



ALTERNATIVE REPORT BY THE ASSOCIATION 'AUTISME FRANCE'
ADDRESSED TO THE COMMITTEE FOR HUMAN RIGHTS IN THE CONTEXT OF
HRC's REVIEW OF FRANCE'S FIFTH PERIODICAL REPORT.

June 2015

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Autisme France

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1 Introduction

1.1 Definition of Autism Spectrum Disorders (ASD)

ASDs are severe and premature neurobiological disorders in child development. They are characterized by several elements of variable intensity:

- Difficulty with social communication and interaction
- Stereotyped behaviors, love of routines, limited special interests
- Often added to other disorders such as sensory sensibility, eating and sleeping disorders

Co-morbidities are frequent: epilepsy, praxis disorders, genetic syndromes....

Difficulties with communication, learning and adapting to daily life may be more or less severe. The characteristics of ASDs are identified before the age of 3 and can significantly vary from one child to another. That is why we talk about Autism Spectrum Disorders (ASD); in France, the terminology Pervasive Developmental Disorder (PDD) is frequently used. It is frequently cited in texts referred to in this report. Although the definition of PDD is broader than the definition of ASD, here we will consider them both as equivalent. The reader who would like to really understand the difference can look up the text from the association "Autisme Ontario" available on the Internet:

[http://www.autismontario.com/client/aso/ao.nsf/object/advisors+french/\\$file/aa11+fr.pdf](http://www.autismontario.com/client/aso/ao.nsf/object/advisors+french/$file/aa11+fr.pdf)

France, according to "la Haute Autorité de Santé" (an independent public body), claims a prevalence of 1 out of 150 for ASDs: worldwide, this figure is in fact 1 person out of 100. Anyone suffering from ASD - whatever their age - can positively evolve provided that the proposed interventions are adapted to their needs, their difficulties and their possibilities. It is absolutely necessary for them to receive regular functional assessments as well as individualized educational programs provided by trained professionals knowledgeable in the field of Autism. In order for them to develop their abilities, people with ASDs need:

- An early diagnosis based on multidisciplinary assessment : neurological, psychomotor, cognitive;
- An early-start intervention with adapted programs that have been officially recognized as efficient;
- Regular assessments and individualized educational programs;
- A type of schooling that includes tutoring within the school and some educational adjustments if necessary;

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- Socialization in any places of living and institutions

1.1 Affected Population

There aren't any official figures concerning people with ASD in France but the epidemiologic data established by the 'Haute Autorité de Santé' (HAS) in 2009¹ allow assessing this population from the available demographic statistics.

In 2009, the estimated prevalence of PDD (Pervasive developmental Disorder) was from 6 to 7 out of 1000 people aged under 20 (that is to say 1 out of 150).

For infantile autism, the prevalence is 2 out of 1000 people under 20. By infantile autism, we mean typical autism cases, appearing before the age of 3, also called KANNER's infantile autism. Among people with infantile autism, 70% present an associated mental deficiency, with 40% of severe mental deficiency and 30% of slight mental deficiency.

In 2009, the available data did not allow knowing whether the incidence of ASD is increasing or not. A more recent study² suggests that there isn't any significant increase, we can thus use as a sensible hypothesis that the prevalence figures can be applied to the entire population. We can also distinguish between the prevalence rates on the entire population according to the type of ASD taken into consideration:

- All of the ASD: 0,67% (1 out of 150)
 - Of which, infantile autism: 0,20% ,
 - Of which, other ASD : 0,47%
 - Of which, infantile autism with severe mental deficiency: 0,08%³

¹ Source :Autism and other pervasive developmental disorders – current knowledge status.

http://www.has-sante.fr/portail/jcms/c_935617/autisme-et-autres-troubles-envahissants-du-developpement

² According to the team of Christopher Gillberg, from the University of Goteborg (Sweden), the prevalence of ASD is stable: the rise in the number of diagnosed cases isn't linked to a rise in the number of real cases in the general population. Parents are increasingly urged to get a diagnosis for their children thanks to a better knowledge of autism in Western societies

<http://www.bmj.com/content/350/bmj.h1961>

³ The point of this report is not to define the difference between severe and slight mental deficiencies. We must also note that the mental deficiency associated (or not) to ASD can evolve for each person in relation to the implemented interventions.

	France - total population	All of PDD	Of which, infantile autism
<i>prevalence rate</i>	100%	0,67%	0,20%
aged under 20	16 122 039	107 480	32 244
from 0 to 4	4 021 277	26 809	8 043
from 5 to 9	4 059 195	27 061	8 118
from 10 to 14	4 084 092	27 227	8 168
from 15 to 19	3 957 475	26 383	7 915
from 20 to 39	16 158 670	107 724	32 317
from 40 to 59	17 639 435	117 596	35 279
from 60 to 74	9 698 383	64 656	19 397
from 75 and over	5 924 389	39 496	11 849
from 95 and over	116 045	774	232
Total	65 542 916	436 953	131 086
Of which:			
from 6 to 18 (school age)	10 515 410	70 103	21 031

Table 1 : Evaluation of the number of people with ASD in France (2013)

We can assess the number of births of people carrying the autistic syndrome at about 6000 to 8000 a year.

Autisme France

1.1 Presentation of Autisme France

Autisme France: 25 years fighting for people with Autism

February 1989: 1st invitation for the “creation of a movement for the right to an educational rather than a psychoanalytical care of people with Autism”, that leads to a **first constituent assembly in June 1989**, in Lyon. The first “Manifesto from parents of autistic children” is drafted. It is composed of 4 main points:

- The right to a diagnosis
- The right to education
- The right to information
- The right to compensation for deficiency (caused by inadequate support)

April 1994: Simone Veil **receives Autisme France on April 12**, and she shares with us her decision in accordance with our request, to conduct investigations (IGAS ANDEM ...) and to publish a text on autism, within a year. This promise will be kept.

June 1994: Autisme France publishes its “**Report on the experience of people with autism and their family at the dawn of the 21st century**” (« **Rapport sur le vécu des autistes et de leurs familles en France à l'aube du XXIème siècle** »). This document will greatly inspire the IGAS Report.

March 1995: (March 27) Autisme France receives from the ministry **the plan for a ministerial circular as promised by Simone Veil. We are the only entity proposing some amendments. Three of these are accepted**, in their principle (recognition that parents can freely choose the nature of care, possibility to create experimental structures, explicit recognition of integrated classes as a mode of care). **Two other amendments are denied** (freely choosing the therapeutic content, recognition of an educational alternative (SESSD) (later called SESSAD) for small children).

April 1995: General rallying within 6 days to obtain the educational alternative.

We fought this fight on our own while other parents associations, mistakenly considering that “a bad circular was better than no circular at all”, had given up right from the start.

February 1996: The bill introduced by a MP from the Loire department, Jean François Chossy is unanimously adopted on first reading at the National Assembly on 26 February. This bill, making autism a disability entitled to specific interventions has become Article L 246-1 of the CASF.

June 2001: the President of Autisme France is received first by **Bernard Kouchner** (06.01) and then, **Ségolène Royal** (06.05). The essential points reviewed are:

- Diagnoses must comply with the international classification, and when possible, must be formed before kindergarten (systematic screening).
- Access to education.
- Right to a decent life for people with Autism.
- Medical investments in the research on Autism.

Ségolène Royal Presents a “**plan to better receive and care for children and adults with Autism**”. The State Secretary commits to “take all the necessary measures so that no disabled child is maintain out of the school system starting from the next school year”.

In 2002, Autisme France also initiates a process taken over by Autisme Europe, towards European institutions.

Autisme France

November 2003: the European Committee of Social Rights states that France is non-compliant with its educational obligations to people with autism, as defined by the European Social Charter. The sentence will be reiterated and confirmed in 2007, 2008, 2010, 2012, and 2013.

2009: Second White Paper about autism

2010: Autisme France participates in the steering committee for the recommendations of good practices for children and teenagers.

2012: Autisme France drafts a proposition for an 'Autism plan'.

2013-2014: Autisme France gets greatly involved so that changes can finally be implemented:

- national recognition of our work and expertise, acknowledged presence in every body and work group
- creation of a national quality frame of reference largely based on our quality grids
- demand to be included in mainstream schools
- respect of the guidelines for good practices when dealing with autism

January 2014: Autisme France creates a legal protection department to help families assert their rights.

- litigations with MDPH (local institutions for disabled people)
- lack of adapted services
- abusive notifications to 'Aide social à l'enfance' – Child social services

The foundations of our charter and our status remain fundamental cornerstones:

- Right to a diagnosis and early intervention
- Right to life-long care through adapted devices
- priority given to the inclusion in a mainstream environment
- revision of core and continuous training
- reallocation of public money from psychiatric health service to the necessary services
- compensation for prejudice caused to people with autism and their family through abuse and lack of an adapted education.

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

November 2014: Based on the International Covenant on civil and political rights, Autisme France notes that many of those rights are not respected in France, for people with ASD. Autisme France made a list of human rights violations towards autistic people in a document available online on the association website:

http://www.autisme-france.fr/offres/doc_inline_src/577/Autisme_et_droits_novembre_2014.pdf

This document was sent the European Commissioner for human rights as well as to the the 'Défenseur des Droits', an independent constitutional body in charge of defending citizens' rights.

February 2015: Autisme France assesses the 2005 law for autism on February 11 2015:

http://www.autisme-france.fr/offres/doc_inline_src/577/Bilan_de_la_loi_2005_au_11.02.2015.pdf

Autisme France

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2 Assessing the failure to respect the International Covenant on civil and political rights

1.2 Violation of article 26 of the Covenant: Non-respect of the law from 11 February 2005 for equality of rights and opportunities

In February 2005, France passed an ambitious law⁴ in favor of the inclusion of disabled people in society and for the education of disabled children. This law was registered in the Family and Social Action Code.

Article L246-1 of this Code defines the rights of people with ASD⁵:

Any person – regardless of age - with a handicap resulting from the autistic syndrome and any troubles associated with it shall benefit from a multi-disciplinary care taking into account specific needs and difficulties.

Adapted to the age and state of the person, this care may be educative, educational, therapeutic or social.

In 2012, a senatorial mission about the implementation of this 2005 law, led by Senators Isabelle Debré and Claire-Lise Champion, interviewed several associations about the respect of this 2005 law. However, Autisme France, or any other association representing people with ASD were ever interviewed (see the annexes in this report). This report doesn't deal with autism in France⁶.

The rapporteur herself (page 119) during the commission examination admitted to a shortcoming:

"Hence, our report, bringing about some elements for further considerations and analyses, must be perceived as a starting point. It requires further study on some major aspects: autism, which President Annie David has included in our work program,"

► [Le texte du rapport sénatorial de Mmes Champion et Debré](#). Transcript from Mrs Champion's and Debre's senatorial report.

► [Lire l'extrait sur l'exemple belge](#). Read and excerpt on the Belgian example.

The association Autisme France makes its own assessment of the February 2005 law:

► [Bilan de la loi de 2005 par Autisme France](#) (June 2012)

The February 2005 law is only partially applied to people with autism. The State doesn't insure that the law appropriately applies to people with autism. France thus breaches Every child shall have, without any discrimination as to race, color, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the State.

Article 26 of the Covenant.

Recommendation 1: insuring the enforcement of the 2005 law and implementing its update

⁴ the 2005-102 Act 'Equal rights and opportunities, participation and citizenship of disabled persons'

⁵ Modified by the 2005-102 Act of 11 February 2005 - art. 90 JORF 12 February 2005. Consolidated version on 18 May 2015

⁶ Even though autism became a great national cause in 2012, the same year the report was published. One chapter deals with the schooling of French autistic children in Belgium.

2.2 Violation of article 17 of the Covenant: Discriminatory remarks towards people with ASD.

Words such as “autism” or “autistic” are commonly used as an insult by politicians, union leaders and so on: these words thus stigmatize people with autism by presenting them as people who refuse to listen to others. They also spread inaccurate ideas about what autism really is. Legal proceedings for discrimination are never carried out against this type of comments and remarks.

<http://www.actu-cci.com/chambres-de-commerce-vie-des-reseaux/13108-j-f-gendron-president-de-la-cci-de-nantes-l-igas-et-l-igs-sont-autistes>

About the reform of the French middle school system: the SNES (a teachers' union) denounces the autism of the board of education of Besançon

“But **autism** is not solely the specialty of the board of education of Besançon, since the government, instead of taken into account the well-founded criticism of its project, thought it would be a good idea to publish an official decree implementing the reform the very day after the strike!” says the union’s spokesperson.

<http://www.macommune.info/article/reforme-des-colleges-le-snes-denonce-lautisme-du-rectorat-de-besancon-124091>

François Sauvadet, deputy and president of the departmental council of Côte-d'Or

The great rallying of the teaching profession, as well as of the parents and the local political leaders from all sides must trigger a reflection in a government locked in its usual autism.

<http://www.info-chalon.com/articles/opinion-de-droite/2015/05/19/13708-francois-sauvadet-denonce-une-politique-educative-gouvernementale-sans-cap-ni-boussole-.html>

Syria: Deputy Jacques Myard denounces a “policy of blindness and autism”

“The policy of blindness and autism is doomed and unacceptable”, condemned the deputy of the Yvelines department, explaining that, in his opinion, there would be no military resolution to the Syrian conflict.

http://www.lemonde.fr/proche-orient/article/2015/02/26/a-l-initiative-de-la-visite-d-elus-a-damas-jacques-myard-denonce-une-politique-d-aveuglement-et-d-autisme_4583478_3218.html*

On public radio France Inter, Serge Bornstein, a neuro-psychiatrist, expert to the Appeal Court, identifies Asperger syndrome⁷ as a particularly dangerous form of schizophrenia:

10/11/2013 - Department 75: “Service Public” » on France Inter today. The topic: serial killers and mass-murderers. Serge Bornstein, a neuro-psychiatrist, expert to the Appeal Court: “They [the killers] have what is called an isolated impulse control disorder, like most schizophrenics who are in this world of divides and of which a type has recently been stubbornly standing out, ‘the Asperger Syndrome’, a kind of schizophrenia which is not obvious and can take on various aspects. (Around 13:30)

10/11/2013 - Department 75: “Service Public” » on France Inter

<http://www.franceinter.fr/player/reecouter?play=737638>.

Recommendation 2: allow complaints for discriminatory remarks when the word autism is used as an insult

⁷ Asperger syndrome is an autism spectrum disorder (ASD) that is characterized, as any form of autism, by significant difficulties in social interaction and nonverbal communication, alongside restricted and repetitive patterns of behavior and interests. It differs from other autism spectrum disorders by its relative preservation of linguistic and cognitive development.

1.1 Violation of article 26 of the Covenant: Non-respect of the right to access a diagnosis in compliance with the Public Health Code

While Pervasive Developmental Disorders have long been defined as neuro-developmental disorders by the international medical community in International Classification of Diseases (ICD – 10) and since 2012, by the 'Haute Autorité de Santé' (French National Authority for Health) as well, the diagnosis of this disorder remains difficult to obtain for the affected people.⁸

Most people with autism in France are still waiting for a diagnosis. Screening and early diagnosis for autism (before the age of 2) remain insufficient. This early diagnosis is essential to start the appropriate care and access to the rights given by the 2005 law with regard to people with autism, see 2.1.

The various 'stocktaking' of autism made by the regional health agencies show that the given diagnosis remains for 60% one of infantile psychosis (and of 'adult' infantile psychosis), a diagnosis which is non-compliant with the International classification of diseases (ICD – 10).

http://www.ars.aquitaine.sante.fr/fileadmin/AQUITAINE/telecharger/01_votre_ars/111_Lettre_info_ext_Aquitaine/Lettre_externes_2014_03/01_Dossier/Plan_Regional_Autisme_2013_2017_Et_atdeslieux.pdf

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

The report from the Fundamental Foundation on "**Autism in France, diagnosis and treatment protocol**"⁹ points out the delay in diagnosis when given.

"..Despite early warning signs, too many parents are victims of misdiagnosis and therapeutic shortcomings that delay the proper diagnosis and then the care process. But more than that, many people denounce a real 'obstacle race' and complain that nobody listens to them, that no one in the medical staff takes them seriously. [...] In our study, the average age to be diagnosed is from 5 to 6 and a half.¹⁰

This lack of diagnosis may be linked to a shortage in specialized centers but also to the unwillingness of some doctors to acknowledge the diagnosis criteria established in the ICD-10 or those defined by the HAS (see 2.6.1 for further information on this topic).

The refusal to diagnose is a very serious matter in the sense that it prevents children from accessing early educational interventions which would allow limiting the extra disabilities linked to autism.¹¹ For the children, this engenders a loss of opportunities for their adult life.

This lack of diagnosis is underlined in the report by the European Commissioner for human rights.

259. The situation of people with ASD or PDD requires special attention and sustained efforts from France. The Commissioner notes the existence of an insufficient screening of ASD and PDD as well as a lack of appropriate care for autistics that lead to the commitment of these people to mental institutions without any assistance. It is necessary that the Authorities invest more means towards adapted care and schooling of autistic children in mainstream education.

⁸http://www.has-sante.fr/portail/upload/docs/application/pdf/2012-03/recommandations_autisme_ted_enfant_adolescent_interventions.pdf

⁹ Consulté sur http://www.fondation-fondamental.org/upload/pdf/dp_autisme_en_france-enquete_doctissimo-fondation_fondamental.pdf

¹⁰ This average only concerns people that have been diagnosed.

¹¹ In 2014, the National Education Ministry created educational units in kindergarten (one in each department) for children with PDD. Undiagnosed autistic children don't have access to them.

Solutions :

- **Recommendation 3 : the creation of services for diagnosis and early interventions in each department ;**
- **Recommendation 4 : The obligation for medical staff to form a diagnosis compliant with ICD – 10, to inform the person or his/her parents clearly and in writing of the diagnosis and to write down the nature of the necessary recommended interventions, in keeping with the good practices guidelines of the HAS from March 2012;**
- **Recommendation 5 : the obligation to respect the diagnosis guidelines from October 2005¹²**
- **Recommendation 6: Punishing doctors breaching The Public Health Code and refusing to form a diagnosis.**

1.3 Inequality in access to Public Services**It remains almost impossible to get the specificity of autism acknowledged in France.**

The guide to providing assistance to disabled people published by the inter-ministerial committee for disability addressed to all public services had forgotten to mention autism which was listed either under mental disability or psychic disability by the signatory associations (associations for people with autism were never asked). Autisme France had to intervene in order for the guide to be modified but only in its online version.

Solutions :

- **Recommendation 7: Organizing of a nationwide awareness campaign and developing the necessary information tools : the only existing screening brochure has been designed by our association:**

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

¹² Circular DGAS/DGS/DHOS/3C no 2005-124 from 8 march 2005 with regard to the care policy of people with ASD or PDD. http://www.autismes.fr/documents/textes/circ2005_124_080305.pdf

1.4 Violation of articles 24 and 26 of the Covenant: non-respect of the law from 11 February 2005 for equality of rights and chances: Discrimination in access to education

1.4.1 Low schooling-rate of children with autism

Autistic children are not even identified by the National Education services: are they listed in the intellectual and cognitive handicap category? Why would they be, when 70% of autistic children have no associated intellectual deficiency? Are they listed in the psychological deficiency category? Why would they be since autism is not a mental disease? In the following document dated from 2004 describing the population of children schooled in primary schools, terms such as 'autism' or 'autistic disorder' or 'PDD' cannot be found anywhere.

http://cache.media.education.gouv.fr/file/2014/03/8/DEPP_RERS_2014_eleves_premier_de_gre_344038.pdf

Admittedly, schooling is often only very partial for children with disabilities and this situation is especially true for children with autism:

http://cache.media.education.gouv.fr/file/8/99/5/ensel2766_annexe1_projet-personnalise-scolarisation_391995.pdf

Plans for the schooling of disabled children (CLIS for primary education and ULIS for secondary education) within the French National Education system are barely accessible to children with ASD.

For example, in Paris, there are

- 6 ULIS classes for children with PDD¹³,
- 23 ULIS classes for children with cognitive and intellectual deficiencies,
- 10 ULIS classes for children with psychological disorders and
- 14 ULIS classes for children with learning disabilities¹⁴.

A ULIS class is generally composed of 10 pupils¹⁵; all of these ULIS PDD classes represented around 60 spots in Paris. For children ranging aged from 10 to 14 (around 100 000 in 2003 according to INSEE polling institute), there is a ratio of 0,6 spot in ULIS PDD for 1000 pupils, whereas the PDD prevalence is around 6 for 1000 pupils. For the CLIS Classes, there are no specific classes for PDD, they are included in CLIS for cognitive and mental deficiencies.¹⁶

Families must constantly visit the 'Maisons Départementales des Personnes Handicapées' (MDHP) to get the right for their children to go to school: orientation in collective devices is only available for a year and can be challenged, or the child can be excluded. In the case of an orientation towards a medical-social institution (IME), often imposed on families, children are usually not entitled to any kind of schooling or, when they do, they go for a few hours (from 1 to 4 a week) without following the ongoing educational program.

¹³ https://www.ac-paris.fr/portail/jcms/p1_857870/trouble-envahissant-du-developpement

¹⁴ https://www.ac-paris.fr/portail/jcms/p1_857857/trouble-des-fonctions-cognitives-et-mentales-tfc

¹⁵ <http://www.esen.education.fr/?id=79&a=73&cHash=2c2142776f>

¹⁶ https://www.ac-paris.fr/portail/jcms/p1_415182/les-clis?cid=p1_403140

The low rate of schooling of autistic children is constantly reported by families and is frequently featured in newspapers:

<http://www.lest-eclair.fr/accueil/80-des-enfants-autistes-sont-exclus-des-salles-de-classe-ia0b0n5546>

<http://www.ouest-var.net/actualite/six-fours-handicap-un-enfant-autiste-encore-menace-d-exclusion-scolaire-7075.html>

<http://www.cahiers-pedagogiques.com/Scolarité-des-enfants-autistes-voyage-au-bout-de-l-enfer>

<http://autisteenfrance.over-blog.com/article-le-combat-pour-integrer-alexandre-enfant-autiste-exclu-de-la-societe-119732225.html> <http://rnc.bfmtv.com/emission/lucas-9-ans-autiste-et-exclu-de-son-ecole-mon-fils-est-pris-en-otage-dans-cette-histoire-865415.html>

France was condemned 5 times on this particular aspect by the European Council for discrimination against people with autism.¹⁷ Excerpts from these condemnations are presented in section 2.5.2 of this report.

Access to education, training, preparation to work-life and to recreational activities is not always possible for children and teenagers with ASD, or only if families pay for them themselves. The “Maisons Départementales des Personnes Handicapées” hardly ever reimburse them. Some families even pay so that their children’s school assistant (AVS) can be properly trained.

This type of discrimination against autistic children is also mentioned in a recent report by the European Commissioner for Human Rights. See section 2.5.3.

The French administration acknowledges in a report published in December 2014¹⁸ a failure in the schooling of heavily disabled and autistic children. This report recognizes that at least 10 000 children aged from 3 to 16 were not in school at all (neither in the mainstream system, nor in the medical-social sector) in 2010 and that among them, there is a large proportion of autistic children (about a third). This proportion is not clearly established since many autistics are not diagnosed as such.

*“It is difficult to say whether the implemented training answers the pupils’ needs even though the available studies and the mission’s assessment reveal that **a great number of youngsters - whose exact number remains difficult to define (10 000? 20 000? 30 000?) - don’t get any form of schooling** and that the teaching volume offered to others is very low.”*

*“Up to today, **the lack of references to autistic profiles** in the data published by the National Education Ministry or even in assessment devices such as GEVA - Sco constitutes a source of confusion and do not foster an efficient management of the education process of these children and teenagers.*

Indeed, the difficulties to acquire knowledge for a child presenting a motor handicap, an intellectual deficiency and a form of autism don’t imply the same needs, constraints and tools.”

Unfortunately, the measures announced in 2015 by the State Secretary for disabled people don’t allow fixing the situation since the National Education Ministry is barely associated with these measures.

¹⁷ COUNCIL OF EUROPE- THE COMMITTEE OF MINISTERS

Resolution ResChS(2004)1 – collective complaint n° 13/2002 - Autisme-Europe v. France

(Adopted by the Committee of Ministers on 10 March 2004, at the 875th meeting of Ministers’ deputies)

<https://wcd.coe.int/ViewDoc.jsp?id=127905>

¹⁸ The complete report:

http://cache.media.education.gouv.fr/file/2015/29/4/2014-046R_-_Unites_d_enseignement_etablissements_medico-sociaux_411294.pdf

Solutions :

- **Recommendation 8: Encouraging mainstreaming education by reallocating funds wasted in obsolete and toxic healthcare practices towards National Education, so that it can finance the necessary educational support for autistic children and teenagers.**
- **Recommendation 9: Financing aids - not provided by the State - given to families to send their children to school.**
- **Recommendation 10: Encouraging inclusion in all of the children's activity (leisure, sports, culture).**
- **Recommendation 11: Inclusion implies that teachers, organizers and any actors of this inclusion must be trained in autism, that the National Education must recruit specifically-skilled educational staff with up-to-date knowledge of autism.**

1.4.2 Excerpts from the five condemnations of France by the Council of Europe

It19 considers [...] that the proportion of children with autism being educated in either mainstream or special schools, is still extremely low and significantly lower than that of other children, whether or not having a disability;

November 2007

Follow-up of the complaint Autisme-Europe v. France (complaint no 13/2002, decision on the merits of 4 November 2003)

Conclusion

The Committee concludes that the situation in France was not in conformity with Article 15§1 of the Charter because it had not been established that persons with autism were guaranteed effective equal access to (mainstream and special) education.

November 2008 : Conclusion

The Committee concludes that the situation in France was not in conformity with Article 15§1 of the Revised Charter because it had not been established that persons with autism were guaranteed effective equal access to (mainstream and special) education.

March 2013 :

The report notes that several of the initiated actions are not over yet and that the results obtained thanks to this plan are being assessed. While taking into account the new measures and the fact that their effects are yet to be determined, the Committee notes that the report doesn't assess the impact of the previous "Autism plan" or the practical changes engendered by the adoption of the new definition of Autism given by WHO. It also notes that it is currently reviewing a new complaint (n° 81/2012, European Action of the Disabled (AEH) v. France), registered in April 2012, with regard to the right to education of children and adolescents with autism and the right to vocational training of young adults with autism. Given the lack of sufficient information on the actual situation of equal access to mainstream and special education for autistic people, the Committee considers that the report doesn't bring enough new elements to revise its previous conclusion on the matter. Conclusion: The Committee concludes that the situation in France was not in conformity with Article 15§1 of the Charter because it had not been established that persons with autism were guaranteed effective equal access to (mainstream and special) education.

¹⁹ The Committee

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

http://www.coe.int/t/dghl/monitoring/socialcharter/complaints/CC81Merits_fr.pdf

With regards to the report containing the decision on the merits of the complaint transmitted by the European Committee for social rights, in which it concluded:

Unanimously, that there is a violation of Article 15§1 with regard to the right of children and adolescents with autism to be educated primarily in mainstream schools

<https://wcd.coe.int/ViewDoc.jsp?id=2157063&Site=COE>

Resolution ResChS(2004)2

European Action of the Disabled (AEH) v. France, complaint n° 81/2012

1.4.3 Report of the European Commissioner for human rights.

235. The Commissioner considers that the particular situation of people suffering from ASD or PDD requires particular attention. The European Committee for social rights notes the violation by France of articles 15 (the right of persons with disabilities to independent social integration, personal autonomy and participation in the life of the community in general), 17 (right of children to a social, legal and economic protection) and E (non-discrimination) from the European Social Charter in two major cases in 2004 and 2013 with regard to children and adolescents suffering from autism. In the second case, the committee found regrettable that “France has not taken sufficient measures capable of ensuring that the work done by institutions caring for children and adolescents suffering from autism and the working methods they utilize are predominantly educational in nature.” (§119). According to the NGOs interviewed by the Commissioner, the care methods used in many establishments constitutes an obstacle to deinstitutionalization and to the right to inclusion.

236. The Commissioner notes that, despite three “Autism plans” making provisions for care measures and the means to implement them, the associations but also the national and international bodies were regularly concerned about the lack of care adapted to people with autism.

249. From the information gathered during the Commissioner’s visit, it appears that autistic children – even though authorities advocate inclusion in mainstream schools – are particularly concerned by the lack of schooling in mainstream schools. The European Committee of Social Rights was seized upon this question on several instances. In 2004, in the case *Autisme-Europe v. France*, it is stipulated that guaranteeing the right to education for children and other people with disabilities constitutes a condition allowing independence, social integration, personal autonomy and participation in the life of the community in general endorsed by Article 15 of the Social Charter. The committee concluded that France was in violation of the Charter, notably, since “the proportion of children with autism being educated in either mainstream or special schools, which was still extremely low and significantly lower than that of other children, whether or not having a disability.”

250. The Commissioner notes that, in its conclusions 2008 and 2012, The European Committee of Social Rights then observed that the situation in France was still in violation of the Charter, because it had not been established that persons with autism were guaranteed effective equal access to education or professional training. The Commissioner notes that schooling outside mainstream schools hasn’t been found satisfying either by The European Committee of Social Rights since it is in violation of Article 15§1 of the Charter in its decision *European Action of the Disabled (AEH) v. France* in 2013: the lack of priority given to mainstream schools for the education of children and adolescents with autism; insufficient appropriate measures regarding the right to vocational training in mainstream or special schools for young autistics; the work done in specialized institutions caring for children and adolescents with autism is not predominantly educational in nature.

262. The commissioner urges the French Authorities to pursue their efforts towards schooling all disabled children and adolescents, especially autistic ones. It salutes the creation of a status called AVS (School Assistants to children with disability) and invites authorities to implement it as soon as possible and to provide enough positions to satisfy the need for assistance in schooling disabled children in mainstream schools. It also urges Authorities to invest in training teaching staff to disability.

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263. Finally, regarding autistic children or children with PDD, the commissioner urges Authorities to allow appropriate care and support through primarily educative, behavioral and developmental methods and to encourage schooling autistic children in the mainstream school system.

1.4.4 The case of Children known as “without solution” (not schooled)

Moreover, many children and young adults have no educative solution at all, either in mainstream schools or in the medical-social system. A study carried out by CREAHI-CEDIAS²⁰ on those children known as “without solution”²¹ in the Ile-de France region recorded 618 youngsters “without solution” in the region, among them, 255 suffered from autism or PDD (41%). The study stated that listing children matching the study field was difficult:

“Listing youngsters under 20 who were referred towards children medical-social establishments by the Commission for the Rights and Self-Reliance of Persons with Disabilities (CDAPH) but to no avail and who were not in school or only very partially was difficult. Indeed, none of the information systems of the Ile-de France MDPH (department for persons with disabilities) allowed getting a list of children referred by CDAPH but not admitted in any medical-social establishment.

http://www.creai-idf.org/sites/cedias.org/files/synthese_enquete_sur_les_enfants_dits_sans_solution.pdf

This abandonment by the State of children with PDD is in violation of article 24 of the Covenant.

1.4.5 Violation of article 12 of the Covenant: Schooling in Belgium of children with no access to schools in France

In order to overcome the difficulties to enroll their children in school, some parents choose to exile them to Belgium in the francophone specialized school system.

To illustrate this point, for the school-year 2014-2015, 2.796 French pupils were schooled in specialized establishments as follows:

- 88 pupils in kindergarten,
- 946 pupils in primary schools and
- 1.762 in secondary schools.

They are primarily divided up in type 2 teaching (pupils with a moderate to severe mental deficiency), type 1 (pupils with a slight mental deficiency) and type 3 (pupils with behavioral or personality disorder). The price for the care of those French pupils is estimated at 40 million euro.

<http://www.joellemilquet.be/2015/04/journee-mondiale-de-sensibilisation-a-lautisme-des-mesures-pour-renforcer-laccompagnement-des-enfants-et-adultes-concernes-ainsi-que-de-leurs-proches/>

Half of these children are autistic, whose parents are either looking for an adapted schooling for their child, or are trying to enroll their child in a facility given the lack of suitable places in France.

There are 325 French pupils enrolled in classes officially declared as pedagogically adapted to autism (TEACCH classes). However, many children end up in specialized facilities, with individualized pedagogy even though the class is not entirely pedagogically adapted.

²⁰ CREAHI: Regional Center for the study and organization of disability and insertion

CEDIAS: Center for studies, documentation, information et social actions

²¹ That is to say full-time in their family without any care and support plan

Recommendation 12: Put an immediate stop to the banishment of children to Belgium by organizing the adapted schooling they should be entitled to on the French territory.

1.5 Violation of article 26 of the Covenant: Inequality in access to appropriate care and to the medical-social plan and of article 7: Degrading treatments imposed on people

1.5.1 Inappropriate medical-social plan for people with autism

An early intensive intervention (from 0 to 4) is currently unanimously recognized as being the best way to ensure a proper development of children with ASD. The Early Start Denver Model (ESDM), an intervention scientifically proven as a way to significantly improve social and cognitive skills in children suffering from autism, is now recommended by the "Haute Autorité de santé" but remains completely unknown in France.

The efficient use of knowledge-sharing in the scientific community regarding autism progresses very slowly, engendering an irreparable delay in the perspective of improvement of young autistics.

The Haute Autorité de Santé published an update of the knowledge of autism in January 2010.

http://www.anesm.sante.gouv.fr/IMG/CP_QR_Vdef.pdf

Then, in March 2012, it released together with ANESM some recommendations of good practices.

http://www.has-sante.fr/portail/jcms/c_935617/fr/autisme-et-autres-troubles-envahissants-du-developpement

http://www.has-sante.fr/portail/upload/docs/application/pdf/2012-03/recommandations_autisme_ted_enfant_adolescent_interventions.pdf

These recommendations are often called into question by health professionals and barely ever applied. Thus, on a website for training in mental healthcare, updated in **April 2015**, we find an inaccurate definition of autism²²:

"Autism: excessive withdrawal into oneself, locking oneself up in a relational shell which main consequence is to protect the autistic from external contacts. People with autism then favor an intense inner life, refusing the frightening life of the outside world."

And the claim for the use of "Le packing"²³:

"The Packing technique means wrapping bodies in cold and soaked sheets. This care method affects the bodies by engendering limiting tactile sensations allowing it and then the individuals to eventually experience their own limits."... "The Packing therapeutic technique is practiced in the specialized sector with a specifically-trained medical staff. It used with positive outcome for autistic children."

Le packing has regularly been denounced by families:

<http://sante.lefigaro.fr/actualite/2015/01/12/23249-autisme-methode-packing-soumise-test>

http://www.lexpress.fr/actualite/societe/sante/autisme-le-traitement-qui-choque_768175.html

<http://leplus.nouvelobs.com/contribution/1141302-chere-eglantine-emeye-moi-aussi-j-ai-un-enfant-autiste-le-packing-n-est-pas-une-solution.html>

²² <http://psychiatriinfirmiere.free.fr/definition/autisme/autisme-theorie.htm>

²³ <http://psychiatriinfirmiere.free.fr/infirmiere/formation/psychiatrie/adulte/therapie/pack.htm>

Famous universities in Paris and in Province still propose training in autism based on scientifically invalid theories. These trainings are broadcast at length on the website of the association "Centres de Ressources Autisme", even though its mission is to inform about autism.

<http://www.univ-paris-diderot.fr/formation/DocFormation/broAutisme2010-2011.pdf>

We can even – with the taxpayers' money – make fun of autistic people by training future social workers: M. Rabanel explains that you have to create hiding spots so that autistic people don't see you or hide.

<https://www.youtube.com/watch?v=NzGOe8PcVW4>

As a result, care in most medical-social establishments is based on a theory claiming that autism is a defense mechanism in which autistic people cannot recognize themselves in their body and refuse the language. This psychoanalytical current led by France constitutes an obstacle to the spread and implementation of educative, behavioral and developmental interventions internationally approved (TEACCH, ABA, PRT, DENVER...), recommended for years in many countries

The resulting practices: Le Packing, wading pool, tales workshops are acknowledged as entirely ill-fitting by every single international classification guidelines. They constitute an unacceptable waste of public money while the affected population lacks most of what they need.

Solutions :

- **Recommendation 13: Organizing real delegations of public service in medical-social establishments in order to control the use of public money.**
- **Recommendation 14: Prohibiting Le Packing and any other degrading and non-ethical practices.**
- **Recommendation 15: Making it mandatory for psychiatric staff in charge of children and adolescents with ASD to be trained in the approved scientific approaches to autism and to apply them.**

1.5.2 Violation of article 26 of the Covenant: A medical-social plan excluding adults with autism

France finances a great number of places in the medical-social sector for disabled adults; however, adults with ASD are often denied a place because those establishments rarely take into account autism disorders in their plans.

Referral towards this or that kind of facilities by Commission for the Rights and Self-Reliance of Persons with Disabilities (CDAPH) within MDPH (local department for people with disabilities) doesn't entitle the disabled person to a place and there isn't any follow-up once the referral has been given.

Admission depends on a different commission within each establishment for disabled adults to which one must put a request.

Commissions for admission²⁴ in facilities for disabled adults can deny an admission without justification and people with autism who are severely disabled (with severe co-morbidities or severe behavioral disorders) are de fact excluded from such plans.

²⁴ Example of admission process :

<http://www.cognacq-jay.fr/etablissements/fam/admission.php>

An admission file from the medicalized hosting facility is transmitted to the service, the establishment or the family that made the request to be filled in and sent back. This file includes administrative, medical and socio-educational information which allows better pinpointing the person's difficulties and the establishment's possibility to respond favorably to his/her request. The application is then studied by the admission commission of the medicalized hosting facility, composed of a psychiatrist, education and health executives and of the director. This commission gives a recommendation. Then, the person, his/her family or guardian, the proper hospital service or hosting facility receive a mail informing them of the commission's decision.

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In many cases, despite families' efforts to fill in numerous files, the person will never be admitted in an establishment in accordance with the referral.

The creation of specific places for people suffering from autism in the various plans doesn't take into account their real needs, since these needs are never assessed. There isn't any follow-up of the attribution of such officially dedicated places which would yet allow ensuring that those places are indeed given to people with ASD. Moreover, there isn't any assessment tool for the needs of disabled people and even less for those of people with autism.

Thus, many people with autism are still dependent on their family, without a diagnosis or any educative interventions recommended by the "Haute Autorité de Santé".

Families also turn to Belgium when the person's care becomes too heavy for the parents or the siblings. Many remain in psychiatric institutes for the same reasons.

A book entitled "Les Exilés Mentaux"²⁵ ("the mental exiles") published in September 2014, describes how families can be at a loss when it comes to finding a solution adapted to their children.

The REPORT N°1662 OF INFORMATION FILED BY THE COMMISSION OF SOCIAL AFFAIRS as a conclusion of the work by the mission on mental health and the future of psychiatry (Mr. Denys ROBILIARD, Deputy) filed in December 2013²⁶, described in I-D e) deals with the lack of capacity in the medical-social sector:

"For lack of capacity in medical-social structures, many patients stay in hospitals for long periods of time which engenders inappropriate hospitalizations hindering their chances of reinsertion and independence.

ARS from the île-de-France region conducted a survey in 2003 showing that 75 % of long-term stays in the region corresponded to hospitalizations by default."

Recommendation 16: Enforcing article 67 of the 2005 law which imposes to offer as many hosting solutions as there are needs for disabled adults

1.5.3 Violation of article 12: Banishment to Belgium of adults and children with autism in the medical-social sector financed by France

Many reports revealed the banishment to Belgium of autistic people. These reports note that it not always about being convenient given the geographical proximity of the border population, but rather about an answer to a lack of adapted care and support. Excerpts from these reports are presented below. One must admit that banishment to Belgium of disabled people, many of whom suffer from ASD has been constantly increasing for ten years.

A decree from April 30 2015 - Article 4 defines a budget for these placements. It doesn't take into account the part financed by the departments²⁷.

Excerpts from Report n° 2005 143, presented by Liliane SALZBERG, Jean-Paul BASTIANELLI, Pierre de SAINTIGNON, member of the general Inspection of social affairs

<http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/064000542.pdf>

²⁵ Jeanne Auber, BAYARD publishing house, september 2014

²⁶ http://www.assemblee-nationale.fr/14/rap-info/i1662.asp#P732_77386

²⁷ The total amount of spending regarding the placement of disabled people in establishments endorsed by 4° of I Article L. 314-3-1 of the families and social action code carrying out this activity in Belgium is set at 70.1 million euro for the fiscal year 2015.

http://legifrance.gouv.fr/affichTexteArticle.do;jsessionid=0EE660B2DDF6B4FED33B94CDDACD55BA.tpdila18v_3?idArticle=JORFARTI000030560859&cidTexte=JORFTEXT000030560846&dateTexte=29990101&categorieLien=id

Structures caring for disabled people are greatly diversified both in France and in Belgium. The complexity of these structures, the national specificities, the various designations make it difficult to compare and assess the situation properly. Thus, the total number of disabled people cared for in Belgium remains inaccurate. According to the mission's estimates, **it is around 5000, from which 3600 are in social establishments and 1400 in school structures.**

There aren't any bodies or any State departments that have coherent, reliable and comprehensive figures concerning the disabled people in foreign institutions.

In total, **42 French departments and 17 regions** are concerned by children being placed in Belgium. We note a progression of the number of placements of young disabled French people over the past six years (around 4, 4% a year).

According to the ERSM of Nord-Picardie, **the most frequent pathology is autism (20,3 %)**, mental deficiency (18,7 %), behavioral disorder (17,3 %), cerebral motor disability (13,4 %) and psychosis (12,4 %). These five pathologies represent 82% of the files treated by ERSM.

- The total number of French disabled adults placed in Belgium has reached around 1700 in 2044,
- **This number was significantly increasing between 1999 and 2004 (between + 10 and + 13% a year depending on the departments, except for one),**
- Regional councils are not familiar with the type of handicap,

In total, the number of French disabled adults placed in Belgian establishments is thus estimated at about 1 900. At least 43% of the establishments hosting them are only authorized to give them care, are not authorized by The Health Insurance or couldn't be listed.

In 2008, the report by Madame GALLEZ, Deputy of the Nord region already dealt with banishment to Belgium:

http://travail-emploi.gouv.fr/IMG/pdf/DP_Rapport_Gallez.pdf

There isn't any national plan for an institution centralizing departmental data.

There isn't any process for coordinating departmental actions.

Moreover, there isn't any institution gathering the data from the Health Insurance and the Social Aid, be it at the departmental or national level.

Meanwhile, the latest estimates from CRAM, DRSM (Nord-Pas-de-Calais region), and General Council of the Nord, allow claiming the following approximation:

6500 (residents and non-residents) in Walloon region, from all ages and suffering from all kinds of disabilities:

- around 3500, in medical-social establishments: 1771 children and adults amendment Creton). 63,53% from Nord Pas de Calais and 14% from Paris region,
- 1800 adults (approximately),
- 2920 young children mainly in specialized Belgian schools, non-residents in Belgium.

If most placements of disabled people obey cross-border logic (68% of all placements come from Nord Pas de Calais), it seems that half of the French departments resort to Belgian facilities, Ile de France being the second most concerned region. This is obviously a source of practical and legal difficulties.

These structures care for all kinds of handicaps, **with a majority of behavioral disorder and autism**. Five establishments are specialized in the care of severely disabled people or people presenting severe behavioral disorders.

Autisme France

In 2012, two studies specific to Ile de France

CEDAIS carried out a study about people from Ile-de-France cared for in Belgian establishments (it doesn't take into account placements financed by Social Security: Out of the listed 353 people from Ile-de-France, **39% (138) are people suffering from autism and other PDDs.**

<http://www.creai->

idf.org/sites/cedias.org/files/enquete_sur_les_franciliens_en_situation_de_handicap_accueillis_dans_un_etablissement_belge_sur_financement_de_la_securite_sociale.pdf

Following these studies, it became clear that most of the disabled adults from Ile-de-France placed in a Belgian institution fell under the financing of the Social Security but benefited from the Department Social Aid (the concerned establishments had a status equivalent to that of supervised living structures (« foyer de vie ») and not that of MAS (SPECIAL RESIDENTIAL CARE ESTABLISHMENTS).

Thus, the MDPH of Paris - considering that the regional survey initiated by ARS Ile-de-France only gives but a partial photography of the important matter of the resort to Belgian equipments (34/173 situations of people suffering from a disability aged 20 and over cared for in a Belgian institution, 20%) - wished to complete this survey so that they could produce a comprehensive analysis of disabled adults' placements in Belgium.

"The MDPH of Paris then asked to the CEDIAS-CREAI Ile-de-France to carry out an investigation about disabled people placed in establishments in Belgium falling under the financing of Social Aid."

The report belongs to MDPH75 and is not communicable.

<http://www.creai-idf.org/dossier/enquetes-pour-besoins-non-couverts-sur-territoire-francilien-dans-cadre-srosm-idf-enfants>

Every survey on this topic are only partial, for lack of national data and of local or national indicators regarding the follow up of referrals made by MDPH. Despite the agreement between France and Walloon region signed in 2011, there isn't any assessment of the number of French disabled people in Belgium.

The Autisme France association continues to receive many phone-calls to its delegation in Belgium from families looking for information about care for people with ASD in Belgium.

Contrary to the schooling of children in specialized institutions From the Walloon region-Brussels federation (see 2.5.5), the quality level of those facilities is not always satisfying and some dysfunctions have been mentioned in the press at the beginning of 2014.

http://www.liberation.fr/societe/2014/01/17/la-france-se-decharge-de-nos-enfants-handicapes-en-belgique_973627

http://www.liberation.fr/societe/2013/10/27/un-lieu-de-vie-la-quete-sans-fin-d-elias-autiste_942773

This exile was highlighted by the European Commissioner for human rights

228. The commissioner notes that the shortfalls in the care and support system for disabled people in France engender the banishment of a significant number of disabled people to Belgium. In spring 2014, the press revealed that several thousands of French disabled people were allegedly placed in Belgian institutions, sometimes in indecent conditions, because of the inability of French Authorities to offer them individualized and adapted solutions.

Recommendation 17: Enforcing article 67 of the 2005 law which imposes to offer as many hosting solutions as there are needs for disabled adults in order to put a stop to the banishment to Belgium and to bring the children and adults wishing it back to France

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2 Violation of article 7: Cruel, inhumane, or degrading treatments in psychiatry

2.1 Le packing

See 2.6.1

2.2 Resorting to restraint and confinement in psychiatry

The "La Croix"²⁸ newspaper cites the yearly report of the general controller of places of deprivation of liberty²⁹, published in March 2014. A question written on the topic was asked to the government³⁰ but the fate of people with autism wasn't dealt with in the answer.

The situation is similar for the decision to put someone in confinement. This decision must be prescribed for a maximum of 24 hours, renewable if necessary. However, some abuses seem to occur. In his report, Jean-Marie Delarue mentions cases of "autistic and chronically impaired" patients, sometimes placed in confinement rooms for weeks, months, even years. "The controllers met a resident who had been placed in a confinement room for 7 years in a MAS (SPECIAL RESIDENTIAL CARE ESTABLISHMENTS)", he mentions.

2.3 People with ASD are particularly affected

The **Report of the General Inspection of social affairs RM2011-071P, « Analysis of accidents in psychiatry and propositions to prevent them »**³¹, from 2011, makes a list of the many abuses observed in psychiatric hospitals. It alerts about the fact that people suffering from autism or PDD are particularly affected. In the following excerpts, **we have highlighted the sentences referring to people with autism.** The paragraph numbers are those of the quoted report.

1.1.4. Physical mistreatment in isolation wards often remains hidden for several years.

*Mistreatments are barely ever reported and we don't have the possibility to know whether they actually are but are just not officially declared. Since the various departments are compartmentalized, the reported abuse could occur in an isolated department and wouldn't 'contaminate' the other structures which could be of excellent quality. When abuses were reported, the health inspection services would spring into action. **Their reports showed that all abuses cases had some common ground: they almost exclusively concerned wards for autistic people or people with PDD.** Medical staff were barely present, health executives were either sick or on leave, the care manager would never visit those wards. Confronted to a daily reality experienced as harsh and without any future prospect, the mistreating people were usually the nurses' aids working mainly on their own, without supervision, with an inexperienced and overwhelmed nurse. Their coworkers were usually aware but wouldn't talk about it for the sake of solidarity. The 'wake-up call' came from the outside, through an intern or a new staff member who denounced a problem that had been going on for a long while.*

2.2.2. The excessive use of confinement rooms contributes to creating tensions between the various departments.

Patients who remain on average more than 30 days in confinement are usually suffering from several mental deficiency, autism or PDD (see annex 7). They represent 5% of patients placed in confinement. Confinement can have a soothing effect in the short-term but can be traumatizing if too long, worsening the patient's feeling of disorientation and anxiety and engendering antagonistic

²⁸ <http://www.la-croix.com/Ethique/Sciences-Ethique/Sciences/La-psychiatrie-s-interroge-face-a-la-banalisation-de-l-isolement-et-de-la-contention-2014-03-17-1121536>

²⁹ http://www.cgpl.fr/wp-content/uploads/2015/04/CGLPL_rapport-2014_version-web_3.pdf
³⁰ <http://questions.assemblee-nationale.fr/q14/14-52832QE.htm>

³¹ <http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/114000287.pdf>

reactions 84, especially if the patient is maintained in confinement longer than necessary. It must answer specific conditions listed in the reference document published by ANAES in 1998 85. The prescription is solely medical: "there isn't any non-therapeutic use". Thus, confinement cannot be decided as a punishment, to offset the shortage of staff or to ease the nurses' aids' workload. Making it a common occurrence constitutes an abuse in and of itself, worsened by the possibility to resort to physical restraint.

2.2 Some inappropriate hospital practices, non-compliant with the right of the patients, create favorable conditions for acting out.

At least three factors increase the risk of running away or of violence during a stay in a hospital. First of all, confining to narrow spaces people from all ages suffering from various pathologies – some of them delirious and in a severe fit or others about to be released – creates unavoidable tensions. Then, the deprivation of any privacy because of accommodation in dormitories, because it is mandatory to wear pajamas during daytime, because of meals systematically taken with others, imposed TV channels and the almost total lack of entertainment, increase those tensions even more. Finally, the excessive use of confinement rooms (sometimes added to physical restraint methods), far from any good practice and almost systematically used on inmates and difficult patients, may make the temptation to run away or to become violent highly predictable.

The inspectors also noted that almost every year, some patients were found (the time was not indicated but it seems to have been in the morning) in their bed or lying on the floor with hematomas and face injuries but we couldn't find out how they got them (aggression or self-mutilation). These phenomena often occurred in the **autistics' ward**, but also in general psychiatry wards.

Examples of denial attitudes, of mistreatment even towards the victims

Last example in a French overseas department in 2007: the IGAS (General Inspection of Social affairs) carried out an investigation requested by the Defender of Children, regarding the fate of a young autistic boy aged 11 placed under the control of the ASE, hospitalized in a locked ward in a department of adult psychiatry for lack of a better solution. This boy was the victim of violence and then of sexual assaults from other patients. To protect him, the staff locked him up in a secured room which actually was a wire-mesh cage built in the center of the ward to be protected from other patients. After a year, a place was found in a child psychiatry ward in another department and the cage was destroyed.

In total, in Guyana, about 120 minors and pre-teens have been allegedly cared for in adult psychiatric wards over the past four years.

Solutions:

- **Recommendation 18: controlling the psychiatry services where there isn't any listing of the carried out processes; prohibiting inhumane and degrading treatments.**

Autisme France

2.4 Violations of articles 14, 17 and 24 of the Covenant: Abusive notifications to child Social Services

A major problem occurs when someone in charge makes the decision to place a child apart from his/her family, basing this decision on expertise formed by doctors strongly influenced by psychoanalysis which tends to consider families and especially mothers as responsible for their children's behaviors. An inaccurate understanding of autism can quickly lead to a wrong interpretation of a child's behavior and to a wrongful separation from the family sphere or to intrusive investigations of an administrative, legal or educative nature. This matter is detailed in an article by a group called Egalited³². Here's an excerpt:

"Some staff confuse the symptoms of this handicap with proof of abuse and want to "save the child" regardless of any common sense and of the recommendations of the 'Haute Autorité de Santé'. Indeed, some of the symptoms of autism, taken separately, can be interpreted as symptoms of abuse. That happens all the more so when the professionals in charge of studying the family's case are not trained in autism, which is unfortunately the case for most childcare professionals.

Unfortunately, in many cases, when parents suspect that their child might be autistic (parents who get informed and trained at their own expenses), they are told that their suspicions are absurd by social workers or PMI (infantile and early childhood protection services) staff, whose training conveys a narrow and outdated notion of autism.

Similar cases were reported to Autisme France (see families' testimonies in Annex).

This matter is also reported in a broader way (without specifically referring to ASD) by a family defense association.

<https://comitecedif.wordpress.com/rapport-sur-la-protection-de-lenfance/>

³² <http://www.agoravox.fr/actualites/citoyennete/article/autisme-et-aide-sociale-a-l-136809>

3 Conclusion:

Autisme France denounces the discrimination against people with autism spectrum disorder in France. Because of the discrimination they are victim of, because most doctors refuse to update their knowledge of autism in spite of the Public Health Code, because of a lack of specific services and their low level of inclusion at school, people with ASD are socially isolated and some of them are suffering from degrading treatments in psychiatric hospitals.

Basing its request on **article 7** of the Covenant, Autisme France demands that bad treatments such as packing, confinement and restraint be terminated in psychiatry since they are not in compliance with the Covenant or the UN Convention for the rights of disabled people.

Basing its request on **article 12**, Autisme France demands that the scandalous banishment of autistic people to Belgium stops.

Basing its request on **articles 14 and 17**, Autisme France demands that professionals from tribunals and child social services be trained in recognizing and understanding autism spectrum disorders in order to prevent mothers from being reported to social services for Münchhausen syndrome by proxy or for not properly raising their children.

Basing its request on **article 24** of the International Covenant on Civil and Political Rights quoted in this report and ratified by France, Autisme France demands that France respect the rights of children with autism spectrum disorder, who are protected by law and are not the fantasy subjects of some Lacan/Freud psycho-therapists: they are, in reality, largely ghettoized children in healthcare or medical-social institutions. We must, at all costs, avoid the exclusion of children with ASD from mainstream schooling in order to allow them to better develop their cognitive and social skills. Autisme France demands that segregation stops and that France implements inclusive schooling as well as specific interventions in compliance with the recommendations of the 'Haute Autorité de Santé'.

Basing its request on **article 23**, Autisme France demands that families be protected and helped and that abusive institutional placements decisions stop to prevent autistic children from being taken away from their mothers.

Basing its request on **article 26** of the same Covenant stating that everybody is equal in front of the law, Autisme France demands that the law of 2005 be enforced – this law states that people with ASD are entitled to an adapted care and support system all through their life. Autisme France demands that autistic people get other solutions than psychiatry and that medical-social establishments caring for adults be more adapted to take care of severely impaired autistic adults. It demands the enforcement of both laws of 2002 putting the patient at the center of the care facility instead of the professionals, and the enforcement of the Public Health Code.

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4 List of Recommendations from Autisme France:

Recommendation 1: insuring the enforcement of the 2005 law and implementing its update

Recommendation 2: allow complaints for discriminatory remarks when the word autism is used as an insult

Recommendation 3: the creation of services for diagnosis and early interventions in each department

Recommendation 4 : The obligation for medical staff to form a diagnosis compliant with ICD – 10, to inform the person or his/her parents clearly and in writing of the diagnosis and to write down the nature of the necessary recommended interventions, in keeping with the good practices guidelines of the HAS from March 2012

Recommendation 5: Obligation to respect the diagnosis guidelines from October 2005 33

Recommendation 6: Punishing doctors breaching The Public Health Code and refusing to form a diagnosis.

Recommendation 7: Organizing of a nationwide awareness campaign and developing the necessary information tools: the only existing screening brochure has been designed by our association:

Recommendation 8: Encouraging mainstreaming education by reallocating funds wasted in obsolete and toxic healthcare practices towards National Education, so that it can finance the necessary educational support for autistic children and teenagers.

Recommendation 9: Financing aids - not provided by the State - given to families to send their children to school.

Recommendation 10: Encouraging inclusion in all of the children's activity (leisure, sports, culture).

Recommendation 11: Inclusion implies that teachers, organizers and any actors of this inclusion must be trained in autism, that the National Education must recruit specifically-skilled educational staff with up-to-date knowledge of autism.

Recommendation 12: Put an immediate stop to the banishment of children to Belgium by organizing the adapted schooling they should be entitled to on the French territory.

Recommendation 13: Organizing real delegations of public service in medical-social establishments in order to control the use of public money.

Recommendation 14: Prohibiting Le Packing and any other degrading and non-ethical practices.

Recommendation 15: Making it mandatory for psychiatric staff in charge of children and adolescents with ASD to be trained in the approved scientific approaches to autism and to apply them.

³³ Circular DGAS/DGS/DHOS/3C no 2005-124 from 8 march 2005 with regard to the care policy of people with ASD or PDD. http://www.autismes.fr/documents/textes/circ2005_124_080305.pdf

Recommendation 16 -17: Enforcing article 67 of the 2005 law which imposes to offer as many hosting solutions as there are needs for disabled adults in order to put a stop to the banishment to Belgium and to bring the children and adults wishing it back to France

Recommendation 18: controlling the psychiatry services where there isn't any listing of the carried out processes; prohibiting inhumane and degrading treatments.

Recommendation 19: reforming the law of 2007 on the protection of childhood, so that departmental and legal authorities acquire the proper skills in autism; enforcing the Project for the Child.

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ANNEX A: Articles from the international Covenant on civil and political rights quoted in this report

Article 7

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

Article 12

Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence.

Article 14

Everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law.

Article 16

Everyone shall have the right to recognition everywhere as a person before the law.

Article 17

No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 23

The family is the natural and fundamental group unit of society and is entitled to protection by society and the State

Article 24

Every child shall have, without any discrimination as to race, colour, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the State.

Article 26

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

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ANNEX B: families' testimonies

Autisme France publishes on its website in the section entitled "tales of ordinary scandal", some families' testimonies received by email or phone-calls to the office of the association.

In order to avoid making this report too heavy, the reader can refer to the testimonies at:

http://www.autisme-france.fr/577_p_35584/chronique-du-scandale-ordinaire.html

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ANNEX C: List of Acronyms used in this report

ABA	Applied Behavior Analysis
ANESM	Agence Nationale de l'évaluation et de la qualité des établissements et services sociaux et médicaux-sociaux (National Agency for the assessment and quality of social, medico-social services and establishments)
ARS	Agence régionale de santé (Health Regional Agency)
ASE	Aide sociale à l'enfance (Child social services)
CDAPH	Commission des droits et de l'autonomie des personnes handicapées (Commission for the rights and the autonomy of disabled people)
CIM 10	Classification internationale des Maladie, révision 10 (International Classification of Diseases ICD – 10)
CLIS	Classe pour l'inclusion scolaire (Class for inclusive education)
CRAM	Caisse Régionale d'Assurance Maladie (Regional Health Insurance system)
DSRM	Directions régionales du Service médical (Regional Direction of medical services)
ERSM	Echelon Régional du Service Médical (Le Service Médical est un organisme médical expert de l'Assurance Maladie) (regional medical experts)
FAM	Foyer d'accueil médicalisé (medicalized hosting home)
GEVA	Guide d'Evaluation et d'aide à la décision pour les MDPH (assessment table for decision-making processes by MDPH)
GEVA-sco	Le GEVA-Sco est le volet scolaire du GEVA (School/education section of the GEVA)
HAS	Haute Autorité de Santé (independent public body for public health)
IGA	Inspection Générale de l'Administration (General inspection of Administration)
IGAS	Inspection Générale des Affaires Sociales (General Inspection of Social Affairs)
IME	Institut Médico Educatif (medical-educational institute)
MAS	Maison d'accueil spécialisée (<i>SPECIAL RESIDENTIAL CARE ESTABLISHMENTS</i>)
MDPH	Maison départementale des personnes handicapées (departmental institutions for the disabled)
SESSAD	Service d'accompagnement et de soins à domicile (service for the care and support at home)
TEACCH	Treatment and Education of Autistic and related Communication handicapped Children. State University Program developed in the 70s in North-Carolina. This program is aimed at people with autism al through their life.

Autisme France

TED	Pervasive Developmental Disorder
TSA	Autism Spectrum Disorder
ULIS	Localized units for school inclusion
UMD	Difficult patients ward (in Psychiatry)
USLD	Long-term Care ward
PRT	Pivotal Response Training (educational method based on motivation)

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