutions and making adapted provision for autism sufferers, Official Gazette, 12 December 1996, p.18176, www.legifrance.com.

¹⁶ Law No.2002-02 of 2 January 2002 containing reforms of social and medico-social provision, Official Gazette, 3 January 2002, p.124, www.legifrance.com.

¹⁷ These codes are available on website www.legifrance.com; the various pieces of legislation have been supplemented by the regulations implementing them (in particular Decree No.75-1166 of 15 December 1975 on the membership and functioning of the Special Education Boards and the District Boards), and also by various circulars specifying how the decentralised services implementing the 1975 and 1989 framework legislation are to apply it. These circulars include: Circular No.91-302 of 18 November 1991 on integration of children and young persons with disabilities, *Ministry of Education Newsletter*, 16 January 1992; Circular No.99-637 (the "Handiscol" circular) of 19 November 1999 laying down guidelines on the schooling of children and young persons with disabilities, *Ministry of Employment and Solidarity Newsletter*, 5 January 2000; Circular No.2001-035 of 21 February 2001 on secondary schooling for pupils with disabilities and on the development of educational units for integrating them, *Ministry of Education Newsletter*, 1 March 2001; Circular No.95-12 of 27 April 1995 (the Veil circular) on treatment, education and social integration of children, young people and adults with autism syndrome, *Ministry of Social, Health and Urban Affairs Newsletter*, 31 July 1995, and Circular No.98-232 of 10 April 1998 on training of staff working with autistic people, *Ministry of Employment and Solidarity Newsletter*, 16 May 1998, **Appendix 5**.

with disabilities to education, the instruments are simply not being applied to people suffering from autism.

Autism-Europe draws attention, for example, to Articles L.111-1 and L.112-1 to L.112-3 of the Education Code¹⁸:

- *“Education is the prime national priority¹⁹. The design of the public education service shall be adapted to the pupils and students ...*

The right to education is secured to all ...

- *Schooling is compulsory for children and young persons with disabilities. They shall meet the compulsory-education requirement either through the general education system or, failing that, by receiving special education, as decided by the district special education board in accordance with the individual’s particular needs.*
- *Special education shall combine educational, psychological, social, medical and paramedical action; it shall be delivered either at establishments within the general system or by specialist establishments or services ...”*

On the face of it, France’s undertakings are likewise met (subject to the reservations set out in section 2.1.2.b below) by Articles L.114-1, L.114-2 and L.242-4 of the Code of Social Action, which read as follows:

- *“Minors and adults with physical, sensory or mental disabilities shall have secured to them the basic rights of all citizens, in particular those ... to education, to training and vocational guidance, to employment ... as a matter of national obligation.*
- *The action taken shall, whenever the aptitudes of the person with the disability and the capabilities of the family so allow, ensure access for the minor or adult with a disability to those institutions open to the whole population ...*
- *The earliest possible provision is necessary. It shall be possible for it to continue for as long as the condition of the person with the disability warrants it and without any limit of age or duration ...”*

2.1.2 Provisions which are open to criticism or ambiguous

a. Provision for autistic people would appear possible only “subject to availability of resources”

In contrast to the above provisions, we find first, in Article L.246-1 of the Code of Social Action:

¹⁸ Article L.242-1 of the Code of Social Action contains exactly the same provisions.

¹⁹ This provision echoes Article 13 of the preamble to the 1946 Constitution, supplementing the 1789 Declaration of Rights of Man, which in turn was carried over into the preamble to the 1958 Constitution, which provides: *“the Nation shall guarantee equal access for children and adults to education, vocational training and culture. The state has a duty to provide education which is free and secular at all levels.”*

- *“Any person with a disability resulting from autism syndrome or related disorders shall receive, regardless of age, multidisciplinary provision catering for his or her specific needs and difficulties. Such provision shall be adapted to the condition and age of the individual and have regard to the resources available. It may be educational, therapeutic or social.”*

This article was introduced by the law of 11 December 1996 on adapted provision for autism sufferers. That legislation, which parents’ associations had pressed for, (i) recognised autism as a disability and (ii) set out the characteristics of provision for autistic people. Amendments to the text during parliamentary debate and the interpretation to which the text is open unfortunately alter the desired objectives and the scope which the law should have had. Autism-Europe accordingly has the following observations on this provision:

- The article cannot be interpreted to suggest that making educational provision for autistic people is purely optional; given the obligation on France to provide education for people with disabilities, the text must be understood as allowing - over and above the educational provision which “must” be made - further provision which “may” be made; the wording of the article is ambiguous, and the ambiguity is particularly worrying as
- the article allows the authorities to make provision only to the extent that resources permit; in our view this runs directly counter to the commitments which France has given under the Social Charter, which requires that the necessary measures be taken and that such measures be adequate and sufficient.

The reference to “available resources” allows the authorities to justify lack and inadequacy of provision for autistic people by arguing that Parliament has failed to allocate adequate finance (*see below, section 2.2.1*).

b. Educational integration, early provision and adult education seem to be optional “obligations”

Autism-Europe notes, secondly, that under Article L.112-1 to L.112-3 of the Education Code:

- *“Educational integration of young people with disabilities shall be facilitated. Health services and establishments shall play a part in this”, and*
- *... Special education may be given before, and continued after, the age of compulsory schooling.”*

Although partly offset by Article L.114-1 and 114-2 and Article L.242-4 of the Code of Social Action, these provisions are ambiguous given that Article L.242-4 states that it *“shall be possible for [provision] to continue for as long as the condition of the person with the disability warrants it and without any limit of age or duration ...”*

As we have seen, Article 15 of the Social Charter, as interpreted in the light of Committee of Ministers Recommendation (92)6, requires states to:

- (i) provide integrated schooling “wherever possible”, with special educational support if necessary; in this legal context, placing obligations on France, it is hard to see what is meant by “facilitating” educational integration with support from the health services alone; the French provision seems to give schools a choice rather than a duty to integrate; alas, that interpretation is in fact supported by actual practice (see *below*, section 2.2.3.a);
- (ii) arrange for early intervention, and in particular provide special education for as long as the person with the disability can profit from it; Recommendation (92)6 additionally states that special attention must be paid to adult education “especially in so far as people with mental disabilities are concerned”; merely to provide that “special education may be given before, and continued after, the age of compulsory schooling” and that “it shall be possible for [provision for the individual with a disability] to continue“ unfortunately suggests that France is confining itself to mere options, as opposed to obligations; the circulars dealing specifically with provision for autistic people²⁰, together with the facts described below, further demonstrate that this interpretation of the text is correct. Educational provision for the autistic adult in France is to all intents and purposes non-existent (see *below*, section 2.2.3.c).

This analysis is in fact consonant with the fact that social action, under which falls provision for people with disabilities, has but one objective.

c. Social action has but one objective

Thirdly, it may be observed, that under Article L.116-1 and 116-2 (recently introduced by a law of 2 January 2002)²¹ of the Code of Social Action:

“Social and medico-social action shall promote, within an interministerial framework, the autonomy and protection of persons ... prevent exclusion and correct its effects. It shall be based on continuous evaluation of needs and of expectations ... in particular those of people with disabilities ... and on making facilities and allowances available to them. It shall be performed by the state, the local authorities and the public establishments run by them, social-security agencies, the voluntary sector and social and medico-social institutions...

²⁰ Special attention needs paying to the two circulars dealing specifically with provision for the autistic, which are highly indicative of how the legislation is to be read. They are Circular No.95-12 of 27 April 1995 on treatment, education and social integration of children, young people and adults with autism syndrome; and Circular No.98-232 of 10 April 1998 on training of staff working with autistic people, **Appendix 5**. Although the two circulars give details of educational provision for children and young autistic people, they are totally silent on provision for adults while confining provision for adults to care or occupational activity where they are unable to do paid work (see pp.5 and 6 of the 1995 circular). The 1998 circular specifies that training of staff working with autistic people is aimed at “improving educational provision for children with autism and specialist social supervision of adults with autism” (p.3).

²¹ Law No.2002-2 of 2 January 2002 reorganising social and medico-social action, *Official Gazette*, 3 January 2002.

Social and medico-social action shall be so conducted as to respect the equal dignity of all human beings, with the aim of making adapted provision to meet the needs of each individual and affording them equitable access throughout the country."

It should be noted that educational provision for children and young people with autism who cannot be schooled through the general system comes under medico-social action, not the education system. In this connection it is surprising that although there is a requirement to base it on continuous evaluation of needs, action is carried out by virtue not of an obligation but of the mere "objective of making adapted provision" so as to meet the needs.

It is unacceptable that the state, local authorities and public services are bound solely by an objective, a state of affairs which the aforementioned provisions of the Code of Social Action seem to allow.

This approach is directly contrary to Article 15 of the Social Charter, under which, as the reader will know, it is not only possible for states to adopt positive measures to assist the handicapped but actually compulsory to do so²² and whose purpose is to "ensure" to people with disabilities "effective exercise" of the right to independence and social integration. It should further be noted that under Committee of Ministers Recommendation (92)6, states are required, in order to implement their policy on behalf of people with disabilities, to "guarantee the right of people with disabilities to an independent life and full integration into society, and recognise society's duty to make this possible"²³

2.2. FRANCE'S FAILURE TO HONOUR UNDERTAKINGS UNDER ARTICLES 15 AND 17 OF THE SOCIAL CHARTER

Despite a legal environment which is partly consistent with the Charter provisions, the facts show that France's international undertakings, and indeed domestic law, are not being, or cannot be, observed, notably on account of what is well known to be grossly inadequate funding.

The vast majority of autistic people are being deprived of the chance to fully exercise their right to education. The inadequacy, whether quantitative or qualitative, of provision for them has been underlined by several reports, some of which we append to the present complaint²⁴.

²² Explanatory report to the Social Charter, section 64.

²³ Recommendation (92)6, Appendix, section I.4.

²⁴ As far back as 1994 the very serious quantitative and qualitative shortcomings of provision for the autistic were confirmed in reports - commissioned by Simone Veil - by IGAS (October 1994), ANDEM (November 1994) and DAS (January 1995). Extracts from those reports will be found in **Appendix 6**.

2.2.1 Unanimous criticism

a. *By the voluntary sector*

On 27 November 1999, during the Autisme France conference, Max Artuso, speaking as president of the association, observed that *“as far as children and young people are concerned, the right to education and families’ right to freedom of choice are recognised. But recognition of those rights has had virtually no practical effects”*.²⁵

Two years later, at the first national autism conference, the newspaper *La Croix* quoted the president of Autisme France as follows: *“In the case of autistic children, [the duty to provide education] is not being complied with and there are any number of children for whom there is no provision or, at best, a few hours in a day hospital. Several thousand autistic adults have had to turn to Belgium for help, while several thousand more are at present in psychiatric hospitals, mostly in secure wards, under heavy sedation ... Most European countries have taken extremely effective measures to improve the lot of autistic people ... We need to induce the state to discharge its duty in full towards a group of people whose exclusion is exceptionally serious.”*²⁶

The newspaper also quoted Marcel Hérault, the president of Sésame Autisme²⁷: *“given the worsening situation as regards provision for the autistic, the authorities at all levels could reasonably be accused of culpable negligence, endangering not only family stability but in many cases human lives. It is criminal to leave children this dependent with their parents all the time, so that they regress for lack of social integration, activities and care.”*²⁸

b. *By the public authorities*

In March 2001 *Le Monde* quoted the state secretary for disability as follows: *“Overall, it is clear that the autistic are a section of the population whose needs are outstandingly ill met, in terms both of a serious shortage of places in institutions and of various inadequacies in the standard of provision when places are actually found”*²⁹. The state secretary added: *“There is nothing new about the inadequacies. Three reports commissioned by Simone Veil - by the General Inspectorate of Social Affairs (IGAS) in October 1994, the National Agency for the Development of Evaluation in Medicine (ANDEM) in November 1994, and the Directorate of Social*

²⁵ **Appendix 7.**

²⁶ Martine de Sauto, *La Croix*, 18 May 2001, **Appendix 23.**

²⁷ The Sésame Autisme federation, like Autisme France, is a national association representing autism sufferers and their families.

²⁸ Martine de Sauto, *La Croix*, 18 May 2001, **Appendix 23.**

²⁹ Report to Parliament, *Autism: an evaluation of action 1995-2000*, Directorate General of Social Action, December 2000, p.3, **Appendix 10.**

Action in January 1995 - were all similarly critical of the very serious inadequacy, both quantitative and qualitative, of provision.³⁰

In a letter of 5 April 2002³¹ the President of the Republic wrote to the president of Autisme France, Marie-Claude Urban, as follows:

“You rightly deplore the inadequacy of provision for the autistic in France, both quantitatively and qualitatively, more than five years on from the legislation which recognised the special nature of autism as a disability³², and you underline the need for more appropriate responses to the difficulties which families encounter. The families, I fully realise, face very serious problems, in particular when children reach adulthood. Large numbers of autistic children remain with their families without benefit of any provision, or are placed in psychiatric hospitals or establishments a considerable distance from their families. Moreover, as you are aware, only 1% of autism sufferers receive treatment adapted to the nature of their disability ...”

Confirming that position, Mr Chirac, in a television interview on 14 July 2002, replied as follows to a question about major projects planned for his five-year term of office: *“I see three major building projects, but ones not involving bricks and mortar ... The third ... is on behalf of people with disabilities in France who are not yet adequately or decently catered for. A great deal of progress remains to be made ...”*³³

2.2.2 Quantitative inadequacy of resources, showing that France is not taking the necessary adequate measures required by Articles 15 and 17 of the Social Charter

Committee of Ministers Recommendation (92)6 states: *“Special schools ... should be set up in sufficient number ...”* and *“it is important to ensure that sufficient financial resources are available in order to overcome the disadvantages affecting people with disabilities.”*

There is a total failure to meet these requirements as regards autism provision.

The quantitative inadequacy of provision for the autistic is evident from the statistics.

³⁰ Paul Benkimoun, “Provision seriously deficient”, *Le Monde*, 1 March 2001, **Appendix 20.**

³¹ **Appendix 9.**

³² Law No.96-1076 of 11 December 1996 amending Law No.75-535 of 30 June 1975 on social and medico-social institutions and adapted autism provision.

³³ **Appendix 9.**

The Veil circular of 27 April 1995 on provision for children, young people and adults suffering from autism³⁴, on the basis of a low incidence of autism (4 to 5.6 per 10,000), put the then number of autism sufferers in France at 27,000, of whom 7,000 were children and young people.

The Directorate General of Social Action report to the French Parliament on action by the authorities between 1995 and 2000, having examined survey-based regional plans for autism provision³⁵, adopted an average rate of 8 per 10,000. On that basis the number of autism sufferers in France was then 48,000, some 13,000 of them children and young people (assuming the same proportion of children to adults as adopted by the above circular).

It is evident from various international studies that the figures used by the French authorities cover only so-called “classic” cases of autism. However, account needs to be taken of the whole range of autism syndrome cases. When these are taken into account, the incidence is 10 to between 7,000 and 10,000³⁶. Applying that rate to a population of 61 million³⁷ we arrive at a figure for autism sufferers in France of between 61,000 and 87,000, giving an average of 75,000, including 19,000 children and young people³⁸.

According to one of the latest international studies on the incidence of autism, a rate of 16.8 per 10,000 could be used, which would increase the number of autism sufferers in France to 102,000³⁹. This figure, which parents’ associations used in 2002 at the most recent national autism conference, has been accepted by the health minister, Jean-François Mattei⁴⁰.

³⁴ Circular No.95-12 of 27 April 1995 on treatment, education and social integration of children, young people and adults with autism syndrome, *Ministry of Social, Health and Urban Affairs Newsletter*, 31 July 1995, **Appendix 5**.

³⁵ Report to Parliament, *Autism: an evaluation of action 1995-2000*, Directorate General of Social Action, December 2000, **Appendix 10**, pp.11 and 12.

³⁶ See “Description of autism”, prepared under the auspices of the Autism-Europe administrative council, May 2000, **Appendix 3**.

³⁷ INSEE Première, population figures 2001, no.825, February 2002.

³⁸ The proportion of children to adults assumed in the present complaint is that used in the 1995 Veil circular - ie one child to three adults, section 1.2 of the circular, **Appendix 5**.

³⁹ Lorna Wing and David Potter, “The Epidemiology of Autistic Spectrum Disorders; Is the Prevalence Rising?”, *Mental Retardation and Developmental Disabilities Research Review*, publication October 2002, p.27 (study no.35), **Appendix 3**. This figure is close to the European Parliament one, putting the number of autism sufferers in the European Union in 1996 at one million, and increasing the number of autism sufferers in France to well over 100,000. See **Appendix 4**.

⁴⁰ **Appendix 9**.

a. A drastic shortage of places

There have been newspaper reports on the dire plight of autistic people in France and the reports have particularly drawn attention to lack of adapted capacity and the shortage of adapted facilities with educational capability.⁴¹

On 24 May 2002 *Libération*⁴² denounced the suffering “*experienced in France by thousands of parents whose children have ‘nowhere to go’, children who do not fit into the ‘normal’ school system and who, for lack of places at specialist medico-social institutions, have no help entitlements. ‘No room’. 13,000 children in France today⁴³ are described as ‘insoluble cases’. They are at home with their parents day in day out, and receive no care, no education and no socialisation ... Such children have been abandoned by the state and by society; they have no care entitlements and are deprived of all outside learning experience and all experience of life in the community”. A year previously the same newspaper reported that “*there are estimated to be around 5,000 places at specialist establishments in France whereas the authorities put the number of sufferers at around 30,000*” (as compared with associations’ estimate of 60,000)⁴⁴.*

In its issue of 11 March 2002 the *Quotidien du Médecin* said “*if anyone is responsible - not to say guilty - it is undoubtedly the state and the district councils that need put in the pillory - the state because its record of providing specialist facilities for autistic children is pitiful, well short of the identified needs; the district councils because they refuse to provide sufficient funding for specialist adult autism establishments worthy of an advanced society*”.⁴⁵

⁴¹ See press articles in **Appendices 20 to 27**. On the general situation (across the whole range of disabilities), the lack of specialist facilities is indirectly revealed by the report, *Policy on behalf of people with disabilities*, published in October 2000 by the employment and solidarity ministry (Directorate General of Social Action) (given its format, the report was presumably forwarded to various European bodies, including the Council of Europe); we find, on p.12 of the report, that 2.4 million people are holders of an invalidity card (invalidity entails 80% incapacity) whereas only 322,400 children and adults have places in medico-social establishments for people with disabilities; 80% incapacity is equivalent to severe disability, which means that the remaining 2 million severely disabled (25% of them - 500,000 - children) have no adapted facilities to turn to.

⁴² Jacqueline Berger, “Nowhere for our children to go”, *Libération*, 24 May 2002, **Appendix 2**.

⁴³ Finding of a study published in March 2001. It was commissioned by the social affairs ministry and carried out by the national disability research centre (CTNERHI), which conducted a survey of 70 district special education boards. See the Jacqueline Berger article.

⁴⁴ Tonino Serafini, “L’autisme face à la barrière de l’accueil”, *Libération*, 19 May 2001, **Appendix 22**.

⁴⁵ Romain Liberman, “Parents and autistic children: the real culprits”, *Quotidien du Médecin*, 11 March 2002, **Appendix 25**.

An article in *Le Monde* reported that “associations of autism sufferers and parents of autistic children will be reminding the authorities that provision for autism sufferers remains drastically inadequate and that for every 20 patients at care centres, 50 to 70 people are on waiting lists. Only a minority are offered early adapted treatment. Without proper provision, a child runs a greater risk of becoming an adult imprisoned in his or her illness and incapable of any independent living. The obstacles for adults are even greater, and here France is lagging far behind most developed countries.”⁴⁶

Lastly *Le Figaro* has pointed out that “provision for these thousands of children, growing into adolescence and adulthood and trapped inside their mental fortresses, is notoriously lacking in France - not only for lack of resources but also for lack of commitment on the part of the authorities and because of a shortage of specialist establishments. Autism sufferers are paying dearly for this multiple malfunctioning.”⁴⁷

The drastic shortage of capacity and of adapted educational facilities is caused by funding and a catch-up plan which are notoriously inadequate (sections b. and c. below).

b. Inadequate funding due to an ill-adapted budget approach

In France, funding for the education of people with disabilities comes under a different set of rules from ordinary children and adolescents. Article 34 of the French Constitution states:

“Finance acts shall determine the resources and obligations of the state ...

Social security finance acts shall determine the general conditions for social security financial balance and, in the light of their revenue forecasts, shall determine expenditure targets ...”

The following explanations show that:

- ordinary education, which is a state responsibility, comes under the education budget as approved through the finance act;
- in contrast, special education is not mainly a state responsibility and comes under the sickness-insurance budget approved through the social security finance act;
- as a result, people with disabilities do not, in practice, have the benefit of the obligation to provide a public education service.

⁴⁶ Elisabeth Bursaux, “National shortage of autism resources”, *Le Monde*, 20 May 2001, **Appendix 20**.

⁴⁷ Catherine Petitnicolas, *Le Figaro*, 19 May 2001, **Appendix 21**.

i. Ordinary education, which is a state responsibility, comes under the national education budget

Where children or adolescents with disabilities are capable of integration into the ordinary school system, the financial provision comes from the national education budget, which is approved under the annual finance act. The national education budget also covers the cost of teachers - there will often be only one - made available to special education establishments.

Article L.351-1 of the Education Code states:

“... the state shall pay for the education and initial vocational training of children and adolescents with disabilities:

- 1. preferably, by integrating into ordinary classes ... all children capable of being integrated despite their disabilities;*
- 2. or by making qualified staff for whom the education minister is responsible available to establishments and services set up and maintained by other ministries, by public law entities or by authorised non-profit groups or bodies*
- ...
3. or by entering into contracts or partnerships with private education establishments ...”*

ii. Special education is not mainly a state responsibility and comes under the sickness insurance budget

In contrast, funding for special education establishments mainly comes under the social security finance act. Article L.242-10 of the Code of Social Action provides:

“Expenses for accommodation and care in special education establishments and vocational establishments, together with the cost of outside care in connection with such education, with the exception of expenses falling to be met by the state under Article L.242-1⁴⁸, shall be wholly met by the sickness insurance schemes, subject to the rates which are the basis for calculation of benefit.

Where such costs are not covered by the sickness-insurance schemes, they shall be covered by social assistance⁴⁹ ...”

It should be noted that instruction at special education establishments is largely given by specialist teachers and not those made available by the national education system, who would not suffice to cover the entire educational need.

As is evident from the provision quoted above, costs relating to educational provision for people with disabilities, as delivered by specialist teachers, are regarded as care expenses, not educational expenses, a clear indication that the financing/budget system is inappropriate.

⁴⁸ This article expressly refers to the aforementioned Article L.351-1 of the Education Code.

⁴⁹ These provisions also appear in Article L.321-1 of the Social Security Code.

Financing of special education (in that special education is misguidedly regarded as care), which is not treated as a state responsibility, is thus determined by the revenue, and shaped by the “expenditure objectives”, of the sickness-insurance system⁵⁰. The expenditure objectives determine the annual amount of expenditure, which is set “by applying an adjustment rate to the previous year’s expenditure”.

Article L.314-3 of the Code of Social Action specifies:

“Funding for those of the services provided by public and private social and medico-social services and establishments which are paid for by the social security bodies shall be subject to an expenditure objective.

The ministers in charge of social security, social action, the economy and the budget shall annually set that objective, which shall be guided by the national objective for sickness-insurance expenditure as approved by Parliament, and they shall set accordingly the total annual expenditure amount on which will be based overall appropriations, flat rates, daily charges and tariffs applying to services. The total annual amount shall be set by applying an adjustment rate to the previous year’s expenditure ...”

In the case of financing of educational or vocational measures under the social-assistance system⁵¹, which is state-run, maximum total expenditure limits are likewise applied. Article L.314-3 of the Code of Social Action states:

“The total annual amount of expenditure by establishments and services ... payable by the state social-assistance system, and in consequence the total annual expenditure amount set for the calculation of overall operational appropriations to such establishments and services, shall be determined by the maximum amount allocated to that head in the initial finance act for the year.”

iii. Consequently people with disabilities are, in practice, not getting the benefit of the compulsorily provided state education service

The necessary expenditure on special education, being set by means of an expenditure adjustment rate and being subject to overall maxima, is therefore not being determined according to real needs - that is, according to the number of people with disabilities who need adapted educational provision.

Conversely, in so far as funding for ordinary education, a state-provided service, is required to meet fully the obligation to provide a state education service (*see above*,

⁵⁰ As has also already been noted (see analysis of Articles L.116-1 and L.116-2), social action and medico-social action, which encompass educational provision for people with disabilities, is conducted by virtue not of any obligation but of the mere “objective of making adapted provision” to meet the needs.

⁵¹ Some of the establishments taking adults with disabilities receive funding under the social assistance system. This funding could therefore cover any work of an educational nature performed by such establishments; though it has to be said that such educational work with adult autism sufferers is virtually non-existent and depends purely on the goodwill of a very few establishments, there being no legal requirement to perform it (*see above, section 2.1.2.b*).

section 2.1.1), the amount of expenditure is not subject to any adjustment rate applicable to the previous year's spending but is calculated according to the number of children and the forecast school population.

Clearly, therefore, the infringement of autistic people's right to education in fact originates in a budget which is tightly restricted and incapable of meeting the needs.

Because of the budget-oriented approach adopted, it is clear that people with disabilities will not in practice (despite the legislation) have the benefit of the compulsorily provided state education service as long as special education remains outside the national education system and is treated merely as a social-assistance measure or as "care", to which health or social-action expenditure limits apply.

c. Inadequate funding and a catch-up plan incapable of making good the deficiencies

In its edition of 18 May 2001 the newspaper *La Croix* noted that the Directorate General of Social Action⁵² recognised that provision for autism sufferers was lagging behind. It said that, since the three reports which Simone Veil had commissioned⁵³, which had been severely critical of the serious quantitative and qualitative inadequacies of provision for autism sufferers, "progress had fallen far short of the needs"⁵⁴.

The Veil circular⁵⁵ estimated that in 1995 only 4,200 children and young people (2,000 in day-hospital child psychiatry services and 2,200 in the medico-social sector) and 5,200 adults (3,000 in psychiatric hospitals and 2,200 in institutions) were being catered for. In so far as, with very few exceptions, day hospitals offer no educational facilities, or only on a very part-time basis, and in so far also as admission of adults to psychiatry services clearly cannot be regarded as educational provision, the only reasonable figure is 5,400 adapted places⁵⁶.

To make good this inexcusable shortfall in provision for autism sufferers, special budget appropriations to create new capacity have been allocated since 1995. In the 1995-2000 period, four appropriations⁵⁷ totalling 312 million francs⁵⁸ were made

⁵² Report to Parliament, *Autism: evaluation of action 1995-2000*, Directorate General of Social Action, December 2000, **Appendix 10**.

⁵³ Reports by IGAS (October 1994), ANDEM (November 1994) and DAS (January 1995). See extracts, **Appendix 6**.

⁵⁴ Martine de Sauto, *La Croix*, 18 May 2001, **Appendix 23**.

⁵⁵ Circular No.95-12 of 27 April 1995 on treatment, education and social integration of children, young people and adults with autism syndrome, *Ministry of Social, Health and Urban Affairs Newsletter*, 31 July 1995, **Appendix 5**.

⁵⁶ Children: 1,000 in day hospitals and 2,200 in the medico-social sector; adults: 2,000 in institutions.

⁵⁷ Appropriations varying from 50 million to 100 million francs.

available. In addition there were appropriations from the sickness-insurance scheme, from district councils and from central government, totalling 207 million francs. Total appropriations amounted to 519 million francs⁵⁹. Officially, 2,033 places - 820 for children and 1,213 for adults - were created⁶⁰.

However, the findings of the Directorate of Social Action report prompt the following observations from Autism-Europe:

1. The number of places actually created needs correcting. A significant number of places officially classed as new ones were in fact existing places which simply received additional finance. The cost of a place in a specialist institution averages at between 250,000 and 300,000 francs per year. On that basis, by way of illustration (exhaustiveness is not possible in view of the many inconsistencies in the report's findings⁶¹). It is plain that 30 residential medico-educational places in Alsace financed with an annual budget of 730,000 francs, ie at a cost per day of 121 francs, cannot be new places. The same goes for 109 places in Alsace which cannot possibly have been created at a cost per day of 300 francs⁶².

- The Autisme France report on national policy since 1995 shows that, between 1995 and 1999, only 1,110 places can really be regarded as new, and only 824 of them actually became available⁶³. Autisme France's analysis is that the plan created, at most, only 1,400 places which were genuinely new⁶⁴. As regards children, only 667 new places were created, not 820, when the report's errors concerning price per day are taken into account.

- Autisme France also notes that *"the allocation of special appropriations for autism completely halted 'normal' financing for new autism places. All new-capacity requests to district social-security services were routinely dealt with under the special autism budget. Plainly, district services did not understand, or resisted understanding, that the special budget was a catch-up plan and not a measure for removing autism, financially, from the general medico-social budget"*.

⁵⁸ Including 50 million francs to increase capacity in establishments for adults.

⁵⁹ Report to Parliament, *Autism: an evaluation of action 1995-2000*, Directorate General of Social Action, December 2000, p.15, **Appendix 10**.

⁶⁰ Ibid., p.16 - a proportion of these budgets went to establish diagnosis centres.

⁶¹ Ibid., Appendix V (Establishments and services financed by sickness-insurance appropriations).

⁶² Ibid.

⁶³ **Appendix 11**.

⁶⁴ The Sésame Autisme federation confirms that analysis and observes, in its evaluation of the Autism Plan, that at best 1,000 new places became available - *Revue Sésame*, no.137, December 2000. See **Appendix 12**.

2. In 2002 the shortfall in places, given an estimated 75,000 autism sufferers, can be put at 68,200⁶⁵ (that figure being subject to correction, given that some - a very few - autism sufferers do not require help from specialist institutions); even taking a figure of 48,000 autism sufferers⁶⁶, the shortfall in capacity can be put at 41,200 places and is still drastic⁶⁷; at the rate of 233 places per year (that being the rate up to the year 2000 - ie 1,400 places over six years), it would take 176 years to meet the needs⁶⁸, and even this takes no account of population growth!

- The French population is growing by an average of 200,000 per year. Given the autism rate (10 per 7,000 to 10,000), the population of autism sufferers is increasing by 233 per year; the multiannual plan for the 2001-2003 period allocates a catch-up budget of 150 million francs⁶⁹; on the basis of the real cost of a place for an autism sufferer, estimated at 275,000 francs, it will be possible to create only some 550 places; the plan will not allow even the new needs to be absorbed; even applying the incidence used in the Directorate General of Social Action report (8 per 10,000), the problem remains huge since, with 160 more autism sufferers per year, once the new needs have been covered there will remain only 70 available places to meet the unmet previous needs.

It follows that unless France radically alters its budgetary and financial policy on provision for autism sufferers, the shortfall will never be made up and the quantitative needs will never be met.

In the context described, France's undertakings, whether internationally, as a result of ratification of the Social Charter, or nationally, by virtue of legislation, implementation circulars, political speeches and other measures, cannot be acted upon unless France gives itself the financial means of providing for autism sufferers (or people with disabilities generally) on a par with its education policy towards children and adolescents without disabilities - bearing in mind that the education budget is rightly the nation's largest budget and that it is unacceptable that education provision for children with disabilities is not covered (except in a very auxiliary way) by that budget.

⁶⁵ 75,000 autism sufferers/5,400 existing places and 1,400 newly created places.

⁶⁶ On the basis of the incidence as stated in the Directorate General of Social Action report.

⁶⁷ That shortfall is as estimated by Howard Buten, interviewed by *Humanité* on 27 June 2000. According to Buten, "*the situation is serious for young autism sufferers, dire for adults. In all, 40,000 of them are waiting for places in facilities*", **Appendix 24**.

⁶⁸ If we take only children's needs - ie a population of 13,000, based on the incidence given in the report to Parliament - the deficit comes to some 9,200 (13,000 minus (3,200 + 667)). At the rate of 111 new places per year (667/6 years), it would take 82 years to meet their needs, by which time they will be anything but children ...

⁶⁹ Circular No.2000-443 of 11 August 2000 on implementation of measures in the three-year plan (2001-2003) for children, adolescents and adults with disabilities, *Ministry of Employment and Solidarity Newsletter*, 9 September 2000, section 3.1, **Appendix 13**.

Here, it is worth drawing attention to various observations in the Directorate General of Social Action report to the Minister for Employment and Solidarity, “Disability: a comparative and forward analysis of provision”: “Obviously, and *without denying the budgetary constraints, we cannot hope to improve the standard of provision for children with disabilities (and their parents) without considerable financial commitment on the part of the state.*”⁷⁰

However, as the president of Sésame Autisme, Marcel Hérault, has argued, the authorities in France seem to use budget restrictions as an excuse for doing nothing: *“the sole argument of successive governments ... has been the need to restrict health and welfare spending. But it is up to government to identify the real priorities (and autism is undoubtedly one) and the argument holds no water when human life is endangered and when people with serious disabilities are being denied any dignity.”*⁷¹

2.2.3 Qualitative inadequacy of resources

As we have seen, the resources France devotes to educational provision for autistic people are quantitatively deplorable. The facts we point out below suggest that resources are also highly inadequate from the qualitative standpoint. Committee of Ministers Recommendation (92)6 states: “All people with disabilities, regardless of the nature or degree of their disability, have the right to *appropriate free education adapted to meet their needs and wishes*”, and this is being ignored.

We shall preface our remarks by pointing out that, in France, the authorities competent for directing people with disabilities towards the ordinary setting or specialist establishments are (i) in the case of children, the district special education boards (CDESS)⁷² and (ii) in the case of adults, the vocational guidance and rehabilitation boards⁷³ (COTOREPs)⁷⁴.

⁷⁰ Michel Fardeau, Directorate General of Social Action report to the Minister for Employment and Solidarity, *Disability: a comparative and forward analysis of provision*, p.52, **Appendix 14**. The report states, in the light of a 1999 OECD study, that “on the whole, educational integration is usually cheaper than, or equivalent in cost to, separate education”. This should prompt France to give precedence to integration into the ordinary system when at all possible for children with disabilities, and autism sufferers in particular, in line with its undertakings.

⁷¹ Marcel Hérault, editorial, *Revue Sésame*, March 1998, **Appendix 8**.

⁷² Code of Social Action, Article L.242-2.

⁷³ Code of Social Action, Article L.243-1.

⁷⁴ The boards are likewise responsible for deciding the incapacity rating of people with disabilities and the amounts of compensatory allowances. Michel Fardeau has drawn attention to the malfunctioning of these boards (Directorate General of Social Action report to the Minister for Employment and Solidarity, *Disability: a comparative and forward analysis of provision*, pp.15 and 16, **Appendix 14**. The report points out, in particular, that the boards are extremely slow to take decisions, depending on the number of referrals, and, in most cases, people with disabilities and their families have to abide by them “often not being allowed to express any preferences”.

a. Autistic children and adolescents are not being educated in the ordinary system “wherever possible” (Article 15 of the Charter)

By way of an introduction, we may quote some of the findings of the two reports with which the present complaint is concerned: “*educational integration is a fragile process constantly liable to be called in question and which is more a matter of goodwill and charity ... integration is being developed on the basis of teachers’ and school heads’ voluntary commitment, which contravenes the republican principle of equal access for all to institutions ... provision for integration into the ordinary classroom remains minimal ... mostly, integration is on a trial basis ... integration is not a genuine right but merely tolerated ... resources for the necessary supervision are inadequate ... there is a shortage of specialist teachers. Training for teachers and school heads is desperately lacking ... and is a hindrance to integration of pupils with disabilities*⁷⁵.”

The fact is that the Handiscol circular⁷⁶ promised more than it delivered, as confirmed by a disability specialist, Professor Charles Gardou, who noted in February 2002 that in France “*the integration rate for people with disabilities is the same as 20 years ago, despite the marvellous work being done by the voluntary sector and despite parents’ very active efforts*”⁷⁷.

⁷⁵ Michel Fardeau, Directorate General of Social Action report to the Minister for Employment and Solidarity, *Disability: a comparative and forward analysis of provision*, p.59 ff, **Appendix 14**. Ministry of Employment and Solidarity (General Inspectorate of Social Affairs), Ministry of Education (General Inspectorate of Education), Report on access to education for children and young people with disabilities, March 1999, p.2 of the summary and p.34, **Appendix 15**.

⁷⁶ Circular No.99-637 (the so-called “Handiscol” circular) of 19 November 1999 setting out guidelines on schooling of children and adolescents with disabilities, *Ministry of Employment and Solidarity Newsletter*, 5 January 2000. In the hierarchy of French standard-setting a circular has no binding legal force, therefore its non-implementation is not punishable.

⁷⁷ Emmanuel Davidenkoff, “Children the system rejects”, *Libération*, 15 February 2002, **Appendix 22**. A general point (concerning the full range of disabilities) is that, on page 15 of the report, *La politique en direction des personnes handicapées* (Policy on behalf of people with disabilities), published in October 2000 by the Ministry of Employment and Solidarity (Directorate General of Social Action), it is stated that 47,000 children are integrated into infant schools and primary schools (individually or collectively) and only 17,000 are integrated at secondary level, in particular through the educational integration units. The same report states, on page 12, that 125,000 children are at specialist institutions (out of 500,000 classed as 80% disabled). These figures match the findings of Michel Fardeau in the Directorate General of Social Action report to the Minister for Employment and Solidarity, *Disability: a comparative and forward analysis of provision*, which states that “*only 7% of young people with disabilities receive ordinary schooling, which means that over 90% are being catered for in facilities which, to varying degrees are segregated, either within or outside the national education system*”, p.59, **Appendix 14**. It must be pointed out, though, that in practice not all the 90% attend specialist facilities - far from it (see the figures in the above-mentioned October 2000 report).

(i) Pre-school provision is virtually non-existent

Recommendation (96)6, referring to the need for pre-school intervention, states:

“Taking into account the principle of early intervention, it is in the child’s interest:

- *to begin medico-educational measures at pre-school age, especially where they are intended to make it easier for the child to obtain a school education at a later stage;*
- *to attend school or pre-school classes from a very early age.”*

Early intervention to assist children with autism is virtually non-existent.

It should be possible for autistic children to receive early help from the specialist Centres for Early Medico-Social Action (CAMSPs), but these remain to be developed. Late diagnosis is a further hindrance to early intervention even though it is recognised that early intervention is essential to prevent autism sufferers from developing behavioural problems⁷⁸.

(ii) Integration into ordinary school is the exception and is only for a few hours a week

Recommendation (92)6 states that education should be provided in an ordinary environment wherever possible and whenever the necessary assistance and support can be given, with supply, in particular, of special therapeutic, technical and educational aids to meet the needs of children with disabilities.

As is well known, the facilities for educational integration - the school integration classes (CLISs)⁷⁹, the educational integration units (UPIs)⁸⁰ and the domiciliary care and special education services (SESSADs)⁸¹ - are too few in number⁸² and teacher

⁷⁸ See paper by Max Artuso, the president of Autisme France, on the situation in France, delivered at the Autisme France conference on 27 November 1999, **Appendix 7**.

⁷⁹ Circular No.91-302 of 18 November 1991 on integration of children and young people with disabilities, *Ministry of Education Newsletter*, 16 January 1992.

⁸⁰ Circular No.2001-035 of 21 February 2001 on schooling for pupils with disabilities at secondary schools and development of educational integration units (UPIs), *Ministry of Education Newsletter*, 1 March 2001.

⁸¹ When not on an individual basis, integration can be collective, through the CLISs at primary school or the UPIs at lower-secondary level; the SESSADs, which are medico-social assistance services are aimed at laying the foundations for individual or collective integration (see the account of experimentally setting up a CLIS for autism sufferers, **Appendix 17**).

⁸² Ministry of Employment and Solidarity (General Inspectorate of Social Affairs), Ministry of Education (General Inspectorate of Education), Report on access to education for children and young people with disabilities, March 1999, second part of the report. On page 2 of the summary there is also the following statement: *“As regards collective integration, the 1991 circular introducing CLISs for four types of disability did not make immediate*

training generally is not appropriate to meeting the needs of people with disabilities⁸³. But the particular point that has to be made is that integrated schooling in the ordinary setting is not being provided for autistic children and young people even when their level of attainment should allow it.

At the 1999 Autisme France conference⁸⁴ the president of the association, Max Artuso, said that while educational integration was making progress in terms of statements about it, in actual practice it continued to be even less than the exception as far as autistic children were concerned.

Two years later those observations were amply confirmed by a mother quoted in *Le Monde* as follows: *“when I told the headmistress and the school doctor that Valentin was autistic, the atmosphere turned chilly. From that point on, nothing was straightforward. An integration meeting wasn’t arranged until September ... It was decided to admit Valentin from mid-October on but only two afternoons a week and without any classroom assistant. The rest of the time he is at home. That decision, which is no kind of an integration plan at all, has left Valentin without any routine. He does not understand why he is not going to school every day. If we go on like this, he is going to lose all the progress he has made - he knows the alphabet and he can count. Despite the law, the education system is not ready, in terms of attitudes or training, for children with disabilities. If parents are not prepared to put up a fight and move heaven and earth the system rejects them. Every week I phone up the special education board (the CDES) to get them to take an interest in Valentin, and there are days when I would gladly take myself off to Canada or Belgium, where the school systems would take him on.”⁸⁵ This is an illustration that, even in the very few cases where an attempt is made at educational integration of an autistic child, only a few hours’ schooling are offered per week. It perfectly reflects the predicament of the parents of all such children, whom the French education system barely tolerates.*

On 24 May 2002, reporting on the second national autism conference, *Libération* added that *“the magic word in recent years has been integration. The Handiscol circular which Ségolène Royal issued in 1999 said that it was part of the function of every primary school, every lower secondary and every upper secondary to take in, and not discriminate against, children and young people with disabilities whose*

implementing arrangements. Although the 1995 circular established UPIs for young people with mental retardation or mental disorders there are not enough of them at present to form a natural continuation of the education provided in CLIS1 at primary level. Continued educational integration in lower-secondary school is likewise hampered by there being too few of the SESSADs.” Appendix 15.

⁸³ Ministry of Employment and Solidarity (General Inspectorate of Social Affairs), Ministry of Education (General Inspectorate of Education), Report on access to education for children and young people with disabilities, March 1999, third part of the report, p.4 of the summary. **Appendix 15.**

⁸⁴ **Appendix 7.**

⁸⁵ Remarks quoted by Sandrine Blanchard in her article “L’école n’a aucune tolérance vis-à-vis de la différence” (If you are different, the school system isn’t interested), *Le Monde*, 28 November 2001, **Appendix 20.**

families requested educational integration". Wonderful - on paper. But in actual fact, "ordinary" schools are not at all equipped to meet such demand, having neither the human resources nor the skills when you remember how easily damaged such children are and how much attention they need. Such children are classed as "school attenders" on the strength of a couple of hours' lessons a week with the help of volunteers. The whole business is just the luck of the draw. It helps the statistics and salves consciences, but that is about all. That apart, the medico-social institutions are drastically short of specialist teachers, who are supposed to be seconded from the education system."⁸⁶

b. Adapted "specialised bodies" (Article 15 of the Charter) are struggling to provide autistic people with any kind of education

(i) Administrative unwieldiness gets in the way of providing specialised new facilities

In addition to the quantitative deficiencies we have pointed to, which in practice restrict the creation of new capacity for the autistic people that the ordinary system cannot accommodate, it needs emphasising, in the words of the president of Sésame Autisme, Marcel Hérault, that getting a new facility opened⁸⁷ is a "battle", in

⁸⁶ Jacqueline Berger, "Nowhere for our children to go", *Libération*, 24 May 2002, **Appendix 22.**

⁸⁷ The main stages in opening a new facility are as follows:

1. depending on the type of facility (for adults or children), the application to open it has to be lodged with the district council (in the case of facilities for adults funded by state social assistance) or the district directorate of health and social affairs (DDASS) (in the case of facilities funded by the sickness insurance system);
- 1b. before the application is made, however, there are invariably lengthy negotiations with the appropriate authorities to get the project included in the district or region priorities; this preliminary period allows thorough preparation of the application, and the file will not be pronounced complete until all the requisite quantitative and qualitative information has been provided that enables the relevant department to take a decision;
2. the authority to which the application is submitted then passes it on to the regional health and social provision committee (CROSS), which delivers an opinion on whether the facility should be set up;
3. permission to open is then delivered by the regional prefect, the district prefect or the chair of the district council, according to the type of facility;
4. in some cases there will be a further wait for public funding - permission is sometimes given for facilities before finance has been found;
5. lastly, the facility cannot be opened until it has passed an inspection to check, in particular, that it meets the requisite standards, that costs are in order and that its characteristics match those for which approval was given.

which the authorities have little understanding of the realities with which the voluntary-sector promoters of facilities are confronted⁸⁸.

(ii) Training for the staff who work with autistic people is in most cases non-existent or ill-adapted

Recommendation (92)6 says that special schools should be staffed by teachers with special teaching qualifications and be linked with mainstream schools to increase co-operation. Neither of these two requirements is met in France in the educational provision for the autistic.

The standard of educational provision for the autistic of course depends on training for the staff of the schools and facilities. Staff need to understand how autistic people interact and communicate, in particular so as to equip sufferers for independent living as far as possible. A number of educational methods used in the English-speaking world meet this type of requirement⁸⁹. It was therefore essential in France to arrange for those in charge of provision for autism sufferers to be given special training. This was the subject of a circular in 1998⁹⁰.

The Autisme France report in January 2001 on national policy on autism since 1995 states, however, that since 1998 only 59 of the 92 facilities opened had put some of their autism staff through special training. As pointed out in the report, *“that means that nearly 36% of facilities which received funding did not make any arrangements for special staff training.”*⁹¹ The report states that in-service training was mostly confined to a one-week theoretical course and notes that alas *“as the regulations*

For a description of the various specialist facilities, see **Appendix 18** (source Autisme France).

⁸⁸ Marcel Hérault, review of the Autism Plan, *Revue Sésame*, no.137, December 2000, **Appendix 12**: *“The administrative and financial decisions do not mean immediately available capacity, with at least a one-year time lapse between the decision and the availability of places. The time lapse is often much longer, because setting up a facility is a real battle - the authorities are increasingly nitpicking and have very little notion of the realities with which the people behind a project are confronted. In the Ile-de-France region, for example, the DRASS forgot to include autism in the national/regional plan, thus depriving autism associations of the subsidies their project needed ... The irresponsibility of a great many people in official positions is saddening and wearing, with obstructiveness and criticism more in evidence than creative initiative. Our associations of volunteers, short of funding as they are ... often have the authorities against them instead of with them in conducting their projects.”*

⁸⁹ See in particular Appendix I to the report to Parliament (p.24 ff), *Autism, an evaluation of action 1995-2000*, Directorate General of Social Action, December 2000, **Appendix 10**.

⁹⁰ Circular No.98-232 of 10 April 1998 on training for staff working with autism sufferers, **Appendix 5**.

⁹¹ **Appendix 11**.

stand⁹², there is nothing to compel facilities to train their staff. There is no safety net if provision is inadequate. The DDASSs would not seem to be aware of the need for autism specialisation. Quite a few budgets for creating new capacity have been granted to associations with no experience of working with autism sufferers, with, in some cases, disastrous results.”

Autisme France’s observations are confirmed by the 1999 IGAS/IGEN report on access to education for children and young people with disabilities, which comments on a visit which the authors of the report made as part of their assignment: *“The worst case was an officially licensed facility in a city ...: ‘Children with serious learning difficulties, combined with personality disorders and/or physical problems and/or emotional disturbances’. Under this novel classification lurk children with intellectual impairments - diagnosed post-admission by a psychiatrist for the purposes of CDES funding - linked to major behavioural disorders and appalling family difficulties. As far as education was concerned, the assignment team discovered a totally unacceptable situation: only one teacher had been seconded to the facility, which has 48 children, of both sexes, aged 6 to 14. Only 26 children are being educated, but part-time and divided into three groups: the ablest have three hours’ teaching each morning (level - second and third years of primary school). The others have one hour a day! The rest of the time the children are busy with vaguely educational activities, among other things, conducted by specialist instructors, but without any properly sequenced programme, far less a pedagogical strategy.”⁹³*

c. Educational provision for autistic adults is non-existent

Here again the requirements laid down in Recommendation (92)6 are not being met. The recommendation said: *“Particular attention should be paid to the role of adult education, especially in so far as people with mental disabilities are concerned. Adult education should provide the maximum range of opportunities for people with disabilities, including training in basic skills and specialised education.”*

As already seen, the French regulations (whether statute law or circulars dealing specifically with autism) fail to lay down any educational obligation which would give autistic adults entitlements. This legal state of affairs explains why - as pointed out by *Le Monde* in its edition of 20 May 2001 - *“the obstacles for adults are even greater, and here France is lagging far behind most developed countries.”⁹⁴*

To provide some background information, the main types of facility dealing with autistic adults in France are the “maisons d’accueil spécialisées” (MASs) (special centres), the “foyers à double tarification” (FDTs) (dual-tariff centres), the “foyers de

⁹² As noted above, a circular, in the hierarchy of French regulations, has no binding legal force and therefore failure to implement it is not punishable.

⁹³ Ministry of Employment and Solidarity (General Inspectorate of Social Affairs), Ministry of Education (General Inspectorate of Education), Report on access to education for children and young people with disabilities, March 1999, p.57, **Appendix 15**.

⁹⁴ Elisabeth Bursaux, “National shortage of autism resources”, *Le Monde*, 20 May 2001, **Appendix 20**.

vie occupationnels” (residential occupational-activity centres), and the “centres d’aide par le travail” (CATs) (work-based support centres). Apart from the CATs, which allow vocational integration, they offer only occupational activity.

The voluntary sector is unanimous in its condemnation of the way France treats autistic adults, particular where there is no room at specialist facilities.

At the start of the first national autism conference, the newspaper *La Croix* quoted the president of Autisme France, who was speaking at the France Telecom press conference on 26 April 2001: “Several thousand autistic adults have had to turn to Belgium for help, while several thousand more are at present in psychiatric hospitals, mostly in secure wards, under heavy sedation.”⁹⁵

d. Hospitals are not “sufficient and adequate” institutions and services (Article 17 of the Charter) for educational provision for autistic people

Hospital provision of course does not constitute appropriate educational provision. In this connection the National Agency for the Development of Medical Evaluation (ANDEM) in 1994 and the National Ethics Committee in 1996 drew attention to “the serious problem of autistic people being admitted to psychiatric services in childhood and remaining hospitalised for most of their lives, for lack of any alternative.”⁹⁶

At the time, Autisme France took up the matter with the National Ethics Committee, viewing the inadequacies of provision for autistic people in France as challenging the most basic ethical principles. The Autisme France petition stated, among other things, that “children are being channelled into the psychiatric sector, where non-interventionist provision based on a psychoanalytic model of awaiting the ‘emergence of desire’ deprives them of the social and educational progress that might stand them in good stead.”⁹⁷

Around the same time the General Inspectorate of Social Affairs was having doubts about the admission of children and young people to day hospitals: “Surely this approach is outmoded and an unsatisfactory compromise between treatment and education?”⁹⁸

Yet eight years on, many children and adolescents continue to attend hospitals, where, in addition, provision for them cannot be supervised by the district special

⁹⁵ Martine de Sauto, *La Croix*, 18 May 2001, **Appendix 23**.

⁹⁶ National Agency for the Development of Medical Evaluation (ANDEM), Research Service, report on autism, November 1994, p.16, **Appendix 6**; National Ethics Committee on the Life Sciences and Health, opinion on provision for autistic people in France, report, January 1996, p.9, **Appendix 16**.

⁹⁷ National Ethics Committee on the Life Sciences and Health, opinion on provision for autistic people in France, report, January 1996, pp.2 and 3, **Appendix 16**.

⁹⁸ General Inspectorate of Social Affairs, “Provision for autistic children and adolescents”, October 1994, p.30, **Appendix 6**.

education boards, whose jurisdiction does not take in the health sector, even though, according to the latest findings of the social affairs and education inspectorates, “*educational provision for children in some health facilities raises serious difficulties.*”⁹⁹

To conclude this section, Autism Europe will quote from the findings of the report on access to education for children and adolescents with disabilities:

“On the ground, we found very serious misassignment of children with disabilities: children with disabilities were being returned home without any professional help being arranged, adolescents with behavioural problems were being withdrawn from schooling, children were being placed in inappropriate medico-social facilities, and at some establishments children were receiving little or no schooling even though the disabilities they had did not justify it, and children with disabilities were being boarded at establishments far from home in cases where removal from the family for child-protection purposes had not been sought.”

“This leads us to advocate, as a matter of urgency, that administrative services and front-line agencies be reminded of the law and the implementing regulations, in two main areas: evaluation of the specific educational needs of the individual child with disabilities, and the CDESS’ central role as regards assignment to the appropriate service. The state’s responsibility in the matter goes without saying.”¹⁰⁰

2.3 CONTRAVENTION OF THE NON-DISCRIMINATION PRINCIPLE

The above analysis demonstrates not only unsatisfactory French implementation of Articles 15 and 17 of the Social Charter but also a contravention of the non-discrimination obligation laid down in Article E, which provides: “*The enjoyment of the rights set forth in this Charter shall be secured without discrimination on any ground such as ... health ... or other status.*”

As we know:

- (i) Article 15 of the Social Charter obliges France to take the necessary measures to provide people with disabilities with education and
- (ii) Article 17 lays down the general framework within which states are required to provide that education, and specifies that the education obligation requires

⁹⁹ Ministry of Employment and Solidarity (General Inspectorate of Social Affairs), Ministry of Education (General Inspectorate of Education), Report on access to education for children and adolescents with disabilities, March 1999, p.65: “*CDES decisions apply only to medico-educational facilities and special classes, sections or establishments in the education system, and do not apply to health establishments, day hospitals in particular. Day hospitals, which large numbers of children and adolescents with disabilities attend, fall within the scope of our assignment*”, **Appendix 15**.

¹⁰⁰ Ministry of Employment and Solidarity (General Inspectorate of Social Affairs), Ministry of Education (General Inspectorate of Education), Report on access to education for children and adolescents with disabilities, March 1999, p.67, **Appendix 15**.

them to establish or maintain institutions and services sufficient and adequate for that purpose.

Thus, autistic people's:

- (i) not having educational institutions or services (in the ordinary system or under special provision) of an adequate standard (that is, meeting their needs from the qualitative standpoint),
- (ii) and not having sufficient numbers of such institutions and services

constitutes discrimination as regards the rights laid down in Article 17 of the Social Charter. By virtue of their disability, autistic people are being deprived of the right to an education, and more generally of their right *"to grow up in an environment which encourages the full development of their personality and of their physical and mental capacities"*.

CONCLUSION

Since the 1995 Veil circular and the law of 11 December 1996, the public authorities have several times recognised the need to make better educational provision for autistic people, and the reports since that time, in particular the 2000 report to Parliament, have pointed out the deficiencies of provision.

In response to that situation, associations of parents of autistic people are regularly given statements and undertakings assuring them of compliance with the law and regulations. Similarly, circulars, sometimes on more general matters (provision for the full range of disabilities), are regularly issued to remind the implementing authorities of their duties.

Such circulars, undertakings and official stances - such as the recent stance by the President of the Republic in his letter of 5 April 2002 - are welcomed by the parents' associations but only have a standard-setting function (if we treat them as akin to the legal instruments to which they refer) but are in no way implementing measures in the legal sense of the term.

On the contrary, this plethora of measures and declarations is tantamount to an admission of non-compliance with the law, whether the Social Charter or the French legislation and regulations. Only where a measure is not being implemented does it become necessary to issue reminders that it needs implementing, in a succession of circulars, political undertakings and other stances. A measure that is being properly implemented is not one that anyone talks about!

Given the situation, Autism Europe now considers it indispensable, with the number of autistic people unprovided for increasing year by year - France's allocations of finance not only do not allow the shortfall to be made good but are not enough to cover new needs - for the European Committee of Social Rights to deliver a firm reminder to France of its duty to comply with Articles 15 and 17 of the Social Charter and implement them satisfactorily.

In this connection Autism Europe would repeat the words of Committee of Ministers Recommendation (92)6, which stated ten years ago that:

- *“the rehabilitation of people with disabilities, by virtue of the economic and social integration it achieves, is a duty of the community, which guarantees human dignity and alleviates the difficulties stemming from society with which people with disabilities are confronted, and ... should be included among the priority objectives of any social policy”;*
- *“failure to protect the rights of citizens with disabilities and improve their opportunities is a violation of human dignity and entails a heavy financial burden, an attitude that results in ... many people becoming unnecessarily dependent on others and incapable of any economically and socially productive activity ...”*

In conclusion, Autism Europe asks the European Committee of Social Rights to:

- **find that France is not satisfactorily meeting its obligations under Articles 15 and 17 of Part II of the Social Charter;**
- **find that France is infringing the principle of non-discrimination laid down in Article E of Part V of the Social Charter in that autistic people are not enjoying the right to education recognised in Article 17 of Part II;**
- **accordingly deliver a negative opinion so that the Committee of Ministers of the Council of Europe can recommend that France take necessary and sufficient measures to provide education for autistic people, in accordance with the position which the Committee adopted ten years ago in its Recommendation (92)6.**

Paris, 25 July 2002

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