

**ALTERNATIVE REPORT
OF THE FRENCH AUTISM ASSOCIATION
AUTISME FRANCE
TO THE COMMITTEE ON THE RIGHTS OF
THE CHILD**

**IN THE CONTEXT OF THE REVIEW OF THE SIXTH
PERIODIC REPORT OF FRANCE
BY THE COMMITTEE ON THE RIGHTS OF THE CHILD**

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Alternative report of the French Autism Association to the Committee on the Rights of the Child

in the context of the review of the sixth periodic report of France by the Committee on the Rights of the Child

Preamble

1. Definition of Autism Spectrum Disorders (ASDs)

ASDs are early and often severe neurobiological disorders of child development. Under DSM 5, they are characterised by two sets of signs of varying intensity (this is why they are referred to as Autism Spectrum Disorders (ASDs)):

- communication and social interaction disorders
- stereotyped and repetitive behaviours, restricted interests

which are often associated with other sensory, eating and sleeping disorders.

Co-morbidities are frequent: epilepsy, intellectual development disorders, apraxia, , genetic syndromes...

Difficulties in communicating, learning and adjusting to daily life may be more or less severe. A ASD diagnosis is reliable from the age of 18 months ; it is necessary to intervene very early, as soon as the first signs appear and before a formal diagnosis is made.

According to HAS, France admits a ASD prevalence equal to 1 out of 100: in the Western world, such prevalence is closer to 2%. Regardless of age, any person suffering from an ASD can make progresses provided the interventions proposed are suitable to his or her needs, difficulties and potentialities. Periodical functional assessments and personalised educational programmes by operators trained in the field of autism are essential. To be able to enhance their abilities, individuals with ASDs need :

- an early diagnosis based on a multidisciplinary, neurological, speech-language , sensory-motor, and cognitive assessment;
- an early intervention with customised, scientifically validated programmes;
- regular assessments and individualised educational programmes;
- schooling with educational support at school and possibly pedagogic programmes ;
- socialisation in all areas of life.

2. Introducing Autisme France

Autisme France: 30 years of struggle in the service of autistic persons

February 1989: 1st call for the "constitution of a movement for the right to educational and non-psychoanalytic care of autistic persons", which led to a **first founding assembly in June 1989**, in Lyon. A first "manifesto of parents of autistic children" was drafted.

It revolves around 4 main points:

- ✓ The right to diagnosis
- ✓ The right to education

- ✓ The right to information
- ✓ The right to compensation for deficiencies (caused by inadequate care)

April 1994 : On 12 April, Simone Veil **received Autisme France** and pursuant to our request, she announced her decision to carry out investigations (IGAS, ANDEM...) and to publish a text on autism within a year. She fulfilled her promise.

June 1994: Autism France published its "**Report on the experiences of autistic persons and their families in France at the dawn of the 21st century**". This document would significantly inspire IGAS report.

March 1995: Autism France received from the Ministry (27 March) **the draft circular that Simone Veil had promised. We were the only ones to propose amendments. Three of them were accepted** in principle (recognition of parents' free choice as for the type of care, the possibility to create pilot facilities, the open recognition of integrated classes as a modality of care). **Two others were rejected** (the free choice of the therapy content, the recognition of an educational alternative (SESSD) (later called SESSAD) for kids.)

April 1995: General six-day mobilisation to obtain an educational alternative.

We fought this battle alone, while other parents' associations, wrongly believing that "a bad circular is better than no circular at all", had given up from the start.

February 1996: The bill tabled by Jean François Chossy, Member of Parliament for the Loire region, was adopted unanimously at first reading at the National Assembly on February 26. This bill recognised autism as a handicap entitling to specific responses and became Article L 246-1 of CASF [**Code de l'Action Sociale et des Familles – Social Action and Family Code**].

June 2001: The Chairperson of Autisme France was received by **Bernard Kouchner** (1 June) and **Ségolène Royal** (5 June). The essential points they addressed were :

- ✓ The obligation to make autism diagnoses according to the international classification, and if possible before kindergarten or preschool classes (routine screening).
- ✓ Access to education.
- ✓ The right of autistic persons to a dignified life.
- ✓ Medical investment into research on autism.

Ségolène Royal's presentation of the "plan to better accommodate and care for autistic children and adults". The Minister undertook to "enforce all those provisions required to ensure that no disabled child is kept out of compulsory education at the next start of the school year".

Meanwhile during 2002, Autisme France initiated a process, later pursued by Autisme Europe with the European authorities.

November 2003: The European Committee of Social Rights concluded that France failed to fulfil its educational obligations with respect to autistic persons, as defined by the European Social Charter.

France's condemnation was repeated and confirmed in 2007, 2008, 2010, 2012, and 2013.

2009: Second White Paper on Autism

2010: Autism France was a member of the steering group for recommendations of good practices for children and adolescents.

2012: Autism France drafted a proposal for a programme on autism.

2013-2014: Autism France was extensively committed to ensure the implementation of the changes:

- ✓ national recognition of our work and expertise, with a strong presence in all forums and working groups
- ✓ development of a national quality reference system largely based on our quality grids, that will become the foundation of the new autism certification
- ✓ claim for inclusion into the mainstream
- ✓ compliance with the recommendations of good practice in autism
- ✓ respect for the rights of individuals, with the 2014 opening of the legal protection service (major disputes with MDPH [**Maisons Départementales de Personnes Handicapées – Department Facilities for Handicapped Persons**], lack of appropriate services, abusive reports to the Child Welfare service)

The foundations of our charter and statutes remain fundamental reference points:

- ✓ the right to early diagnosis and intervention
- ✓ the right to lifelong support through suitable arrangements
- ✓ focus on inclusion into the mainstream
- ✓ overhaul of initial and on-going training
- ✓ reallocation of public money from psychiatric healthcare to the services required
- ✓ compensation for the harm caused to autistic persons and their families by abuse and lack of proper education.

Findings of non-compliance with the Convention on the Rights of the Child

In 2015 Autism France had already provided the UN Committee on the Rights of the Child with an alternative report and had highlighted a number of violations of such rights.

Based on the Convention on the Rights of the Child (CRC), in 2020 Autism France has noted that many of those rights are still not always respected in France when it comes to children and adolescents with an Autism Spectrum Disorder.

Autism France has listed the violation of rights for autistic persons in document available on the association's website :

http://www.autisme-france.fr/offres/doc_inline_src/577/Autisme_et_droits-2020.pdf

This document takes a 2020 overview of the application of the law enforced in 2005; it was forwarded to the European Commissioner for Human Rights and to the Human Rights Defender.

In spite of its revolutionary intentions the law passed in 2005 is still of little use for autistic persons. In fact, autistic persons are the redheaded stepchildren of the disability: no census; no or very little correct diagnosis; definition of the specific difficulties of the disability and of the forms of support needed not applied; no evaluation of the needs for compensation according to their disability, difficult schooling and little effort to make it accessible, as accessibility is hardly considered by CDMs, except for motor or sensory disabilities. There is still a lot to be done.

1. Inadequate diagnosis

The majority of autistic children in France have still not been diagnosed. Screening and early diagnosis of autism (before the age of two) are still insufficient.

Moreover, although in this respect the last three years recorded an improvement, healthcare professionals do not always report parents about their child's ASD, and this prevents parents from taking the steps necessary to ensure their child a proper growth, in violation of article 5 of CRC.

The status report on autism prepared by the Regional Health Agencies in 2014 showed that 60% of the diagnoses still referred to a child psychosis, a diagnosis not complying with ICD 10 and being inspired by a psychoanalytical interpretation of autism. http://www.ars.aquitaine.sante.fr/fileadmin/AQUITAINTE/telecharger/01_votre_vars/111_Lettre_info_ext_Aquitaine/Lettre_externer_2014_03/01_Dossier/Plan_Regional_Autisme_2013_2017_Etatdeslieux.pdf

http://www.ars.midipyrenees.sante.fr/fileadmin/MIDI-PYRENEES/0_INTERNET_ARS_MIP/ACTU/AUTISME_1042014/Etatdeslieux_tour_de_Franceautisme.pdf

This state of facts has hardly improved in 2020. A diagnosis is still difficult and time-consuming to obtain. A very large number of children are still in psychiatric institutions, without diagnosis, nor educational action. As noted in a recent user-satisfaction survey, on average the diagnosis is made at the age of seven, while the diagnosis of autism becomes poor after 18 months of age.

https://www.ipsos.com/sites/default/files/ct/news/documents/2020-06/etude_ipsos_tnd_2020_def.pdf

No psychiatrists' union supported the Programme Autism 3 (2012-2017) focussed on the High Authority for Health's recommendations for good practice; no healthcare union supported the recommendations for good practice dated March 2012 and the Programme Autism 3 to implement them. The healthcare, hospital-centred, psychoanalytical vision of autism persists, to the detriment of internationally validated educational interventions.

The new strategy on autism 2018-2022 also urged the French Federation of Psychiatry to take a stand. When the Secretary of State ventured to say that autism was not a property of psychiatry, she underwent an attack:

https://fedepsychiatrie.fr/wp-content/uploads/2019/04/Communique_Cluzel-2019.pdf

<https://fedepsychiatrie.fr/wp-content/uploads/2020/04/SFPEADA-Courrier-de-contestation-Psychiatrie-et-handicap1.pdf>

The French Federation of Psychiatry defended the archaic vision of medical-psycho-educational centres, exclusively psychoanalytical, attacking violently the Regional Health Agency of New Aquitaine which demanded an update in expertise and skills.

A refusal to diagnosticate is serious in the sense that it prevents children from accessing early educational interventions that would limit the over-disabilities associated with autism. It results in a loss of opportunity for children.

This lack of diagnosis was highlighted in the Report of the European Commissioner for Human Rights.

237. The Commissioner notes that in France there is a long-standing and marked opposition between the essentially psychoanalytical approach to autistic syndromes and to PDDs adopted by some psychiatrists and the aspirations of family associations to gain access to the educational, behavioural and developmental methods recommended by the High Authority for Health (HAS).

259. *The condition of persons with autistic syndromes and PDDs requires special attention and sustained efforts from France. The Commissioner notes that the screening for autistic syndromes and PDDs is insufficient, and that autistic persons lack appropriate assistance, which results in the psychiatric institutionalisation without support for these persons; authorities need to invest more resources in providing appropriate support and schooling for autistic children in ordinary schools.*

In France, it is still difficult to have autism recognised in its uniqueness.

All statistical documents, including in the French National Education system, use an old classification: autism spectrum disorders must be classified under intellectual deficiencies or psychic impairments. Even a law of 2005 (loi no. 2005-102 of 11 February 2005 on equal rights and opportunities, participation and citizenship of persons with disabilities) fails to recognise autism spectrum disorders and, more broadly, neurodevelopmental disorders.

Solutions :

- implementation of early diagnoses and intervention services in each department;
 - obligation for healthcare professionals to make diagnoses in accordance with DSM5, while waiting for the implementation of ICD 11, to inform parents clearly and in writing about their children's diagnoses and to complete explicit written documentation specifying what kind of action is required, or recommended, in line with the recommendations for good practice of March 2012;
 - obligation to comply with the diagnostic recommendations of the High Authority for Health of January 2018
 - sanctions for doctors violating the Public Health Code and refusing to make a diagnosis
 - arrangement of a national awareness campaign and development of information tools as required
- : the only existing screening brochure is our association product:

http://www.autisme-france.fr/offres/file_inline_src/577/577_P_21141_2.pdf

2. Discrimination in accessing education

Article 23.1 of CRC states the "right of mentally or physically disabled children to enjoy a full and decent life, under conditions ensuring their dignity, promoting their self-reliance and facilitating their active participation in the community life »

Autisme France participated in the Parliamentary committee of inquiry on inclusive schools:

http://www.autisme-france.fr/offres/doc_inline_src/577/Rapport_Autisme_France-Commission_enquete-eleves_handicapes_dans_dans_ecole_et_universite-14_ans_apres_loi_2005-2019.pdf

Figures speak for themselves: out of 100,000 autistic children theoretically identified in France, only 36,200 are enrolled in a school, details on their full-time or part-time involvement not being available. There is a school assistant for 71% of the children, often enjoying little training in autism: usually associations finance the assistants' training out of their own pockets.

Poor schooling of autistic children is regularly lamented by families and makes a regular topic of newspaper articles:

- ✓ https://www.huffingtonpost.fr/2018/06/06/apres-le-refus-dune-classe-specialisee-au-college-de-son-son-autiste-le-cri-du-coeur-dun-pere-sur-facebook_a_23451098/

- ✓ <https://informations.handicap.fr/a-ecole-ordinaire-mere-autiste-deboutee-11496.php>
- ✓ <https://www.20minutes.fr/societe/2435171-20190124-schooling-medium-ordinary-sea-teenager-autist-deboutee-cedh>

As shown in the document below:

http://cache.media.education.gouv.fr/file/2014/03/8/DEPP_RERS_2014_eleves_premier_degre_344038.pdf

Autistic children are not even listed in National Education services: are they intellectually and cognitively handicapped, and in what capacity, if 70% of autistic children have no associated intellectual disability? Are they psychically disabled, and in what respect, as autism is not a mental illness?

It is accepted that schooling can be incomplete for children with disabilities, and this particularly affects autistic children: http://cache.media.education.gouv.fr/file/8/99/5/ensel2766_annex1_project-personalization-schooling_391995.pdf

Families have to keep pressing Departmental Facilities for Handicapped Persons in support of their children's schooling: the orientation in a collective programme (called ULIS) is often only valid for one year and can be questioned, or the child can be excluded. They often have their right to schooling denied as families are often imposed guidance by a medical-social institute, thus forcing parents to resort to court to assert their rights, and often to hire a lawyer to do so.

In January 2014, Autism France opened a dedicated legal safeguard service to help families to assert their rights.

http://www.autisme-france.fr/offres/file_inline_src/577/577_P_31365_5.pdf

When, every so often, children are referred to institutes for developmentally disabled persons against their families' will, they are mostly not entitled to any education, or to some schooling that does not take into account current programmes, and is limited to a few hours a week (from 1 to 4).

For this specific point, the Council of Europe condemned France five times for discrimination against autistic persons.

It considers ... as established that the proportion of autistic children in the total population of the group - considering it extensively or narrowly - in mainstream facilities or in special schools – is still extremely low, as even authorities admit; and significantly lower than the percentage of other disabled or non-disabled children.

Abstracts of the five condemnations issued by the Council of Europe against France

November 2007

Follow-up of the complaint of Autism-Europe vs. France (complaint No. 13/2002, decision on the merits of 4 November 2003)

Conclusion

The Committee concludes that the state of affairs in France does not comply with Article 15§1 on the grounds that equal access to both ordinary and special education for persons with autism is not effectively guaranteed.

November 2008

Conclusion

The Committee concludes that the state of affairs in France does not comply with Article 15§1 of the Revised Charter on the ground that it does not provide for persons with autism to be effectively guaranteed equal access to (ordinary and special) education.

March 2013

The report also states that several of the actions initiated have not yet been completed and that the results achieved through this plan are currently being evaluated. While taking note of the new measures and bearing in mind that their effects have yet to be determined, the Committee acknowledges that the report does not specify the impact of the previous "autism programme" nor the actual changes that the new WHO definition of autism brought about. It also draws attention to the fact that there is a new complaint currently (No. 81/2012, European Action for the Disabled (AEH) v. France), registered in April 2012, concerning issues of access to education for autistic children and adolescents and access to vocational training for autistic young adults. Without sufficient information on the reality of equal access of autistic persons to mainstream and special education, the Committee considers that the report does not provide sufficient new information to reverse its previous conclusion in this regard.

Conclusion

The Committee concludes that in France the situation does not comply to Article 15§1 of the Charter, on the ground that it could not be established whether the equal access to (ordinary and special) education is actually guaranteed to autistic persons.

5th condemnation dated November 2013 after a new complaint to the Council of Europe

http://www.coe.int/t/dghl/monitoring/socialcharter/complaints/CC81Merits_en.pdf

regarding the report containing the decision on the merits of the complaint forwarded by the European Committee of Social Rights, in which the Committee concluded :

- unanimously, that there is a violation of Article 15§1 of the Charter with regard to the rights of autistic children and adolescents to schooling as a matter of priority in ordinary schools.

Access of children and adolescents with ASD to schooling, training, job preparation and recreational activities is often only possible if families fund them at their own expense. The Departmental Facilities for Handicapped Persons make little or no reimbursements. Some families even finance their children's school training assistants out of their own money.

This discrimination against autistic children is also mentioned in the recent report of the European Commissioner for Human Rights.

235. The Commissioner considers that the particular situation of persons with autistic syndromes and pervasive developmental disorders (PDDs) requires a special attention. The European Committee of Social Rights found that France has violated Articles 15 (right of disabled persons to independence, social integration and participation in community life), 17 (right of children and adolescents to social, legal and economic protection) and E (non-discrimination) of the European Social Charter in two major cases in 2004¹⁴³ and 2013¹⁴⁴ mainly concerning autistic children and adolescents. In the second case, the Committee regretted the insufficiency of "appropriate measures likely to ensure the predominance of an educational character in work and working methods fulfilled and implemented " in institutions caring for autistic children and adolescents" (§ 119). According to those NGOs consulted by the

Commissioner, current support methods in many institutions represent an obstacle to de-institutionalisation and to the right to inclusion.

*In 2014, this led the European Committee of Social Rights to state regarding the case of *Action européenne des Handicappés (AEH) vs. France*, that "the French Government makes financial contributions to the relocation of French autistic children and adolescents to Belgium in view of accommodating and schooling them in specialised institutions, operating according to appropriate educational standards, instead of financing the establishment of specialised institutions complying with such standards and operating on the French territory". ECSR, *Action européenne des Handicappés (AEH) v. France* (no. 81/2012), 5 February 2014, §§99 and 135.*

*249. The information received by the Commissioner during his visit reveal that autistic children - whose integration into mainstream schools is advocated by the authorities - are particularly affected by the lack of schooling in mainstream schools. Moreover, the European Committee of Social Rights has dealt with this matter on several occasions. In 2004, in the case *Autisme-Europe vs. France*, the Committee stated that guaranteeing the right to education for children and other persons with disabilities is a condition for "autonomy, social integration and participation in the community life" specified in Article 15 of the Social Charter. The Committee concluded that France had violated the Charter because, inter alia, "[a] percentage of autistic children attending ordinary or specialised schools is still extremely low and significantly lower than the percentage reported for other children, whether disabled or not".*

262. The Commissioner encourages the French authorities to continue their efforts to provide schooling for all children and young persons with disabilities, particularly with autism. He welcomes the creation of the status of "Accompagnant des Élèves en Situation de Handicap" [Supporter of Handicapped Students] and calls on the authorities to implement this role as soon as possible, providing a sufficient quantity of jobs to meet the needs of disabled students in ordinary schools. He also urges authorities to invest in the training of teachers on disabilities.

Solutions :

- End discrimination
- Promote regular schooling by reallocating funds misspent in healthcare for old-fashioned and toxic practices towards the National Education, so that it can finance the necessary educational support for autistic children and adolescents.
- Promote inclusion in all children activities (leisure, sports, cultural life).
Inclusion implies that teachers, facilitators and all those involved in inclusion should be trained to autism, that the National Education system recruits educational staff with specific skills and up-to-date knowledge of autism.
- Finance schooling assistance to families that State services do not provide.

3. Interventions not in line with with most updated experience on autism of January 2010 by the High Authority of Health [Haute Autorité de Santé (HAS)] and its good practice recommendations of March 2012.

3-1. Lack of knowledge about autism and abuse of autistic children

The vast majority of day hospitals, medical-pedagogical centres and early medical-social action centres are incompetent in autism, ignore the scientific knowledge on autism and reject the recommendations of the High Authority for Health (coordinated educational, pedagogical and therapeutic interventions, without psychoanalysis).

Intensive early intervention (from 0-4 years) is currently unanimously recognised as the best way to ensure development of children with ASD. The Early Start Denver Model (ESDM), an intervention scientifically proven to lead to a very significant improvement in the social and cognitive skills of children with autism, recommended by the Haute Autorité de Santé, is virtually unknown in France. The 6 to 8000 autistic babies born in France are not entitled to it.

Adolescents from the age of 16 are considered adults in psychiatry where they can be overmedicated and abused (tied up and locked up). This point is underlined by the European Commissioner for Human Rights:

234. Despite the many challenges to their validity and their infringing nature on individual freedoms, unwanted hospitalisations are still numerous and in 2011 more than 80,000 persons were involved. A 2012 study by the EU Agency for Fundamental Rights also reported evidence that in France the opinions of patients affected by these involuntary placements and treatments are rarely collected and insufficiently taken into account. The Commissioner considers that the opinion of the person to be placed in a closed facility should always be collected and that placing someone in such an institution without his or her consent should be considered as a deprivation of liberty and should be subject to the safeguards set out in Article 5 of the European Convention on Human Rights¹⁴².

In medical-educational institutes, monitoring of children and adolescents is not systematically based on functional assessments of their needs and skills, therefore objectives are general and not based on the specificities of a child's disability. In 2017 administrative approvals of the institutions were modified to include autism, but this cosmetic change does not permit to verify the quality of the interventions carried out there. Thus, an autism "approval" is given to institutions and services but there is no national standard specifying the quality required for these establishments. An association has prepared a certification on autism to verify their quality, but it is still taken into account only marginally.

Individualised projects, although precisely described in the autism recommendations of March 2012, are poorly implemented, poorly evaluated, and most institutions are unaware of the quality approach in autism and supervisory practices. The professionals required: speech therapists, psychomotor therapists, occupational therapists, psychologists, are missing or are available for ridiculously insufficient time.

The appeals for programmes to set up institutions dedicated to autism arise our concern:

Such projects are extensively granted to associations which are absolutely ignorant on autism, if not even promoting psychoanalysis.

Without acceptable quantitative and qualitative interventions, families are often forced to pay for freelancing professionals and hardly obtain a reimbursement. With the exception of speech-language therapists, who are not easily accessible because of a never-questioned, limiting numerus clausus, the professionals required by families are never covered by the Social Security service outside hospital or medical-social services.

Psychologists, occupational therapists, educators, particularly essential for autistic children are not reimbursed by the Social Security.

Such shortcomings were pointed out by the European Commissioner in his report of February 2015:

236. The Commissioner notes that, despite three "autism programmes" providing for support measures and the means to implement them¹⁴⁵, the lack of appropriate support for autistic persons has regularly been a matter of concern not only to associations but also to national and international bodies.

250. The Commissioner notes that, in its 2008 and 2012 conclusions, the European Committee of Social Rights eventually found that the state of affairs in France remains disrespectful of the Charter, since equal access to education or vocational training is not effectively guaranteed to persons with autism. The Commissioner notes that the European Committee of Social Rights did not find support to schooling outside the ordinary environment, in violation of Article 15§1 of the Charter Action Européenne des Handicapés (AEH) v. France. France of 2013 because of: the insufficient priority given to ordinary law institutions to educate autistic children and adolescents; the lack of adequate measures concerning vocational training for autistic young people under ordinary law or in specialised institutions; the lack of predominance of an educational character in specialised institutions caring for autistic children and adolescents.

263. Finally, with regard to children with autism or ASDs, the Commissioner invites authorities to allow them to be accompanied by means of methods placing great emphasis on educational, behavioural and developmental methods and to encourage the education of autistic children in ordinary schools.

Abuse can also exist in medical-educational institutions: padded rooms to lock children in, lack of communication tools and educational interventions, unstructured environment, lack of schooling.

This makes the object of regular media alerts:

- ✓ <https://www.ash.tm.fr/child-of-family/pedophilia-in-leglise-one-survey-follow-554341.php>
- ✓ https://www.west-france.fr/ile-de-france/essonne-un-educator-condamne-a-15-months-with-privileged-for-violent-children-vulnerable-6882654?fbclid=IwAR2wGZfZq2S0eMBU8hdhYe-htHnW5aai3qWmGB3BvGzJD7_BIMXHU4wG_hs

Solutions :

- the obligation for professionals making diagnoses and the services of the Departmental Institutions for Disabled Persons to inform parents about the social benefits to which they are entitled and to provide assistance to obtain them;
- the creation of the profession of autism counsellor;
- organization of public service delegations for medical-social establishments in order to control the use of public money
- control psychiatric services where there is still no classification of the acts performed; prohibit inhuman and degrading treatment.
- Finance the freelancing professionals required by families for recommended action in autism.

3-2. Non-compliant trainings

Article 23.4 of the International Convention on the Rights of the Child :

"In a spirit of international cooperation, Member States shall promote exchange and access to relevant information in the field of preventive healthcare and medical, psychological and functional treatment of children with disabilities, also through the dissemination and access to information concerning rehabilitation methods and vocational training services, with an aim to enabling Member States to improve their capacities and skills and to broaden their experience in these areas. In this regard, the requirements of developing countries shall be particularly taken into account »

France regularly violates this standard: erroneous information on autism disseminated even on websites of some autism resource centres, lack of knowledge and refusal of internationally recommended interventions.

Here is an example of what can be found on the Nurse Psychiatry website:

<http://psychiatriinfirmiere.free.fr/definition/autisme/autisme-theorie.htm>

False definition of autism, demand for psychoanalysis, no educational intervention in accordance with the recommendations of the High Authority of Health.

The reference framework for the profession of psychiatrist dated March 2014 says a lot about the absence of scientific approaches. The plurality of theoretical references makes it possible to continue to justify the status quo.

<http://www.psydoc-france.fr/en/Research/PLR/PLR80/PLR80.pdf>

Certain psychiatric treatments imposed on children and adolescents with ASD, such as "packing" (wrapping in wet, cold sheets until the child calms down) and the use of medication in the first instance (chemical straitjacket) constitute cruel, inhuman and degrading treatment within the meaning of article 37 of the Convention.

Some children or adolescents with ASDs with significant behavioural issues may be placed in psychiatric units, deprived of their liberty. The psychoanalytic view of the child and adolescent psychiatric unit may lead to violations of the rights of the child such as restricting or denying access to parents perceived as being harmful to the child. Internment often worsens the child's condition due to the lack of understanding of the child's needs and frequently leads to the use of psychotropic drugs.

Furthermore, there is no support and training programme for parents to prevent family burnout and reduce the risk of abuse.

Advocacy of the barbaric practice of packing (ice straitjacket) :

Source:

https://books.google.fr/books?id=o52XBgAAAQBAJ&pg=PA296&lpg=PA296&dq=Devons-nous+%C3%A9thiquement+r%C3%A9sister+to+recommandations+to+the+HAS+to+do+more+to+packing&source=bl&tsig=k9_b3CvVGI500kt4p8_6fCjXquE&hl=en&sa=X&ei=8sPpVPu3F4LxUPr8_gdAL&ved=0CCMQ6AEwAA#v=onepage&q=Devons-nous+%20%C3%A9thiquement%20r%C3%A9sister%20aux%20recommandations%20de%20la%20HAS%20de%20une%20plus%20make%20de%20packing&f=false

In 2020 the National Union of Psychomotricians has proposed courses in which autism is described as a psychopathological disorder requiring a psychoanalytical approach, and there we find, just as in 2015, a paddling pool course.

http://snup.fr/wp-content/uploads/2019/10/S35-module3_Formations-2020.pdf

(- Images of the body/water. Primitive anxieties/water. - Construction of the body-psychic envelopes and psychogenesis of the skin-self.)

In wading pools, children up to pre-adolescence are watched, mostly naked, by "professionals" who do nothing.

<http://www.critiqueslibres.com/i.php/vcrit/20450> http://gallica.bnf.fr/ark:/12148/bpt6k5452436z_image.r=revue+fran%C3%A7aise+de+psychanalyse.f203.pagination.langF

Ongoing training for autism doctors is mainly imbued with psychoanalysis and the situation has hardly changed since 2015.

To alert ANDPC, the National Agency for On-going Professional Development for Healthcare Professionals, our association had to make an extensive list of training courses that are not updated yet are eligible for public funding.

http://www.autisme-france.fr/offers/doc_inline_src/577/2020.02-Non_compliant_autism_training.pdf

As a result, support in most healthcare and medical-social institutions is based on the Freudian-Lacanian catechism: the child chooses to be autistic, it is his or her choice, because of a terrifying family environment, autism is a defence mechanism, and the autistic child does not represent his or her body, he or she refuses language.

The resulting practices are packing, paddling pool, storytelling workshop, which are recognised as totally unsuitable by all international classification recommendations. In this respect, France can be considered even less well placed than developing countries, since the historical psychoanalytical trend, of which the country is a leader, hinders the dissemination and implementation of internationally validated educational, behavioural and developmental interventions (TEACCH, ABA, PRT, DENVER...), which have been recommended in many countries for decades.

Solutions :

- improving initial and continuing education in autism for paediatricians, child psychiatrists and early childhood professionals ;
- creating specific training courses with up-to-date knowledge in autism, scientifically validated in psychology departments, nursing training institutes social workers, psychomotricity institutes etc...
- bringing Autism Resource Centres up to standard, whereas most of them still disseminate pseudo--knowledge about autism;

- organizing regular national autism awareness campaigns;
- prohibiting packing and all degrading and unethical practices;
- Ensuring the creation and the operability of a national autism quality reference system effective against third parties;
- consolidating national regulations on approvals ;
- obliging all institutions and services to comply with the recommendations of good practice in autism
- reviewing all basic and on-going training. Refusing public funding of old non-compliant training
- use of ASD-specific educational interventions to the maximum extent to reduce the incidence of behavioural disorders;
- the requirement for psychiatric staff caring for children or adolescents with ASDs, to be trained according to scientifically recognised approaches in the field of autism and apply such approaches;
- providing families with individualised support and training programmes, and places and time for relief.

4. Exile in Belgium

A meeting on 30 April 2019 on disabled persons exiled in Belgium provided updated figures for 2015.

With regard to children, an annual survey is carried out on children being educated in accredited Walloon schools. This survey specifies the specialised educational line that such children enjoy. Each educational line includes instruction adjusted to the general and special educational needs of students belonging to the same group; their requirements being determined on the basis of the main disability common to that group.

Out of 1,046 young people in accredited Walloon schools receiving special education on 31 December 2017:

- ✓ 49% was included in the educational line of Type 3 (behavioural disorder) 37% was included in the educational line of Type 2 (moderate to severe mental retardation)
- ✓ 10% was included in the educational line of Type 1 (mild mental retardation)

Please note here the poor diagnosis, as behavioural disorders is not a diagnosis.

Autistic students can be enrolled in all types of schools, depending on the type of education, especially some types because of co-morbidities.

Out of the total number of French students there are several types of students:

- ✓ Cross-border pupils who only attend school and commute daily to and from school, often by taxi.
- ✓ Pupils accommodated in WBE boarding schools (Wallonia-Brussels-Education)
- ✓ Pupils accommodated in structures with APC (Autorisation de Prise en Charge – Authorisation for Care) issued by the AWIPH (Walloon Agency for the Integration of Disabled Persons).

Out of the total number of French students we must distinguish several types:

- ✓ Cross-border pupils who only attend school and commute daily to and from school, often by taxi.
- ✓ Pupils accommodated in WBE boarding schools (Wallonia-Brussels-Education)
- ✓ Pupils accommodated in structures with APC (Autorisation de Prise en Charge) issued by the AWIPH (Walloon Agency for the Integration of Disabled Persons).

This exile was pointed out by the European Commissioner for Human Rights.

228. The Commissioner notes that one of the consequences of the inadequacies of the French care system for the disabled is that a rather consistent quantity of disabled persons move to Belgium¹⁴⁰. In spring 2014, the press revealed that several thousand French disabled persons would be placed in Belgian institutions, sometimes in undignified conditions, due to the inability of the French authorities to offer them individualised and appropriate responses¹⁴¹.

5. Abusive Reports to Child Welfare services

A major problem arises when authorities decide to place a child outside his/her family following expert opinions of doctors who are still strongly influenced by psychoanalysis, which tends to consider the family as responsible for their child's behaviour. Misunderstanding autism can quickly lead to a misinterpretation of the child's behaviour and wrongly end up with a separation from the familial environment, or to intrusive investigations of administrative, educational or judicial kind.

A specialised lawyer handles 40 to 50 cases of misreporting per year, filed by families affected by autism. One fourth of the files of our legal protection service involve information of concern and abusive reports.

In 2016, Autism France produced a report entitled "Aide Sociale à l'Enfance et autisme", forwarded to the Defender of Rights: the public version of the report had to delete the families reports, terrified as they were at the idea that their words, even though anonymous, would give rise to the retaliation of social services.

- ✓ http://www.autisme-france.fr/offres/doc_inline_src/577/Rapport%2Bsur%2Bles%2Bdysfunctions%2Bde%2BI5C27Aide%2BSocial%2BE0%2BI5C27Enfance%2BAutisme%2BFrance%2B2%2Bversion%2Bpublique.pdf
- ✓ http://www.autisme-france.fr/offres/doc_inline_src/577/CommuniquE9%2Placements%2Babusive%2Children%2Bautists.p df
- ✓ <https://www.la-croix.com/Journal/Social-Helpers-Childhood-painful-business-business-autism-2017-08-10-1100868755>
- ✓ <https://adikia.fr/2019/04/autisme-les-pratiques-inavouables-de-laide-sociale-lenfance/>

A parliamentary mission is underway:

http://www.assemblee-nationale.en/dyn/15/reports/miaidenf/l15miaidenf1819024_reporting

The symbolic case of Rachel, a mother deprived of her children for 4 years, only because she dared to ask for a diagnosis of autism for her second child, has a Wikipedia page and made the object of a film presented by Public Sénat.

An on-going French shame.

https://fr.wikipedia.org/wiki/Affaire_Rachel

<https://www.publicsenat.fr/emission/documentaires/rachel-l-autisme-a-l-epreuve-de-la-justice-139103>

Conclusion

Autism France denounces the discrimination and the violence that children and adolescents with ASD suffer in France. Because of the discrimination they have to experience, the refusal of most doctors to update their knowledge on autism, in disregard of the Public Health Code, and because of the lack of specific services, children and adolescents with ASD are socially isolated. However, socialisation is a determining factor for the development of an autistic person, as one of their difficulties involves the understanding of social relationships.

On the basis of CRC and CRPD articles ratified by France, Autisme France asks that France respects the rights of children with ASD who are persons with rights and not subjects to the fantasy of Freudian or Lacanian psychoanalysts, nor people confined in ghetto-institutions. Autism France calls for an end to discrimination and for the establishment of inclusive schools, notably pursuant to Article 24 of CRPD, stipulating the right to education and establishing that education must be inclusive at all levels: the exclusion of children with ASD from mainstream education must be avoided at all costs, in order to enable them to develop their cognitive and social skills to the fullest possible extent.

France needs to set up intensive early intervention services and resources for inclusive education (teachers and carers trained in ASD for children). It must finance private services for families that it is unable to organise in the public service or publicly funded establishments.

The large majority of autistic children are either in day hospitals at an average daily cost of € 700 to 1,000, or in medical-educational institutes at an annual cost of € 35,000 to 80 euros.

Several studies show that an early educational action facilitates later schooling, yet this barely exists in France. The average cost of schooling for a so-called ordinary child is € 7,400. It is therefore possible for the French authorities to finance an inclusive policy, by redirecting money wasted elsewhere to the National Education system and to engage an educational support within the school. France is not a poor country; it has the means to respond adequately to the needs of children with ESD and to ensure that their rights are respected on an equal level as those of all children.

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