



**ALTERNATIVE REPORT FROM THE ASSOCIATION AUTISME
FRANCE to the committee against torture
In application of article 19 of the Convention against Torture and Other
Cruel, Inhuman or Degrading Treatment or Punishment
In the context of the 7th periodical report by State Parties**

Autisme France

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Reminder**The States Parties to this Convention,**

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Recognizing that those rights derive from the inherent dignity of the human person,

Considering the obligation of States under the Charter, in particular Article 55, to promote universal respect for, and observance of, human rights and fundamental freedoms,

Having regard to article 5 of the Universal Declaration of Human Rights and article 7 of the International Covenant on Civil and Political Rights, both of which provide that no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment,

Having regard also to the Declaration on the Protection of All Persons from Being Subjected to Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, adopted by the General Assembly on 9 December 1975,

Desiring to make more effective the struggle against torture and other cruel, inhuman or degrading treatment or punishment throughout the world,

Have agreed as follows:

PART I**Article 1**

1. For the purposes of this Convention, the term "torture" means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.

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Autisme France

1 Introduction

Assessing the failure to respect the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment:

France violates this convention on several grounds: it promotes the packing method, lets people in mental institutions be mistreated, allows degrading treatments on children, lets mothers of autistic children be subjected to mental cruelty while they are denied a proper diagnosis for their children and while their children are threatened to be committed if they don't comply.

2 Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

2.1 Le packing

Le packing – wrapping people in cold, soaked sheets against their will – has already been reported twice in UN's observations but France still refuses to ban it:

Committee on human rights:

Dignity and integrity of disabled people

20. The Committee is concerned about revelations regarding offences to dignity and physical and mental integrity of disabled people placed in institutions in the State Party and in a neighboring country. The Committee is also concerned about the fact that the "packing" method consisting in wrapping autistic children or psychotic adults in freezing, wet sheets is still being used for experimental purposes (art. 7, 16 & 26).

Committee on children's right:

The Committee is concerned about cases of bad treatments on disabled children placed in institutions and about a lack of independent control over these institutions. The committee is also concerned about the "packing" method (wrapping children in cold, wet sheets) which amounts to bad treatments. This method is not prohibited by law and is still used on some children with ASD.

Packing has often been reported by family associations:

<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>

<http://www.balat.fr/Le-Packing-une-video.html>

<http://troubles-du-spectre-autistique.e-monsite.com/pages/packing/avis-infirmier-sur-le-packing.html>

Renowned universities in Paris and province still offer trainings about autism based on non-scientifically approved theories. These trainings are complacently relayed on the website of the association Centres de Ressources Autisme (Autism Resource Center) whose mission is yet to inform about autism.

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

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A website of online training asserts the merits of the Packing¹:

“The Packing technique consists in wrapping the body in cold and wet sheets. This care method is used to engender limiting tactile sensations allowing the body to eventually acknowledge its own limits.” “The therapeutic technique called Packing is practiced in specialized environments with specifically-trained care staff. It is used with very positive outcomes on autistic children”.

Claim against the barbaric use of the Packing method (iced strait-jacket):

Source :

https://books.google.fr/books?id=o52XBgAAQBAJ&pg=PA296&lpg=PA296&dq=Devons-nous+%C3%A9thiquement+r%C3%A9sister+aux+recommandations+de+la+HAS+de+ne+plus+faire+de+packing&source=bl&ots=nmiu_RUCav&sig=k9_b3CvVGI500kt4p8_6fCjXquE&hl=fr&sa=X&ei=8sPpVPu3F4LxUPr8gdAL&ved=0CCMQ6AEwAA#v=onepage&q=Devons-nous+%20%C3%A9thiquement+%20r%C3%A9sister+%20aux+%20recommandations+%20de+%20la+%20HAS+%20de+%20ne+%20plus+%20faire+%20de+%20packing&f=false

Moreover, the National Union of psychomotor therapists proposed in 2015:

- A workshop named “therapeutic wet packing”

Source : <http://www.snup.fr/download/2015-Stages-S27.pdf>

You can find videos online promoting the Packing technique and books and journal articles dedicated to it. In one of the two books about Packing edited by M. Delion, you can read that the Packing method can recreate erogenous areas. These perverse tendencies, bordering pedophilia can also be found in an online video:

<http://www.hesav.ch/recherche-et-developpement/evenements-activites/autres-evenements-hesav/journees-d-etude-pack>

We are inviting international experts to assess the doctor’s words, breaching medical ethics by claiming that it is normal to start with worsening a patient’s state in order to reach an improvement. We also invite them to appraise the sexualization of such practice and its appalling aspect.

A journalist, who had her son committed to a day hospital facility where the packing method is used, has made headline news:

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

¹ <http://psychiatriinfirmiere.free.fr/infirmiere/formation/psychiatrie/adulte/therapie/pack.htm>

Several IME (medical-educational institutes) of the Rhône-Alpes and other regions are being trained to Packing, they acknowledge it themselves:

http://www.cra-rhone-alpes.org/IMG/pdf_IME-Grand-Boutoux--Livret-Autisme-Rhone-Alpes.pdf

Psycho-motor therapists contributing to continuing adult education (they are from now on authorized to give such trainings) solely teach psychoanalysis, wading pool and Packing:

<http://www.snup.fr/download/2015-Stages-Dossier-Formation.pdf>

Solutions:

- **Recommendation 1: Ban packing and all other degrading and non-ethical practices.**
- **Recommendation 2: Make it mandatory for psychiatric staff in charge of children and teenagers with ASD to be trained to scientifically-approved methods accepted in the field of autism and to apply them**

2.2 Resorting to restraint and confinement in psychiatry

The newspaper « La Croix »² quotes the annual report from the General Controller of places of deprivation of liberty, published in March 2014³. A question written on the issue was asked to the government, however, in its answer, the government failed to mention the fate of people with autism.⁴

The situation is similar when putting an individual in isolation for a period that cannot be prescribed for more than 24 hours, extendable if necessary. However, some abuses seem to occur. In his report, Jean-Marie Delarue mentions the case of “autistic and chronically impaired patients”, who are sometimes placed in confinement chambers for periods lasting several weeks, months or even years.

“The controllers met a resident who had been placed in isolation for more than 7 years in an IME”, he said.

2.3 People with ASD particularly concerned

The **Report from the general Inspection for social affairs RM2011-071P, «Analysis of accidents in psychiatry and propositions to avoid them»⁵** dating from 2011, identifies a number of abuses observed in psychiatric hospitals. He highlights the fact that people with autism or pervasive development disorder are particularly affected. In the following excerpts, **we have highlighted in bold the sentences relating to people with autism.** The paragraph numbers are those of the quoted report.

² <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>

³ http://www.cglpl.fr/wp-content/uploads/2015/04/CGLPL_rapport-2014_version-web_3.pdf

⁴ <http://questions.assemblee-nationale.fr/q14/14-52832QE.htm>

⁵ <http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/114000287.pdf>

1.1.4. The physical abuse, in isolation wards, often remains hidden for several years.

Abuses are hardly ever reported and it is difficult to determine whether they are indeed reported or just not officially declared. Since the various services are compartmentalized, the reported abuses could occur in an isolated department and would not '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 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.*

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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.

http://www.liberation.fr/france/2016/03/25/psychiatrie-l-enfer-derriere-les-portes_1442156

The General Controller of liberty has harshly criticized a psychiatric hospital in Ain for its abusive resort to confinement and restraint and its unacceptable abuses:

“All this with “a resort to confinement and restraint used at a level never witnessed before and non compliant with the commonly-applied regulations”. In short, patients were locked up and bound. “Besides those placed in confinement chambers, many patients hospitalized in “follow-up care” wards are locked up in ordinary rooms, the controller observes. We notice that this confinement that often lasts more than 20 hours a day can be extended for several months. To this, a bed or armchair restraint can be added up to 23 hours a day for, some patients this can last months or even years.”

The Committee against torture can note that this Psycho-therapeutic center (where the therapy is confinement?) houses the Autism Resources Center.

Autisme France got a patient released from a psychiatric hospital. When he got to one of our FAMs, this autistic adult was tied and strapped. You can see the scene in this video: <https://www.youtube.com/watch?v=xbKnxfUxoQ>

The so-called Tim affair has become emblematic: a child was committed to an adult ward. <http://blogs.lexpress.fr/the-autist/2015/09/26/tim-ado-autiste-en-hp-malgre-la-condamnation-de-lonu-la-juge-confirme-la-decision-de-placement/>

Regarding inhuman and degrading treatments, we have learnt about electroshock therapy practiced on autistic teenagers at La Pitié Salpêtrière.

USIDATU asserts its merits:

www.afg-web.fr/IMG/pdf/USIDATU_presentation_ARS.pdf

See page 17 of this document: Use of electro-convulsion therapy (e.g. electroshock therapy) in refractory case of self/hetero aggressiveness. These electroshocks are illegally practiced since the **Haute Autorité de Santé has never given any instructions regarding their use for autistic patients.**

Some business are specialized in confinement chambers and strapping beds and prospect managing agencies claiming that they are approved by the Haute Autorité de Santé and the National agency for the assessment of the quality of Social and medico-social facilities. This is an overstep since these agencies have never given any approval of this kind. Yet, this says a lot about the general atmosphere: an autistic person has to be locked up.

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The hypo- sensitivity room is reassuring and appeasing as it lowers the number of stimuli it triggers. It allows answering the sensory hyper stimulation issues as well as serious behavioral deficiencies and aggressive attitudes directed to oneself or to others by reassuring both the patient and the care staff.

ANESM (national agency for the assessment and quality control of social, medico-social services and facilities) has recommended such pacification spaces in 2010 for the care of a patient in situation of crisis.

The pacification room is thus used for patients with troubles corresponding to the following indications:

- Preventing an imminent burst of violence from the patient against him/herself while other means of control are neither efficient nor appropriate.
- Preventing a risk of therapeutic break while the patient's state requires care (psychiatric).
- Confinement prescribed within a therapeutic program.
- Confinement in order to decrease excitement (calming down).
- Use on patient's request (prevention, decrease in the needs for stimuli).

In France, it seems absolutely normal to lock up 13-year old autistic children in psychiatric hospitals:

HOSPITALISATION DES ADOLESCENTS DU PÔLE DE PÉDOPSYCHIATRIE DU VINATIER SUR LE PÔLE PHASEDDIA

- 1 - Possibilité d'hospitalisation d'adolescents âgés de 13 ans révolus à 16 ans, relevant des secteurs du Pôle de Pédopsychiatrie du Centre Hospitalier du Vinatier, présentant des pathologies diverses avec déficience intellectuelle grave, associées ou non à un TED, sur ceux lits de l'unité Requet du Service DAPHA.

Les hospitalisations se feront suivant les moyens soignants du projet en cours et ne permettent pas pour l'instant un accueil au delà des deux lits.

- 2 - Afin de déterminer le lieu d'hospitalisation le plus approprié, nécessité de consultations conjointes d'un médecin de l'unité de Flavigny et d'un médecin du Service DAPELA pour en décider.

- 3 - L'hospitalisation au DAPELA est placée sous la responsabilité du médecin du DAPELA. Des consultations et interventions de l'équipe de secteur de pédopsychiatrie de référence se mettent en place pendant le temps de l'hospitalisation et permettent entre autre la préparation de la sortie.

Sauf exception, le secteur pédopsychiatrique de référence de l'adolescent est en lien avec l'adresse de la résidence parentale.

- 4 - Pour ces patients, le DAPELA peut adresser une demande de prise en charge d'hospitalisation de jour à l'Hôpital de Jour Roger Misès du Pôle de Pédopsychiatrie qui statuera sur l'indication.
- 5 - Le Pôle de Pédopsychiatrie s'engage à assurer un relais de suivi au sein des CMP des secteurs, dès la sortie de l'hospitalisation de l'adolescent.

Avril 2015

Translation of the above-form:

HOSPITALIZATION OF TEENAGERS FROM THE CHILD PSYCHIATRY POLE VINATIER TO THE PHASEDDIA POLE

- 1- Possibility of committing children from 13 up to 16 years old from the child psychiatry pole of the Vinatier hospital when they present various pathologies with serious intellectual deficiencies associated (or not) with ASD, to the 2 beds of the Requet unit of the DAPHA service.

Hospitalization will be decided according to the means of care of the ongoing project which cannot currently exceed more than 2 beds.

- 2- In order to determine the most appropriate hospitalization area, it is necessary that both a doctor from the Flavigny unit and a doctor from the DAPELA service concur.
- 3- The reference area child psychiatry team sets up consultations and interventions during the time of hospitalization that also allow preparing the patient's release.

With some exceptions, the reference child psychiatry area for teenagers is linked to the parents' home-address.

- 4- For those patients, DAPELA can address a request for day care in the Roger Misés day hospital from the child psychiatry pole which will determine the proper indication.
- 5- The child psychiatry pole commits to ensure a monitoring follow-up in medical-psychological center of the proper area starting right from the teenager's release.

Children aren't treated any better in medical-social institutes: they can be deprived of any outside activity and can be placed in confinement.

This IME that had to open following the article below is neither better nor worse than any other: it only shows the French culture: an autistic child must first be isolated from the outside world and then locked up. Facilities banning this kind of mistreatments are extremely rare.

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TASSIN-LA-DEMI-LUNE Le futur établissement pour jeunes artistes se dévoile

Projet. Visite guidée, pour les nouveaux arrivants, du chantier de l'établissement spécialisé pour les enfants artistes en cours de construction, au numéro 1 de l'avenue Clémenceau. Ouverture prévue au deuxième trimestre.

Vendredi, Bernadette Clémenceau, d'Accueil des villes françaises (AVF), qui aide les nouveaux arrivants à s'intégrer dans une ville, a saisi la proposition que lui avait faite M. Maton. Ce dernier a proposé de faire visiter le chantier du futur établissement pour jeunes artistes aux adhérents d'AVF et de les informer sur l'activité de l'association Les Lisérons, qui gèrera les

« L'autisme n'est pas une maladie »

Christine Bon, Responsable autisme de l'établissement



« L'autisme ne se résume pas facilement. Ce n'est pas une maladie mais un trouble envahissant du comportement, du langage, de la communication et des relations sociales, souvent associé à des déficiences intellectuelles. Ils voient le monde en petits morceaux. Ils ont souvent des gestes répétitifs. Ils ont un besoin d'une éducation particulièrement adaptée, d'où la présence d'équipes pluridisciplinaires dans notre établissement. Il faut tout leur apprendre, même à jouer. Nous nous attachons aussi à accompagner les parents. »

lieux une fois les travaux finis. Cette visite complète était d'autant plus nécessaire que le handicap de l'autisme est difficile à cerner, et que les aménagements des locaux ne sont pas ordinaires. Difficile de s'y retrouver entre les différents sigles qui désignent ces activités. Le lieu sera à la fois un IME Teranga (Institut médico-éducatif) et une Sessad (Service d'éducation spéciale et de soins à domicile).

Ce centre aura la charge d'une vingtaine de jeunes âgés de 6 à 14 ans, essentiellement des garçons. Il occupera environ 25 spécialistes de disciplines les plus diverses (psychologues, enseignants, orthophonistes, pédiatres...), à temps partiel pour la plupart. Un internat est prévu avec six chambres.

Une architecture bien pensée

L'association gestionnaire, qui gère déjà une dizaine d'établissements dans le Rhône, dont le président est André Genhial et le directeur Bertrand Gauthier, est spécialisée dans l'accueil des enfants ayant des besoins spécifiques en matière d'éducation, d'enseignement et de soins. C'est grâce à elle et à sa sœur Gisèle, qui représente la tutelle de la congrégation des



Bertrand Gauthier, le directeur de l'association Les Lisérons, souligne qu'il s'agit de tout sauf d'un établissement fermé et caché. Photo Y.M.

Les acteurs du projet (de gauche à droite) : Christine Bon, responsable autisme ; André Genhial, président des Lisérons ; Sœur Gisèle ; Bertrand Gauthier, directeur ; M. Maton ; Virginie Gourrier, directrice adjointe. Photo Yves Maruy



sœurs de Saint-Charles, présente lors de la visite, que le quartier a échappé à un nouvel immeuble de cinq étages. L'originalité majeure de cette réalisation réside dans sa conception architecturale. C'est en effet une multitude de détails sur les locaux en cours de construction que la visite par Bertrand Gauthier, directeur, a permis de découvrir. La construction de 1 000 m², prise sur le jardin contigu à l'école Saint-Charles, fait la part belle aux matériaux bois avec toit

végétalisé et chauffage par le sol. Les panneaux extérieurs de couleur sont du meilleur effet. Avec le chauffage par le sol, les radiateurs, sources éventuelles de problèmes avec les jeunes résidents, sont bannis. Plus globalement tout ce qui heurte le regard (angles droits, arêtes etc.) est évité. Les couloirs ne sont pas rectilignes mais en forme de V avec une largeur qui diminue progressivement. Toutes les fenêtres sont à une grande hauteur

pour que le regard ne puisse se porter à l'extérieur, ce qui est source d'inquiétude et d'angoisse pour les autistes. Il existe même une chambre noire, sans fenêtre, dite « de remise au calme ». Pour les cas les plus difficiles et les plus dangereux (surtout pour eux-mêmes), une « salle de crise » capitonnée est prévue. On trouve enfin une salle de répit nitrissage aux jeux et les tuyauteries de ventilation ont été surdimensionnées pour réduire le bruit du flux d'air. ■

TASSIN-LA-DEMI-LUNE Le maire Pascal Charmot souligne l'importance de « travailler ensemble »

Vœux du maire

Vendredi matin, le maire Pascal Charmot, a réuni l'ensemble du personnel communal dans le théâtre de l'Atrium pour lui présenter ses vœux. Ils étaient nombreux à être venus pour écouter, à cette occasion, des paroles réconfortantes sur l'importance qu'est la leur dans la commune. Rappelant que l'ensemble du personnel communal représente 320 personnes, dont 220 pour la Ville et une centaine pour le CCAS (Centre communal d'actions sociales), Pascal Charmot souligne l'importance de « bien travailler ensemble devant les multiples tâches et malgré la



Une partie de l'assistance autour d'un déjeuner, vendredi pour les vœux de la mairie. Photo Jacques Abat

diminution des moyens financiers ». Pour la Ville, c'est tout un éventail de professions administratives, mais aussi de l'entretien des bâtiments (électriciens, menuisiers), des techniciens des espaces verts, des agents d'entretien des écoles ainsi que

des Arsem (agents territoriaux spécialisés des écoles maternelles). Ça a aussi été l'occasion pour Yvon Naudé, responsable des services, de faire ses adieux en vue de la retraite, et pour Vincent Chagneau, nouveau responsable adjoint des services, de prendre ses marques. ■

TASSIN Le Groupe de recherches historiques prépare 2015



Les membres du groupe en ont profité pour tirer les rois. Photo Jacques Abat

Vendredi, Maurice Noirard, président du Groupe de recherches historiques, a réuni ses troupes à l'espace Leclerc pour les traditionnels vœux de la nouvelle année. Ça a été l'occasion pour le président de faire le bilan de l'année 2014 et de parler de 2015. Le grand projet des douze mois à venir est le livre en préparation

sur les poilus de la commune et les 740 soldats de Tassin qui ont pris les armes durant la Grande Guerre. Robert Roux est toujours à la recherche d'archives sur le sujet. Autre objectif : poursuivre les expositions sur le patrimoine de la commune dans les écoles. Le groupe rendra visite aux CMI-CM2 de l'école Leclerc. ■

Translation of the article:

The future facility for young autistic people is being unveiled

Project. Guided visit, for the newcomers of the construction site of the specialized facility for autistic children located 1 Clemenceau Avenue. Opening planned for the second semester.

On Friday, Bernadette Clemençon from the association Accueil des Villes Françaises (AVF) helping newcomers to settle in a new town accepted the proposition made to her by Mr. Maton. He proposed a visit of the construction site of the future facility for autistic children to the members of AVF in order to inform them of the activities of the association Les Liserons that will manage the place when construction is completed. This thorough visit is all the more necessary that autism is a very complex disability to understand and the facility's features are nothing but ordinary. It is hard to figure out the various acronyms that refer to its activities. The space will be an IME (medical-educational institute) Teranga and a SESSAD (special education and home-care services).

This center will be in charge of around 20 youngsters from 6 to 14 years old, essentially boys. It will be staffed by about 25 specialists from various disciplines (psychologists, teachers, speech therapists, pediatricians...); most will be employed part-time. The facility will have a dorm with 6 rooms.

A well-thought through architecture

The managing association – which already manages 10 facilities in the Rhône region, whose president is André Genthial and its director, Bertrand Gauthier - is specialized in the care of special need children in terms of education, schooling and medical care. Thanks to this association and Sister Gisèle representing the tutelage of the Saint-Charles' Sister Congregation, who was present during the visit, the neighborhood escaped yet another construction of a 5-storey building.

The main originality of this project resides in its architectural design. Indeed, the visit led by B. Gauthier allowed discovering a multitude of details placed on the premises. The 1000m² construction located next to the Saint-Charles school gives a predominant place to wood material with a vegetal roof and floor heating. The outside panels' colors are striking and elegant. Thanks to the floor heating system, the radiators are no longer a potential source of problem for the young residents.

More generally, everything that can disturb the onlooker's eyes (right angles, edges...) is avoided. Corridors are not straight lines but form a V with a width that slowly decreases. All windows are placed high enough so that it is difficult to look on the outside – a source of anxiety and anguish for autistic children. There is even a windowless darkroom called "the calming down" room. For the most difficult and dangerous cases (especially for themselves), a "crisis" room with padding has been installed. Finally, we can find a room to re-learn how to play with oversized piping and ventilation in order to reduce the noise of the air flow.

"Autism is not a disease"

Christine Bon, supervising the autism aspect of the facility.

"Autism is not easy to sum up. It is not a disease but a disability, a pervasive behavioral, communication and social relation disorder that is often associated with intellectual deficiencies. They see the world in tiny pieces. They often have repetitive gestures. They need a particularly adapted education, hence the presence of multi-discipline teams in our facility. We even have to teach them how to play. We also focus on parents' support."

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Solutions:

- **Recommendation 3: controlling psychiatric services where the undertaken actions aren't listed; banning inhuman and degrading treatments; banning the commitment of autistic children to adult psychiatric wards.**
- **Recommendation 4: architectural projects of facilities for people with autism should not be approved if they contain confinement chambers or if the outside is not accessible.**

2.4 The wading-pool, a degrading and humiliating treatment that feeds psychoanalysts' pedophile tendencies

The wadding-pool, also called therapeutic puddle, remains largely used in day hospitals where 40% of autistic children usually stay, as well as in medical-social facilities:

<http://www.alterite.eu/uploaded/projet-etablissement-ime-le-buisson-01-12-2013-da-finitif.pdf>

It relies on a psycho-analytical vision of autism: scatological and pedophilic obsessions are sensitive issues there: in her book, La pataugeoire : contenir et transformer les processus autistiques, (Wadding-pool : containing and transforming autistic processes), Mrs Latour, the writer who works as a trainer for the psycho-motor professionals union, talks about children and pre-teens being naked while submitted to this barbaric practice. She says that the level of nudity depends on what the care staff can bear.

The "care" staff projects their scatological and sexual fantasies onto naked and defenseless children: it is a degrading, humiliating, pedophile practice.

Excerpts:

"They learn (the observers) that there is no shame in feeling anxious or bored to death" page 52

"Our wading-pool is located outside the main building and has no adjoining restrooms. Thus, when a child had to use the bathroom, he or she just had to hold it in until the session was over.... Or... he or she was wrapped... and brought... to the main building whatever the weather. Page 24

"Understanding why pooping or peeing was happening then... it is not so trivial that we stumbled so long over this matter of anal issue". Page 24

"If I think back on those sessions when we were just observing the slow movement of the bathtub at the surface of the wading pool, I recall being in turn either intrigued, or annoyed or bursting out laughing and then extremely weary, feeling as if I was attending a wake".

"We notice that the child takes no interest in the bottom half of his body, no exploration of the genital or anal areas even though there can be some grappling of the sex or clogging activity (Paul's excrement between his buttock)". Page 106

"For autistic children, there seems to be an amputation of the muzzle due to a too brutal separation from the breast". Page 109

Autisme France

“When the whole around the mouth is constructed, it is then possible to play at keeping and discharging and so at ‘sphincterizing’”. page 113

“Confusion between breast-head and rectum”

“The regulation regarding whether to wear a bathing-suit or not depends on the care staff’s tolerance to the child’s nakedness” page 128 (there are 12-13 years old children...)

“The average care period lasts around 3 years once a week”. Page 153

“Masturbation, exhibition can be accentuated by the fact that children are half-naked”.

Sexual fantasies imposed on vulnerable people are a common occurrence in the psychoanalysis field:

www.valas.fr/IMG/pdf/extrait_r_abibon_et_commentaires.pdf

The wading pool technique is taught during training sessions that are frequently relayed in Autism Resources centers:

<http://www.cra-rhone-alpes.org/spip.php?article2713>.

- A workshop on the wading-pool technique meant for “psycho-motor therapists and care staff involved in the care of autistic or psychotic patients”. Children up to puberty - often naked - are observed by “professionals” doing nothing but that.

Source :

<http://www.snup.fr/download/2015-Stages-S15-module4.pdf>

<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>

In 2016, the promotion of both packing and wading-pool techniques for children with ASD is still going on in psycho-motor therapy schools.

Good practices guidelines are not enforceable on professionals: no psychiatrists unions in France have supported those guidelines, no health professionals unions either. They are only enforceable to professionals of the medical-social field during internal and external assessments; however, the regional Health Agencies have no use for such assessments. Besides, very few institutions have an autism agreement (an agreement that is not regulatively defined) and most autistic people are committed to institutions not dedicated to autism, without a formed diagnosis (60% of children haven’t received a diagnosis). Thus, it is merely an illusion to try and enforce anything on any institutions.

Recommendation 5: Banning the wading-pool technique and reserve public funds for interventions in compliance with the recommended guidelines for good treatments.

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2.5 Abusive notifications to Child Protection Services: inhuman treatment for autistic children and their mother

A major problem arises when the authorities make the decision to place children out of their family sphere, basing their decision on expertise given by doctors strongly influenced by psychoanalysis. These doctors have a tendency to consider the family and especially the mother as responsible for their children's behavior. A false comprehension of autism can quickly engender a wrong interpretation of a child's behavior and thus wrongfully lead to a separation of the child from his/her family, or to intrusive investigations of an administrative, educational or legal nature. This issue is described in an article from an association called Egalited⁶. Here is an excerpt:

"Some staff confuse the symptoms of this handicap with proof of mistreatment and want to 'save the child' regardless of any common sense or of the HAS guidelines. Indeed, some symptoms of autism, when taken separately, can be interpreted as symptomatic of potential mistreatment or abuse, especially when the professionals studying the case haven't been trained to recognize autism. This is unfortunately the case for most professionals dealing with infancy".

Unfortunately, in most cases, when parents (who get informed and trained with their own money) claim that they think their child might be autistic, they are completely ignored by social workers or PMI employees who tell them that such claims are absurd. Indeed, they have a narrow and obsolete conception of autism due to their training".

Many cases such as this have been reported to Autisme France (See families' testimonies in Annex).

Mothers are subjected to a real form of psychological torture: their children are taken away from them if they persist in wanting to get a proper diagnosis whereas these children are indeed autistic. Mothers can visit their children half an hour per child every other week; visits are prohibited on birthdays and Christmas Day; mothers are obliged to acknowledge their own disease: since they want their children to be diagnosed with autism, they must be insane and thus, cannot raise their children.

The mental cruelty is endless: At the tribunal, the mother is reminded that she is insane. To one mother, Rachel - for whom we are going to refer to the Special Rapporteure – the general attorney said: "but why do you want your children to be autistic?" During the appeal, the judge refused to give her children back to her because she wanted to "stigmatize" them.

Day after day, month after month, mothers see their children suffer, see them being deprived of maternal affection, being schooled without knowing the school they are attending; being placed without knowing the host family's address. The children cannot get any news from their family; they cannot ever see their grand-parents; they move from place to place, deprived of the proper care necessary to their disability.

⁶ <http://www.agoravox.fr/actualites/citoyennete/article/autisme-et-aide-sociale-a-l-136809>

This situation is appalling.

See all the articles linked to a simple Google search:

<https://news.google.com/news/story?cf=all&hl=fr&pz=1&ned=fr&q=rachel+placement&ncl=dzz6qr8oKim0ldMEGetj1eRiaZjXM&scoring=d>

http://www.huffingtonpost.fr/sophie-janois/affaire-rachel-placement-enfants-autistes_b_7974940.html

http://www.liberation.fr/france/2016/01/22/dans-ce-dossier-tout-le-monde-nie-l-autisme-alors-qu-on-a-les-diagnostics_1428126

http://www.liberation.fr/societe/2015/08/11/autisme-ou-maltraitance-la-grande-confusion-de-l-aide-sociale-a-l-enfance_1362131

<http://dlangloys.blog.lemonde.fr/2015/07/12/jaccuse-autisme-et-aide-sociale-a-lenfance/>

<http://dlangloys.blog.lemonde.fr/2015/08/09/la-justice-francaise-acharnee-a-detruire-les-familles-denfants-autistes-ou-le-bal-des-faux-cul/>

Recommendation 6: reforming the law from 2016 about Child Protection so that the departmental and legal authorities acquire the necessary skills regarding autism; enforcing the ‘Projet Pour l’Enfant’ (The Project for Children) by making it mandatory for parents to sign any decisions, favoring family life and banning and punishing abusive notifications and placements.

3 Conclusion:

Relying on **article 7** of The International Pact on civil and political rights as well as on the Convention against torture, Autisme France demands that bad treatments stop in psychiatric facilities and medical-social institutes – bad treatments such as packing, confinement and restraint or wading-pool, are not only in conflict with The International Pact on civil and political rights as well as on the Convention against torture but also with the UN convention on the rights of Disabled people.

Autisme France demands that professionals from tribunals and Child Protection services be trained to recognize and understand ASD in order to protect mothers from being subjected to abusive notifications on the ground of Munchausen syndrome by proxy or of lack of education.

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List of Recommendations by Autisme France:

Recommendation 1: Ban packing and all other degrading and non-ethical practices.

Recommendation 2: Make it mandatory for psychiatric staff in charge of children and teenagers with ASD to be trained to scientifically-approved methods accepted in the field of autism and to apply them.

Recommendation 3: controlling psychiatric services where the undertaken actions aren't listed; banning inhuman and degrading treatments; banning the commitment of autistic children to adult psychiatric wards.

Recommendation 4: architectural projects of facilities for people with autism should not be approved if they contain confinement chambers or if the outside is not accessible.

Recommendation 5: Banning the wading-pool technique and reserve public funds for interventions in compliance with the recommended guidelines for good treatments.

Recommendation 6: reforming the law from 2016 about Child Protection so that the departmental and legal authorities acquire the necessary skills regarding autism; enforcing the 'Projet Pour l'Enfant' (The Project for Children) by making it mandatory for parents to sign any decisions, favoring family life and banning and punishing abusive notifications and placements.

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4 Definition of Autism Spectrum Disorders and presentation of Autisme France:

4.1 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. We can often find this term quoted in reference with this report. Although the definition of PDD is broader than that of ASD, we consider here both as equivalent. If readers want to understand the difference, they can refer to the text from Autisme Ontario available on the following internet page:

[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;
- Socialization in any places of living and institutions

4.2 Affected Population

There are no official figures regarding people with ASD in France. However, epidemiological data drawn up by the HAS in 2009⁷ allow to assess this population from available demographic statistics.

⁷ Source : Autisme et autres troubles envahissants du développement – État des connaissances.
http://www.has-sante.fr/portail/jcms/c_935617/autisme-et-autres-troubles-envahissants-du-developpement

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 study¹ 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%⁹

⁸ 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>

⁹ 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

4.3 Presentation of Autisme France

Autisme France: 25 years of 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.

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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

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ANNEXE A: families' testimonies

On its internet site, in a section named « chronique du scandale ordinaire » (Chronicle of an ordinary scandal), Autisme France publishes families' testimonies received either by email or by telephone at the association's office.

To avoid making this report too tedious, readers can refer to the following page:

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

The report called « Autisme et Protection de l'Enfance » (“Autism and child protection”) by Autisme France is available at the following link:

http://www.autisme-france.fr/offres/doc_inline_src/577/Rapport%2Bsur%2Bles%2Bdysfonctionnements%2Bde%2BI5C27Aide%2BSociale%2BE0%2BI5C27Enfance%2BAutisme%2BFrance%2B2%2Bversion%2Bpublique.pdf

The alternative report by Autisme France to the committee of human rights:

http://www.autisme-france.fr/offres/doc_inline_src/577/Rapport%2Balternatif%2Bdroits%2Bde%2BI5C27homme%2BAutisme%2BFrance.pdf

The alternative report by Autisme France to CIDE as well as additional observations:

http://www.autisme-france.fr/offres/doc_inline_src/577/Rapport%2Balternatif%2Bdroits%2Bde%2BI5C27homme%2BAF_03.pdf

Additional observations:

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

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ANNEXE B: List of Acronyms used in this report

ABA	Applied Behavior Analysis
ANESM	National agency for the assessment and quality control of social, medico-social services and facilities
ARS	Regional Health Agency
ASE	Child social services
CDAPH	Commission for the rights and the autonomy of disabled people
CIM 10	International Classification of Diseases, revision 10
CLIS	Classes for inclusive education
CRAM	Regional Health Insurance system
DSRM	Regional Directions of medical Service
ERSM	Regional medical experts from the Health Insurance body
FAM	Medicalized hosting facilities
GEVA	assessment guideline for decision-making processes by MDPH
GEVA-sco	GEVA-Sco is the educational section of GEVA
HAS	Independent public body for public health
IGA	General Inspection of Administration
IGAS	General Inspection of Social Affairs
IME	Medical educational Institute
MAS	Specialized residential care facility
MDPH	Departmental institutions for the disabled
SESSAD	Service for 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 all through their life.
TED	Pervasive developmental disorder
TSA	Autism spectrum disorder
ULIS	local units for school inclusion
UMD	Difficult patients ward (in Psychiatry)
USLD	Long-term care ward
PRT	Pivotal Response Training (method based on motivation)

Autisme France