

### Alliance Autiste

ONG d'autistes pour l'entraide et la défense globale des autistes

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# ONG **Alliance Autiste**

- France -

# **COMPLEMENTARY REPORT**

Concerning autistic persons

### For the

## **Committee against Torture**

- United Nations Organization -

## Regarding the

# Convention against torture and other cruel, inhuman or degrading treatments or punishment

as part of the examination of FRANCE

March 25, 2016

This non-confidential report is available in its original version in French, and in a translation, in English.

## **Introduction: presentation of Alliance Autiste**

This alternative report was prepared by the NGO "Alliance Autiste", a French national association of autistic persons aimed for mutual aid and global defence of autistic persons of all ages and from all parts of the spectrum of autism. Our group wants to promote understanding and cooperation with all organizations involved in autism, including parents' associations, NGOs, government and international agencies.

We work closely with the NGO Minority Autistic International, based in Geneva, the central organ of the "self - advocacy" movement for autism in the world, which is very active at the UN. We believe that the minority of autistic persons (about 1% of the world population) do not live in fair and decent conditions, and that substantial injustice could be reduced through better understanding of our particularity, autism, which is not a disease.

Autistics who are able to communicate are well placed to understand and to help understand autism, furthermore we believe that any category of people should have the possibility to defend themselves and take part in decisions affecting them.

## Provision in the Convention violated by France - Article 2.1.

Each State Party shall take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under its jurisdiction.

Inhuman and degrading treatments are implemented in some psychiatric day hospitals (which are concentrated many autistic persons) and / or institutions.

#### Namely:

- forced restraint over long periods (greater than 06h),
- forced over-medication,
- the packing therapy
- the "therapeutic puddle".
- I- Description
- 1. Physical restraint and overmedication

#### 1.1. Current context

These practices are very common in psychiatric hospitals, inasmuch as they are considered as "care", so enabling to treat the patient. Victims are autistic children, teen-ager and adults, or persons suffering from mental disorder or with intellectual disabilities.

These practices are considered by those professionals as inevitable: they are part of daily of the person (ie living in a psychiatric hospital, attached to long periods and subjected to heavy treatment whose primary drug is one or more neuroleptics).

#### 1.2. Example

Timothée, an autistic tee ager (16), has always been schooled in mainstream schools, and his mother and stepfather fought for that. They were deeply involved, from the beginning, in teaching him how to speak, read, write, count, and to be relatively autonomous. He plays the piano, he can cycle, he loves doing housework, cooking and shopping. His mother had custody and parental authority regarding schooling.

#### **Exclusion from school**

At the beginning of September 2014, when the school year was starting, Timothée was opposed, by the High school's management, a categorical refusal to let him enter into the school<sup>1</sup> where he had been studying the year before with the help of schooling assistant.

<sup>&</sup>lt;sup>1</sup> Video footage of the exclusion of Timothée, September 3, 2014 « <u>Lyon : un collégien autiste empêché physiquement de faire sa</u> rentrée »

This refusal was opposed despite the fact that his mother had been challenging the decision of the local authority in charge of the disabled persons (the "MDPH") ordering an orientation in an institution. The "MDPH" had indeed ordered this institutionalization without the mother requesting for it.

#### Forced institutionalization

The judicial machinery then started against Timothée, in order to implement the decision of the MDPH, despite the choice of his mother and stepfather with whom he lived.

At no point in the judicial procedures he was asked the opinion of Timothée.

As a consequence, Timothée has been ripped out of his family, to be sent directly to an institution (June 2015).

#### Forced hospitalization in a psychiatric unit

When he was entrusted to his father, Timothy went back to the institution (31 August 2015). After three days, the Director of the institution asked the father to present his son to the consultation of the psychiatric hospital in Lyon Vinatier. The decision to intern him was then taken with the agreement of the father, neglecting to seek the agreement of the mother<sup>2</sup>.

His mother tried to visit but they closed the door, claiming that it was not in the interests of Timothée. In this psychiatric unit, against his will and his mother's will:

- he was tied during at least 2 days (shackled to a bed) and had no other choice but urinate on himself,
- he was constrained to absorb massive doses of neuroleptics (Tercian and Rispedal), which is devastating for his psyche, intellectual and cognitive skills and is associated with numerous side effects. He had never taken any neuroleptic before.

His mother and stepfather recovered him after 9 days; he was in the state of a "zombie". The UN has published a few days later a statement condemning the hospitalization.

Given this new element, his mother requested for the revision of the judicial judgement but the Tribunal upheld it (on September 25, 2015).

She then decided to leave France (28 September 2015) with him for Ireland, in order to protect him from a probable re hospitalization.

Four days later, her husband, joined her in Ireland with their daughter (Daria, 10 years).

They all four have the Irish resident status.

His mother was arrested December 17 by the Irish police, pursuant to a European arrest warrant issued by the France.

The legal proceedings to rule on her extradition is ongoing in Ireland.

#### 2. The packing

A child, practically naked, is tightly wrapped in wet sheets that have been refrigerated for one hour. The therapists (4 or 5 for a child) maintain the child for half an hour, and comment on his or her reactions. This treatment is repeated regularly, several times a week. This practice is based upon psychoanalytic concepts and has not been validated on scientific grounds, i.e. there is no evidence based research to support such practices.

Almost all the parent's associations have raised objections against this practice, which remains with the psychoanalytic therapy the only solution proposed in some day care psychiatric hospitals.

The reason is, that many professionals of the psychoanalytic school support packing, and are extremely critical<sup>4</sup> of the HAS, opposed to this treatment.

 $<sup>^{\</sup>rm 2}$  However, this agreement is mandatory required, since the mother also has the parental authority.

<sup>&</sup>lt;sup>3</sup> « <u>Des experts de l'ONU demandent à la France la cessation de l'institutionnalisation d'un enfant autiste dans un hôpital psychiatrique</u> », UN, 17 september 2015

#### Example

Alexandre, 8 years old, was being cared for his autistic problems in a care center (psychoanalytic treatment). His parents, dissatisfied, put him in a medico-social centre where he was then put into a psychiatric day care centre. The psychiatrist in charge right away suggested testing packing on the child but the parents refused again. The care center followed the child's progress in school. After 3 years, Alexandre's challenging behavior in the class managed by the psychiatric centre is noticed, and the child psychiatrist again suggested packing that the parents again refused.

This refusal was interpreted by the psychiatrist as a refusal by the father of a treatment which could benefit his child.

#### 3. The therapeutic puddle

It is a dark room. The ground is uneven with a hollow space containing a paddling pool. The idea is that the child, almost naked, can work on his body image. "For an autistic child, it is not clear that his body has an envelope which contains him, and he is afraid of seeping out through all his orifices"<sup>5</sup>.

The therapists stay in the room and merely watch and interpret gestures and expressions of the child, following psychoanalytic theories.

The parents are not told what kind of a therapy it is, and it is very awkward to imagine, for example, a little girl locked up in a room (the room is actually closed), with 3 adults spending their time watching her "stimming"<sup>6</sup>, or urinating and/or defecating.

There are actually training sessions for professionals wanting to learn how to practice packing or "the therapeutic puddle"<sup>7</sup>. This training is actually financed by the public health organization that employs such professionals.

#### II. Recommendations

#### We recommend:

- that the State stop financing organizations which teach packing and the therapeutic puddle for autistic children and use the funds more judiciously to promote the therapies recommended by the High Health Authority, the scientific results of which are proven;
- to forbid the practice of packing in public establishments, as recently urged by the Committee on the Rights of the Child in its concluding observations on France issued February 4, 2016.
- the implementation of effective monitoring of psychiatric hospitals by regional health agencies (ARS), without informing the staff in advance, and the implementation of coercive measures in case of treatment described above

The non-application of the recommendations of the HAS is a disaster for the autistic children who receive packing and their parents. This decision taken by a scientific authority is against the scientific, clinical and therapeutic reality. (...)

<sup>&</sup>lt;sup>4</sup> <u>Stand</u> following the recommendations of the HAS on the coverages(care) of the autistic children, Pr Delion. (...)The HighHealth Authority (HAS) opposes formally any practice of wet enveloping (packing), even exceptionally, with the exception of the ongoing research.

 $<sup>^{5}</sup>$  "The paddling pool, to contain and to transform the autistic processes", book written by A.M Latour, S. Pinchon

<sup>&</sup>lt;sup>6</sup>Repetition of the same movement in the same way, without apparent aim, sometimes inappropriate, and which can become pervasive