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NGO  
**Alliance Autiste**  
- France –

# COMPLEMENTARY REPORT

## concerning autistic children

to the  
**Committee on the Rights of the Child**  
- United Nations Organization, Geneva -

regarding the  
**Convention on the Rights of the Child**

as part of the  
examination of the fifth French report

**February 25, 2015**

*This non-confidential report is available in its original version in **French**,  
and in a translation made by autistics and parents, in **English**.*

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## 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.

To write the various sections, we have focused on the recurring situations breaching some Articles of the convention using:

- a description of the current situation ;
- the reasons behind the current situation ;
- recommendations based on this assessment.

## The context in France

France has been condemned 5 times by the Council of Europe<sup>1</sup> for neglecting to uphold its educational obligations towards autistic persons, such as defined in the revised European Social Charter (2004, 2007, 2008, 2012, 2014). Following the first condemnation in 2004, evaluation and therapy centres for autistic children, as well as three governmental plans for autism, have been implemented. Government funds were allocated for 2 or 3 years (2005-2007, 2008-2010, 2013-2017), but these funds were widely insufficient.

In 2012, the European Action of the Disabled (AEH) filed complaints against France to the Council of Europe, alleging that France failed to respect the right to education for autistic children and teenagers owing to different treatments in the fields of education and vocational training between autistic persons and persons with other disabilities.

In September 2013, the European Committee of Social Rights<sup>2</sup> condemned France, concluding that « there is a violation of Article 15§1 of the Charter with regard to the right of autistic children and adolescents to be educated primarily in mainstream schools [and] because the work done in medico-social establishments caring for autistic children and adolescents is not predominantly educational in nature. »

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<sup>1</sup> Cf. Autism, France and the Council of Europe, [Autisme France](#).

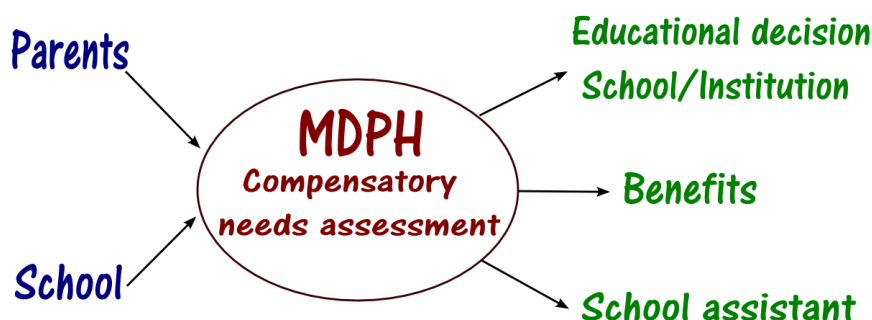
<sup>2</sup> Cf. [Decision](#) rendered by the Council of Europe, September 2013. Complaint No. 81/2012 : the Committee concludes: unanimously, that there is a violation of Article 15§1:

- with regard to the right of autistic children and adolescents to be educated primarily in mainstream schools ;
- with regard to the right of autistic young persons to vocational training;
- because the work done in specialised institutions caring for autistic children and adolescents is not predominantly educational in nature.

In 2012, the French High Health Authority (HAS) issued therapeutic and educational recommendations<sup>3</sup> for autistic children and teenagers, i.e. coordinated interventions based on educational, behavioural and developmental approaches.

The French Equal Opportunity Act 2005<sup>4</sup> guarantees for every child the right to education in a mainstream school, to a compensation of the disability via teaching arrangements, human assistance, and benefits for parents to finance the interventions required for their advancement.

The French School Reorientation Act 2013<sup>5</sup> is deeply focused on the principle of inclusion. Compensations are decided upon by the French Departmental Units for Persons with disabilities (MDPH), a public-interest organization. Decisions are taken depending on children skills assessments, the family's choice, along with the judgement of educational staff and health professionals. The MDPH renders also educational decisions for children, in a mainstream school or a medico-social establishment.



The situation in France is particular, owing to the influence of psychoanalysis among professionals. It results among others things in:

- a misconception of autism among professionals;
- unsuitable treatments based on a psychoanalytical approach towards mental care<sup>6</sup>, along with an often improper use of useless or harmful psychotropic substances;
- delayed or refused diagnoses: the country cannot give reliable figures concerning the number of autistic persons.

Moreover, there are two distinct types of education: normal education for children without disability (school) and the medico-social sector for children with disabilities ("institutions"), restricting the inclusion of autistic children in mainstream schools. Those are mainly guided towards medico-social establishments. Professionals, teachers and establishments show strong resistance, fearing that inclusion (in normal schools) would affect the continuity of their vocational situation.<sup>7</sup>

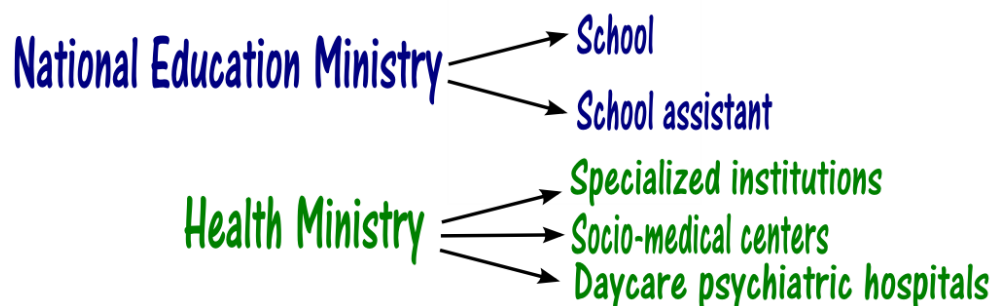
<sup>3</sup> The H.A.S was pressured in to declaring psychoanalytic practices « non-consensual » when it was expected that they be declared « not recommended »

<sup>4</sup> Cf. [Act](#) issued in France on February 11<sup>th</sup> 2005.

<sup>5</sup> Cf. [Act](#) issued on July 9<sup>th</sup> 2013.

<sup>6</sup> This consists in observing the child without interacting with him. This is detrimental to the child because when an autistic child is left to himself, he engages in repetitive behaviours that become invasive and prevents his development (see more details in appendix).

<sup>7</sup> Special needs & education in Europe in 2003 [European Agency for Development in Special Needs Education](#), p. 14: A few countries, like France, consider class sizes in mainstream schools to be a negative factor for inclusion. These countries point out that it is extremely difficult for teachers to include pupils with special needs when they already have a relatively high workload.



## General principles: non-discrimination (art. 2)

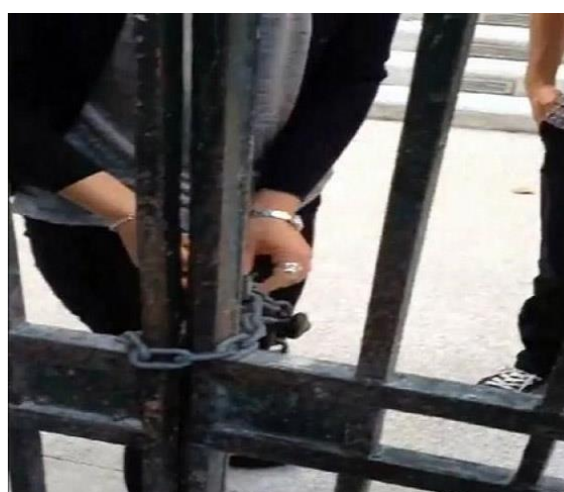
### I- Current situation

In 2012, the AEH asserted in a complaint<sup>8</sup> to the Council of Europe against France “that there was a general discrimination because of the situation of autistic children with regard to education.” Indeed, as some media pointed out<sup>9</sup>, many autistic children are considered ineligible for mainstream education, leisure and sport.

• E.g. Timothée, 15 years old, was to integrate his secondary school for the year 2013-2014, and everything was fine. However, he was physically barred<sup>10</sup> from entering on the first day. Some days later, his mother attempted again to get him into the school: he was accepted but put apart from the other pupils, in an empty room. She definitely removed him from his school to avoid him the pain of rejection.



Mother and step-father: "exclusion = mistreatment"



The Secondary School door locks down before Timothée

### II- The reasons behind the current situation

The grounds for such exclusion are a lack of human assistance in the school and the absence of education of educational staff or moderators about the syndrome. They have crowded classes, do not manage or take the time to elaborate learning objectives adapted to their special needs.

<sup>8</sup> [Complaint](#) of AEH against France, submission of the parties, A-1, p. 30., Complaint No. 81/2012

<sup>9</sup> Autistic children – France condemned for discrimination, article published in [Euronews](#), February 2014.

<sup>10</sup> « Fight against mother of an autistic child and his school », article published in [Le Monde](#), September 2014.

Moreover, because there are medico-social establishments, teachers do not really understand the reason why parents want their child to enter a mainstream school. So they do not feel that they practice discrimination by not letting in such children for their autistic features. In their opinion, such children come within the scope of disabilities, i.e. medico-social establishment.

And yet, autistic persons especially, need to live in an ordinary society to learn social codes to help reduce their social disabilities, which is very difficult when living in isolation, not to mention the feeling of exclusion and inferiority resulting from "institutionalization", while autistic children specifically need to develop their self-esteem.

As a consequence, they are not considered as pupils but children to take care of. At best, they are accepted as the law requires, until parents accept guidance towards a medico-social establishment.

### III- Recommendations

Discriminations result from a misconception of the syndrome: we recommend that all teaching staff be granted relevant training, and more school assistants be assigned to help those children, with a sufficient hourly volume to make sure that they go to school under proper conditions.

## Right not to be subjected to inhuman or degrading treatment (art.37-a)

### *CRC Article 37*

*States Parties shall ensure that :*

*(a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment.*

Inhuman or degrading treatments are being practiced in some psychiatric day care centers (attended by many autistic children) and / or in medical establishments.

Namely: packing and therapeutic puddle

#### I. Description

##### 1. 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>11</sup> of the HAS, opposed to this treatment.

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<sup>11</sup> [Stand](#) 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.

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. (...)

• 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.

2. 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>12</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>13</sup>, or urinating and/or defecating.

There are actually training sessions for professionals wanting to learn how to practice packing<sup>14</sup> or "the therapeutic puddle"<sup>15</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 stop the practice of packing in public establishments (which anyway does not exist in private establishments).

## Family environment and alternative care: separation from parents (art. 9.1)

### *CRC Article 9*

1. *States Parties shall ensure that a **child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.***

<sup>12</sup> "The paddling pool, to contain and to transform the autistic processes", [book](#) written by A.M Latour, S. Pinchon

<sup>13</sup> Repetition of the same movement in the same way, without apparent aim, sometimes inappropriate, and which can become pervasive

<sup>14</sup> [Description](#) of a training course in 2015 on the packing, organized by the national syndicate of the psychomotor therapists. (...)The internship is conceived to be a place in which is going to be able to come true the quiet marriage between theories (explicit and implicit) of the care and the psyche with the effective practice of the not verbal therapeutic relation and the therapeutic wet envelope (...)

<sup>15</sup> [Description](#) of a training course on the therapeutic puddle, organized by the Institute of training SOFOR, 2015

## I- Current situation

Because of the prominence of psychoanalysis<sup>16</sup> among social and socio-medical professionals, many autistic children, considered as "at risk" in their family environment, are placed by the juvenile courts in establishments or foster homes<sup>17</sup>.

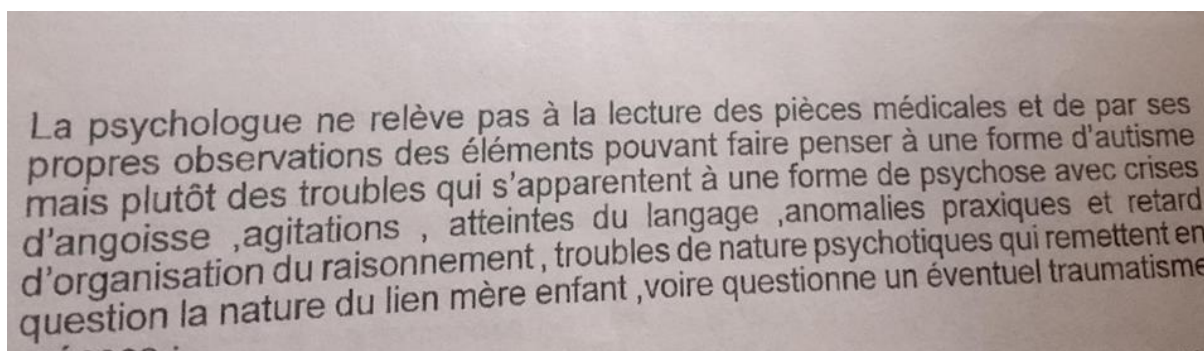
## II- The reasons behind the current situation

In fact, these professionals, considering that autism is a psychosis caused by a poor maternal relationship explain autistic troubles as a consequence of ill-treatment by the mother, who is often seen as too fusional, or suspected of suffering from Münchausen syndrome by proxy<sup>18</sup>. They don't hesitate to question the diagnosis of autism or even to put pressure on the screening center in order not to diagnose such and such a child.

Ideal targets are single mothers with low incomes, therefore vulnerable. If the parents want to change the psychodynamic inspired support (which is carried out in public socio-medical centres) for alternative treatment, they risk being reported by the social services for neglect or because a change in treatment might perturb the child<sup>19</sup>.

### • Example<sup>20</sup>

X is a child who has been diagnosed as autistic and is under the care of a public establishment. His mother wants to withdraw him and arrange for an educational support. The establishment then considered him as "child in danger" in order to place him in an establishment. Following is an excerpt of the report written by a person belonging to the social service, which will be read by the judge.



Translation :

“Upon examination of the medical records, and through her own observations, the psychologist makes no conclusion of any form of autism, but rather of a form of psychosis – with anxiety attacks, agitation, speech defects, dyspraxia, delayed organisational reasoning, and psychotic disorders – which calls into question the very nature of the mother-child relationship or even the possibility of early childhood trauma.”

<sup>16</sup> “France’s autism treatment shame” [BBC](#), 04/2012

<sup>17</sup> “Autism, parents in the pillory”, [L'Express](#), 02/12 (...) Every year families which oppose the methods of certain psychiatrists find themselves in the court with the risk that their child is removed from them (...)

<sup>18</sup> Münchausen syndrome by proxy is a psychological disorder marked by attention-seeking behavior by a caregiver through those who are in their care. The person gains attention by seeking medical help for exaggerated or made-up symptoms of a child in his or her care. As health care providers strive to identify what's causing the child's symptoms, the deliberate actions of the mother or caretaker can often make the symptoms worse.

<sup>19</sup> Proposed [resolution](#) tending to create a commission of inquiry to end the French scandal regarding autism, Mr Fasquelle, Deputy, chairman of the parliament group on autism (...) Over and above the fact that the parents who refuse the placement of their child in a day-care hospital to take care of it at home, incur legal proceedings for neglect and their children are taken away from them by force (...)

<sup>20</sup> “France, on 2014: the mother again and again made responsible for the autism of her child” [L'Express](#).



### III- Recommendations

Abusive placements are the result of obsolete professional training concerning autism, which dates back to the 1970s. This initial and ongoing training is however financed in part by the State. We demand that it no longer be financed and that new training based on advances in neuroscience and other scientific research be installed. We recommend that the juvenile courts take the responsibility of naming a psychiatric expert whose competence on autism is up to date.

## Disability, basic health and welfare

Health services, in particular primary health care (art.3-3, 23 and 24-1)

### **CRC Article 3**

*3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children **shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.***

### **CRC Article 23**

*1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance **and facilitate the child's active participation in the community.***

*2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.*

### **CRC Article 24**

*1. States Parties recognize the right of the child to the enjoyment **of the highest attainable standard of health and to facilities for the treatment** of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.*

## I. Current situation

### 1. Support not adapted to the child's condition

A report by the Economic, Social and Environmental Council<sup>21</sup> in 2012 indicates that diagnosing autism is happening too late: according to this report, waiting lists in screening centres and social inhibition that still exists regarding autism often prevent obtaining a diagnosis before the age of 6, which represents an extremely damaging and irrecoverable loss of time, since early action is essential to improve development prospects.

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<sup>21</sup> [Opinion](#) on the Economic, Social and Environmental Council (CESE), on 2012.P.4 (...) the expectations of families are immense with regard to the shortage of the answers which would now be concretely brought. The diagnosis can be established before 30 months. In reality, it intervenes only rarely before the age of 6 years for lack of availability in screening units. (...)

The chairman of the parliamentary group on autism<sup>22</sup> (Mr. Deputy Fasquelle) stated in 2012 that “associations of parents regularly denounce the complete lack of information that too often exists regarding their children’s care. In total violation of the right “to be informed of their health condition”, a clear diagnosis of an autism spectrum condition is often refused as is appropriate care and therapy”

- Example:

Tristan<sup>23</sup> 2 years old, is being cared for in a medico-psychological center. The center’s child psychiatrist refuses to diagnose him: in her opinion, he suffers from psychological disorders. As years go by, Tristan’s disorders get worse. The child psychiatrist does not answer the mother’s questions, and provides no diagnosis or advice. At last, as Tristan reaches the age of 6, upon his mother’s insistence, the psychiatrist replies: “Your son suffers from pervasive development disorders, however I do not advise you to search on the Internet because you will find this term related to autism, and your son is not autistic. He is psychotic.”

- Blocking points:

Autism plan 3 (2013-2017) includes measures for an early diagnosis, but the government is having difficulties in enforcing these measures.

Indeed, it has assigned the medical-social establishments a key role in the organization. In fact, the staff in such establishments are still guided by outdated psychoanalytical concepts.

They refer to the French psychoanalysis-oriented classification<sup>24</sup>, even though the High Health Authority (HAS) has recommended, in a 2005 publication, best practices for screening and early diagnosis of autism.

However, these recommendations are only guidelines. There are no coercive measures against professionals and public health centres who do not take such recommendations into consideration<sup>25</sup>.

- Consequences of late diagnosis:

Due to late or missing diagnosis, it is difficult to estimate the amount of public funding required to support their needs.

This is a lost opportunity for the child who could have taken advantage of the appropriate therapy, had he been diagnosed early enough.

This however raises several issues: (a) the severe lack of competent freelance professionals<sup>26</sup> and (b) the cost of such therapy, which is underestimated and not sufficiently reimbursed by the organizations in charge of setting the financial allowances (these organizations are the MDPH).

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<sup>22</sup>Proposed [resolution](#) to create a commission of inquiry to end the French scandal regarding autism (...) While the High Health Authority ( HAS) pronounced clearly for intensive support (minimum of 20 hours a week) with the educational and behavioural methods, these treatments remain all too rare and, still are not affordable for all the families, while considerable sums are still granted to professionals who use ineffective methods as well as by psychiatric hospitals where many autistic people are still inappropriately placed. (...)

<sup>23</sup> Sylvie's [testimony](#), mom of Tristan

<sup>24</sup> French [classification](#) of the mental disorders of the child and of the teenager. This classification still uses the term of infantile psychosis

<sup>25</sup> [Report](#) in 2013 about the situation of autism in France, p.10

<sup>26</sup> The shortage of competent professionals is understandable by the fact that a big part of the professionals of public health have an erroneous vision of the autism: as a consequence it is the total desert regarding adapted coverage

## 1. Autonomy and active participation to the community discouraged

The great majority of autistic children are concentrated in psychiatric day care hospitals or in medico-social establishments for disabled children with learning disabilities but without staff specialized in autism: the autism professionals do not apply the approaches recommended by the independent, scientific High Health Authority (HAS).

Some of these children are deported to Belgium, to institutions that the Belgians call “usines à Français”<sup>27</sup>(factories with French). This is being financed by France.

In medico-social establishments, schooling is not very effective: when there is a class-room in the establishment, activities in the classroom often only represent a few hours a week, where all the children are together, without precise educational goals, neither taking into account the level nor the potential nor the specific profile of each child.

Following the study of the class action against France brought by AEH (European Action of the Disabled) in 2012, the European Committee of Social Rights<sup>28</sup> at the Council of Europe unanimously concluded that there is a violation of article 15-1<sup>29</sup> of the Revised European Social Charter “because the work done in medico-social establishments caring for autistic children and adolescents is not predominantly educational in nature.”

In general, parents don't really know what their children are doing in the institution all day long. (The child comes and goes by taxi, hence parents never really have the opportunity to speak with the staff). In addition, evaluations of the children's skill levels and the training objectives are usually very vague.

Their autonomy and participation in the social life of the institutions are in no way supported.

Practically speaking these institutions offer at best some kind of occupational therapy, at worst nothing at all or therapies based upon psychoanalysis (observation without interaction, storytelling workshops, working with clay, therapeutic puddle: a room with a shallow pool and a dry area where therapists observe the child at play, and packing: where the children are bound in tight, cold wet cloths which are allowed to dry and shrink).

As a consequence, an autistic child will have practically no opportunity to make progress and to acquire autonomy (without stimulation, the child will learn nothing). While growing up, behaviour problems will increase as he will not have learned how to communicate. This often leads to excessive use of psychotropics (in particular neuroleptics) used as chemical strait jackets to control behaviour problems, which a psycho-educational approach would have avoided or at least limited their aggravation.

As the National Ethics Advisory Committee for Health (CCNE) observed, all this constitutes abuse by neglect<sup>30</sup>.

## II- The reasons behind the current situation

### 1. Lack of control by State authorities, no transparency in financing

In theory, medico social establishments and centres are regularly assessed<sup>31</sup> every 7 years and the State's Regional Health Agency (ARS) should control day care hospitals.

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<sup>27</sup> “Handicap: more and more factories with French along the border” RTBF, in January 2014

<sup>28</sup> Decision of Council of Europe, 2013, page 34

<sup>29</sup> (...)the Parties undertake, in particular : to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private

<sup>30</sup> Avis 102 of CCNE, 2007, (...)The absence of early diagnosis, access to the education, socialization, and adapted premature coverage thus leads, in this grave handicap, to a loss of luck for the child who constitutes a "ill-treatment" by default (...)

<sup>31</sup> ANESM national agency of the evaluation and the quality of establishments and medical and social services(departments)

In reality there is almost no State control of these establishments and hospitals. Budgets are renewed year after year without reporting: article 3.3 of the Children's rights convention is not respected.

Financing care in hospitals isn't based upon specific medical acts. If a child comes in for a 30 minute psychotherapy session, the hospital charges the Health Service for a full day i.e. 900 €, which entails abuses by professionals for whom autistic children are a great income source with little effort.

When a child is present in a medico-social establishment in the morning up to and including lunchtime, the Health Service (Social Security) pay the price for a full day that is on average 300 €, encouraging a vested interest among management staff centred upon how much each child contributes rather than upon the children's well-being and development.

The projects for medico-social establishments are often promoted by large organizations which manage many institutions, and who are experts in the art of preparing projects which at least on paper correspond to the expectations of the financing authorities.

But in practice the project on the ground will not respect the recommendations of the High Health Authority (HAS) concerning autism.

These large organizations usually care for the mentally handicapped, and autism is different from mental handicap. In France, we continue to not fully comprehend the autistic disability, public services keep assimilating autism with mental handicap or poly-handicap.

## 2. Consequences

A report from the commission of General Welfare Inspectorate (IGAS) realised on the abuse of persons with disabilities in institutions, supports the view that this way of passing financial interests before children's interests constitutes a form of child abuse<sup>32</sup>.

In institutions, even if some of the specialist teachers are trained in the techniques recommended by the High Health Authority (HAS), they have to face the opposition of the institution's director to apply them: indeed all that requires much investment with rigor and determination. Since nobody expects anything from these children and the budget will be renewed year after year, the director has no interest in making things evolve.

In view of this alarming situation and the lack of adapted centres, some dozens of associations of parents of children in medico-social establishments have themselves created some educational centres which are following the National Health Authority's (HAS) recommendations of good practice in order to allow their children to make progress and to flourish. But these centres don't receive state funding, which makes the whole thing inconsistent and absurd.

For example, the parents' association « Autisme besoin d'apprendre <sup>33</sup>» (Autism - the need to learn) has created an educational centre managed and financed by parents, that is organising and financing in-service professional training. In this centre children are welcomed in the afternoons. They spend the mornings and lunchtime in a public medico-social establishment.

This public medico-social establishment is state financed and receives the full day care allowance even though the child is only there for the morning and lunchtime and the activities they offer are more like « babysitting » without any possibility for the child to make progress.

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<sup>32</sup> "Ill-treatment to the disabled people, to break the code of silence", [report](#) of General Welfare Inspectorate (IGAS), on 2003 The commission of inquiry considers that (...) the fact that establishments made cross their financial interests before the interest of the adult or the child constitutes a kind of ill-treatment (...)

<sup>33</sup> [Autisme besoin d'apprendre](#) association

The private educational centre receives no state funding although it is the educational strategies applied in that centre that allow the child to make progress.

### III- Recommendations

As we have already stressed, the initial training as well as in-service training of childhood professionals in the medical, socio medical and social as well as the psychiatric domains are still largely influenced by psychoanalysis<sup>34</sup>.

We recommend:

- that these professionals receive training adapted to autism with up to date knowledge, enabling them to interact with a fragile and vulnerable group of children with specific needs ;
- that professional training with content that does not meet the High Health Authority (HAS) recommendations on the training of health professionals should not be considered as "in-service training" (label allowing state financing of such training);
- that the Government take enforcement measures on universities which continue teaching methods which do not conform to current knowledge about autism;
- that France follow precisely the common European guidelines<sup>35</sup> towards a progressive de-institutionalisation in order to eliminate segregation, which is possible since Italy, among others, has done this in 1977 in less than one year<sup>36</sup>;
- that currently existing establishments are effectively and regularly controlled by external organisms in order to see on the ground if the type of support is in conformity with recommendations of good practice. We demand that institutions' accreditation be withdrawn when the institution doesn't promote the autonomy and personal development of these children;
- that day care psychiatric hospitals follow a tariff system based upon medical acts and not a daily charge as is currently the case, as this makes it impossible for the Health Service (SS) to control anything. There is a total lack of transparency on the use made by the hospital of the money received from the Health Service. Yet this adds up to billions of Euros<sup>37</sup>, which could be used to help autistic children to live outside these medical detention centres for example, and for funding improved school facilities etc. ;
- that diagnostic centers are independent of local hospitals, where psychoanalytic influence is excessive<sup>38</sup> ;
- to develop structures that meet best practice recommendations, to replace the institutions in which children have no opportunity to progress.

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<sup>34</sup> The financing of the full-time training offered by educational establishments to be recognised and taken into account by the State even though the content of this training is essentially a psychoanalytic approach (see the [blacklist](#) of training courses offered in 2012)

<sup>35</sup> Common European [Guideline](#) on the Transition from Institutional to Community-based Care, 2012.

<sup>36</sup> [Italian policies for inclusive education](#), 2014

<sup>37</sup> The president of the parliamentary group about autism made in 2012 a budgetary projection allowing to consider about 13 billion euros the potentially practicable total savings on the total life expectancy of 8000 autistic children being born every year in case of refund of 25 hours(13 pm) weeklies of support adapted during 16 years (from 2 to 18 years)

<sup>38</sup> As an example, the Rhones Alpes regional diagnosis [centre](#) has publicly announced its acquisition of publications with a psycho-analytical view of autism dating from the 1970s

## Social security and facilities (arts. 26-2 and 18-3)

### **CRC Article 23**

*3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development*

### **CRC Article 26**

*2. The benefits should, where appropriate, be granted, taking into account the resources and the circumstances of the child and persons having responsibility for the maintenance of the child, as well as any other consideration relevant to an application for benefits made by or on behalf of the child.*

#### **I- Current situation**

Parents who opt for private care of their child are entitled to receive financial support from the State, the amount of which depends on the child's needs and on the parent's reduction or cessation of professional activity needed to care for the child.

The formal procedure requires parents to submit a request to the departmental unit for persons with Disabilities (MDPH), which examines their case and decides on the level of support.

However it takes the MDPH an average of six months<sup>39</sup> before replying. Furthermore, the amount of support, determined by current rules, is generally set at a level that is largely below what should be allocated to cover actual needs, which is illegal.

As they are not informed about their rights, most parents accept this abnormal situation without questioning it. The most knowledgeable parents appeal the decision, but it takes several months before the appeal is judged delaying that much more the whole process during which the parents receive no financial aid.

Often, the mother has no other option than to quit her job (in order to organize the private care appointments and take care of her child who is only integrated in school for a few hours of schooling per week, if at all). However, the financial support she gets for her child does not take into account the fact that she no longer earns a living.

Facing such a situation, families borrow money which they have difficulty reimbursing, rather than accept an inappropriate institutionalisation that the government offers, sliding gradually into poverty<sup>40</sup>. Parents with reduced financial means of existence and who wish to put in place a private care solution have to renounce this project.

The only choice left to them is to put their child in a public institution, which most often lacks the competency to help autistic children. Financial assistance and other support are attributed for a period of one to two years. Almost each year, parents have to go through the whole formal request process again and fill out the whole set of administrative documents.

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<sup>39</sup> (...)Among the criticisms sent by NGO's on the operations of the MDPH include in particular inadequate assessment tools for the needs of the disabled and important delays in the treatment of files.(..) [Report](#) of Nils Muiznieck, commissioner for Human Rights, 17 february 2015, comDH(2015)1, p.46, 227

<sup>40</sup> (...)The total income of a family with an Autistic child is on average 28% less than that of a family with healthy children (...) Mr. Deputy [Fasquelle](#), may 2012

This is a heavy bureaucratic burden and it takes again six months for MDPH to reply to the request for renewal of support. Many families find it practically impossible to prepare these complicated applications and social workers are at a loss to help them as they feel themselves quite powerless and out of their depth in front of this heavy bureaucratic machinery.

## II- The reasons behind the current situation

The administrative burden is so enormous that many families are incapable of making their application. It is an obstacle course that does not motivate parents to apply for this financial support to which they are legally entitled or renounce filing an appeal when the financial support granted by MDPH is blatantly insufficient to cover their child's needs.

One should note that the level of financial support is determined by MDPH staff members, who evaluate the needs using rules listed in an evaluation guide, but who have a marked tendency to grossly under-estimate the child's needs, leading to highly insufficient financial aid proposals.

It must also be noted that there is usually a complete lack of knowledge about autism among the members of the MDPH committees who take the final decisions. Indeed, the only members who could be concerned about autism among such committees are representatives of associations of parents with disabled children; unfortunately, most of them know very little about autism.

The result is that these committees make decisions about the autistic child's future without the presence of a single autism specialist.

Each case, judged on the basis of papers contained in the file, is processed in only five minutes.

Generally, this is done in the absence of the parents, although they have the right to attend the meeting. However, parents are rarely informed about this right, and do not know when the meeting will take place.

The financial benefits which are aimed at covering the needs, in terms of human and material assistance, are only attributed to help with the person's physical autonomy. The cost of putting in place private care using educational and behavioural methods is generally not covered, as they do not correspond to the official criteria.

Furthermore, many MDPH (there is one per French department) reject methods for the management of autism which are not based on psychoanalysis. Often, they refuse to grant financial assistance when the parents wish to put in place an educational approach.

For instance, the president of MDPH Isère (a French department) does not hesitate to publicly express her indignation<sup>41</sup> about the recent recommendations of the High Health Authority (HAS) which endorse behavioural approaches and disavow psychoanalytic methods in the management of autism.

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<sup>41</sup> "The point of view of Madam Gisèle Perez, President of the MDPH - Isère " [La main à l'oreille](#) association

### III- Recommendations

We recommend:

- that the State develops the training of staff working in the MDPH;
- more visibility and clarity on the rights of families in relation to services and benefits, for example with publicity campaigns;
- that the application processing time (4 months maximum) be respected;
- that the benefit to compensation for their disability should equally be attributed to compensate for the educational and psycho-educational needs of autistic children and not only for their physical autonomy.

## Education, leisure and cultural activities

Right to education (art.28-1)

### **CRC Article 28**

*1. States Parties recognize the **right of the child to education**, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular :*

*(a) Make primary education **compulsory and available free to all** ;*

*(b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;*

*(c) Make higher education accessible to all on the basis of capacity by every appropriate means;*

*(d) Make educational and vocational information and guidance available and accessible to all children;*

*(e) Take measures to **encourage regular attendance at schools and the reduction of drop-out rates.***

### I- Current situation

On paper, the 2005 French Equal Opportunity Act for persons with disabilities meets the requirements of Article 28. However, in reality, this law is almost never applied.

In 2012, in the legal action against France filed with the Council of Europe, the association *Action européenne des handicapés*, (European Action of the Disabled, AEH) stated that France did not grant autistic children and adolescents the possibility to have a regular school education.

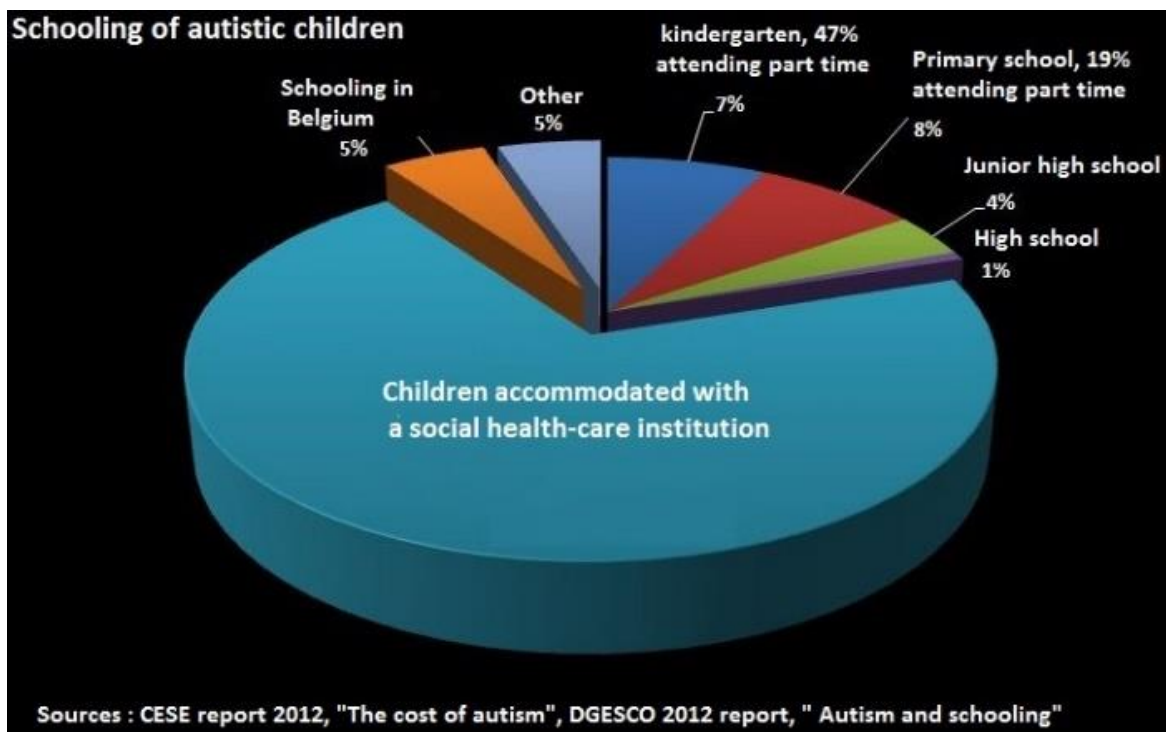
Upon examination of the merits of the legal action, the European Committee of Social Rights<sup>42</sup> unanimously agreed that there was “a violation of Article 15§1 of the European Charter with regard to the right of autistic children and adolescents to be educated preferably in mainstream schools.”

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<sup>42</sup> [Decision](#) of council of Europe, 2013, p. 34. Complaint No. 81/2012



The following graph shows the distribution of autistic children by type of education in 2011-2012:



The French National Education Ministry indicates that 20 375<sup>43</sup> autistic children have access to mainstream school education, either on a full time or part time basis. This corresponds to less than 30%<sup>44</sup> of the total population of autistic children.

This school education is delivered in either ordinary classes or in specialized classes where children with mental disabilities are grouped together with autistic children.

Furthermore, the number of autistic children attending school diminishes when the level of education increases: in 2012, 47% of autistic children attending school were in pre-schools and kindergarten, against 19% in primary school, 4% in junior school (lower secondary) and only 1% in high school (upper secondary)<sup>45</sup>.

When considering the above statistics, one must bear in mind that school education provided to autistic children is mostly ineffective: often autistic children are simply *registered* as attending a school in order to meet the legal obligation of school attendance by disabled pupils, but in reality the child is not actually welcome to attend classes, or is forcibly home-schooled, but nonetheless counted in the school statistics.

<sup>43</sup> [Opinion](#) on the Economic, Social and Environmental Council (CESE), on 2012 p.4

<sup>44</sup> These figures do not really reflect the reality, because of the absence or the delay of diagnosis, it is impossible to know the number of autistic children, who is estimated in France at 100 000, on the basis of the prevalence rate of the autism of 1/150

<sup>45</sup> [Survey](#) of the head office of the school education, on 2012

Furthermore, these statistics do not take into account the time autistic children actually spend at school. For instance, 47% of autistic children attend preschools and kindergarten on a part time basis, even on a very reduced part time, such as 3 hours per week. This figure is 19% for primary schools.

Where they exist, special education classes (12 pupils per class) are *ghettoised* within the school and offer virtually no opportunity for integration with ordinary classes. In general there is a specialised teacher, who is most often not trained to deal with autistic children, and an educational assistant for the entire class, while many autistic children require one-on-one assistance.

To cater for their special needs, autistic pupils can have a school assistant if their parents submit a request to MDPH. However, there are too few assistants to accommodate the needs of all autistic children and they are available only a few hours per week, so even if the MDPH agrees to grant this need, very often it is not followed through in fact.

Finally, due to the lack of capacity in medico-social establishments and to the State's inability to create and finance specialised classes, France is left with a paradoxical solution: to finance the education of French autistic children in *Belgian* schools, which have specialised classes led by professional educators who are trained in the management of autism.

## II- The reasons behind the current situation

### 1. Abusive institutional placement decisions

Today's adults grew up without being in contact with persons who were different from them; so they feel frightened when they meet one, because of a lack of knowledge, and think it is normal that these persons (children and adults) are concentrated in medico-social establishments, which is mostly the case today. They are unaware of the system of segregation maintained by the State. It seems natural that someone "different" has to live apart (leave society to live in an institution), instead of changing the society to encourage the inclusion of all, each one with their own particularities<sup>46</sup>.

The State does not assume its responsibilities towards these persons who are different and has left the parents' associations to themselves create and manage these medico-social establishments. They filled a void<sup>47</sup>.

The children of those parents who are managers of institutions are today autistic adults and there is a generational conflict between these parents (for whom the notion of integration didn't even exist at that time) and parents of younger children, who want mainstream schooling and refuse specialised institutions.

At present the establishments are managed by the federations of associations of parents of handicapped children (mentally handicapped and autistics), which are firmly in place and well established. There is a whole economy in the disability sector behind the establishment and management of such institutions. The federations continually seek to fill them in a cost effective way and to develop other establishments. As mentioned earlier, they could be influenced by the fact that there is little or no state control: the Health Care finances them without adequate accountability, and nobody knows how it is actually used.

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<sup>46</sup> Thus the children of this generation grow up without having the opportunity to interact with their special needs peers. They will grow into adults who fear people with disabilities, or who simply ignore their existence. They will educate tomorrow's French society, a society where people with differences will still not be accepted.

<sup>47</sup> "Ill-treatment for the disabled persons: breaking the code of silence" : [report](#) of a commission of enquiry n° 339 (2002-2003) made by MM. Jean-Marc JUILHARD et Paul BLANC, in 2003. This commission of inquiry considers that the fact that establishments are prioritizing their financial interests before the interest of the adult or the child establishes a kind of ill-treatment.

- Example:

In 2013, a medico-social establishment managed by ARISSE<sup>48</sup>, a big association which manages establishments and medico-social centres, organised a conference on autism. They put up some posters in nearby schools for the teachers. In the association description, we read that its purpose is to support children with intellectual and/or psychic dysfunctions, with somatic and/or psychic causes.

Here is what an autistic child's mother reports from this conference:

*"I was deeply shocked by the views expressed by this man about our autistic children. He began with an introduction in which he called autistic persons 'bizarre'. He said that when frustrated, autistics demonstrate aggressive behaviour, directed at themselves and others. Therefore an autistic person has no place, neither in ordinary life nor in world of work. In the room, there were very few parents, but many professionals: family doctors, speech and language pathologists, school directors, primary school teachers, and elected officials. To a grandfather who questions the future of his 11-year-old grandson in ordinary life, one of the brightest pupils in his class, who says at each crisis that he wants to kill himself, he replied, « But, sir, your grandson cannot be autistic, autistic persons cannot consider suicide ». Speaking of sexuality among adolescents and young adults in his institution, who must masturbate violently as long as they do not reach ejaculation. He said and I quote, "Unfortunately, the law prohibits that I masturbate the patient, but authorizes parents to do it.""*

Some representatives of these associations are on the commission of the Departmental Units for the Disabled (MDPH) that makes placement decisions for disabled and handicapped children. They are judge and interested party, and they must reconcile the interests of the children and their own interests as establishment managers.

These representatives make their choices (they "do their market") in the commission, deciding to place this or that child in one of their medico-social establishments.

That's why a large number of autistic children are guided towards medico-social establishments instead of staying in regular schooling.

Moreover, even if all decisions are supposed to be made with the agreement of the family, in practice the commission often decides alone, without consulting the parents and this decision is almost always a placement in a medical-social establishment even if there is no place in the said establishment<sup>49</sup>.

- Example<sup>50</sup>

A mother of a boy, who was previously educated in secondary school, asked the Departmental Service for the Disabled (MDPH) to renew the contract for her son's school assistant for the 2014-2015 school year. The commission decided to place him in a medical-social establishment, saying that that her son will not need a school assistant, because he will be placed in an establishment.

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<sup>48</sup> The [ARISSE](#) association manages 37 establishments (institutions, medical and social centers, daycare psychiatric hospitals).

<sup>49</sup> Even if there is no place in establishment, this decision is an argument for the ordinary school to refuse the child who, therefore, does not benefit any more from any schooling, and, often, stays at home.

<sup>50</sup> "The alliance justice-MDPH-Inspection to exclude Tim, autistic, of the ordinary environment", [L'Express](#), October, 2014

## 1. The lack of school assistants

When parents request a school assistant for their child, the Departmental Unit for the Disabled (MDPH) decides on the request, approving or not a school assistant. The Ministry of National Education is then responsible for recruiting this assistant.

Since the commission of the Departmental Unit for the Disabled (MDPH) tends to place children in establishments, it generally approves only a few hours of school assistance per week.

Furthermore, even when the Departmental Unit for the Disabled (MDPH) notifies hours of school assistance, the Ministry of National Education is having a difficult time recruiting school assistants, so even though a child is eligible for assistance, there is no-one to help them.

However schools allow an autistic child to attend school on condition that they are accompanied by a school assistant. The low number of hours approved by the Departmental Units for the Disabled (MDPH), combined with the difficulty in recruiting assistants, leads to discrimination against autistic children.

These assistants are not trained in autism, and have a very precarious employment status<sup>51</sup>. For example, their contract can end during the school year, and the child, without an assistant, will be removed from school before the end of the school year<sup>52</sup>.

When a family wants to contest the departmental unit for the disabled's (MDPH) decision about the hours of assistance or the non-attribution of the assistant by the national education ministry, they have to lodge an appeal. Unfortunately, because of the significant delays, this appeal is rendered *de facto* ineffective: indeed, even when the appeal has been accepted, the court's decision will not become effective until the next school year... So the child will not have a school assistant because the appeal takes too long: this constitutes a violation of the fundamental right to education and school enrolment.

## 2. The pressures from school

Another reason for this creeping de-schooling (of autistic children) is that the Ministry of National Education, despite the French School Reorientation Act<sup>53</sup> to promote an inclusive school, does nothing to encourage inclusion. This Ministry was the most notable absentee when recommended best professional practices about autism were being developed. Consequently, the emphasis is not upon mainstream schooling.

Teachers are not trained for this, and the educational program for ordinary children is already overburdened. Moreover, because they didn't grow up in an inclusive society, they consider that the place of these children is in medico-social establishments.

Furthermore, the teachers who wish to get involved personally don't receive recognition from their hierarchy for the efforts they could make to improve schooling for the autistic pupil. Actually, the opposite is true, for school hierarchies generally favour their orientation in a «specialised environment» (i.e. in an "institution" ("Institut Médico-Social", medico-social establishment), i.e. one that doesn't depend on the Ministry of National Education. The relationship between mainstream and special education has historically been compartmentalised. Inclusion is often perceived by the both sides as a threat on the professional front: fear of job losses in special education, fear of

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<sup>51</sup> Situation of the supports of the pupils in situation of handicap, [oral question](#) N 1004S of Mrs Nicole Bricq to the Senate, in February 05th, 2015 "Hired with temporary employment contracts, educational assistants are paid at minimum wage and face a particularly precarious situation. There are 28 000 such jobs in France, and the precariousness of their contracts has a direct adverse effects on the care and integration of handicapped children, as these assistants may end their contracts during the school year."

<sup>52</sup> "The absurd eviction of a special needs assistant of Montpellier", [Midi-Libre](#) newspaper on 2014

<sup>53</sup> Cf. [Act](#) issued on July 9th 2013.

losing their points of reference by mainstream teachers. Indeed, a common argument to justify denying them schooling is « I am not a specialist teacher », implying that their enrollment in school requires a special needs teacher.

The psychologists and school doctors who participate in the meetings aimed to relay their needs to the departmental units for the disabled (MDPH) are often trained in psychoanalysis (which considers the mother responsible for her child's autism), so they usually support a decision to place these children in a psychiatric day-care hospital unit or local specialised institution.

Reports written during these meetings frequently highlight only the negative aspects of school enrolment, omitting the positive aspects. These reports are then sent to the departmental units for the disabled (MDPH) that takes its decisions on the basis of this simplistic and partial report.

- Example:<sup>54</sup>

X., 5-year-old, is suspected of having Asperger's Syndrome (a form of autism). He is in nursery school, with a private follow up. The referent teacher (coordinating between school and MDPH) pressures the mother to accept a placement in a psychiatric hospital day-care unit. The referent sends to the MDPH doctor a report in which she affirms that the private care is not good.

During meetings in school, school doctor, psychologist, teacher and referent insist that the mother should accept partial hospitalisation for her son. In her report, the referent does not mention any positive aspects, and suggests that the child assaults other children (which is not true).

### 3. An evaluation guide inappropriate for autistic children

The Departmental Units for the Disabled (MDPH) decisions are based, among other criteria, on an evaluation guide<sup>55</sup> which records observations about the students in school, to understand their needs. This guide is mandatory, and must be completed by the teacher.

However, this guide is not adapted to the nature of autism: one can choose to check the “mental health disabilities” box (often checked by the teacher), or to check the “cognitive or intellectual disabilities” box.

Checking boxes is not enough, and this guide leaves no room for detailed, useful information for the MDPH. Parents are left out, they are usually not consulted when the guide is completed. Once it is completed by the teacher, there is only a little box left to give their point of view and make proposals.

Moreover, this guide is not in accordance with the principle of an inclusive school: boxes have to be checked by reference to an ordinary child of similar age. The reference to the standard is a problem because there is a risk of indicating a deviation from the norm, and to the conclusion that the child should no longer be in ordinary school.

## III- Recommendations

We recommend:

- that the 2013 education law, which was founded on the principle of inclusive schools (adaptation of the school to the child's needs), be applied in concrete measures: all teaching staff should be trained in inclusion

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<sup>54</sup> "Handicap: when the Department of Education does not respect the choice of the parents", [L'Express](#), on 2013

<sup>55</sup> Geva-Sco, [guides](#) of evaluation and decision-making support in the MDPH

and inclusive education in order to promote inclusion and awareness that it is beneficial for the child, for themselves and for other students ;

- the end of the segregation between special education and “regular” education;
- a contribution of human and material resources (specialized teachers available in the school, specific educational materials available for all schools ...);
- that teachers be encouraged and recognized by their superiors concerning the inclusion of an autistic student in their class ;
- an up-to-date training related to autism for school psychologists and doctors;
- an up-to-date training related autism for persons working for regional authority responsible for funding special needs (Departmental Units for Persons with Disabilities, MDPH) ;
- adequate teacher training on the specifics of autism and educational strategies which can be implemented ;
- an improvement of the professional status of school assistants, as well as specific training on autism for these professionals ;
- an increase in the number of hours of school assistance allocated during school time ;
- an increase in the number of places available within SESSADs ("special education and home care services" involved in school to support teachers and suggest adjustments). The number of places announced by the Autism Plan 3 (850 places) is clearly insufficient;
- that the action brought by parents to dispute the non-attribution of school assistants be treated quickly and effectively, and followed through in action;
- that parents be informed of their rights. This can be done for example through practical training on disability laws, or sessions on how to fill in the complicated forms of the local authorities (MDPH) to request services and funding;
- that the assessment tools used to determine the child's needs be adapted for the disability of autism, and that they be based on the child's competencies in order to better tailor an individual education plan to help the child progress.

## Aims of education with reference also to quality of education (art. 29)

### ***CRC Article 29***

*1. States Parties agree that the education of the child shall be directed to:*

*(a) The development of the child's personality, talents and **mental and physical abilities to their fullest potential** ;*

#### **I- Current situation**

An autistic student who is in school for a few hours a week is penalized compared to an ordinary student, thus adding to a further handicap to his autistic disability.

There is no systematic inclusive education for autistic students, and inclusion remains the exception rather than the rule in France. Yet, inclusion has been proven to be the most effective answer to this handicap because autism is primarily a communications disability. Thus, the development delay in communications skills can gradually diminish only by maximizing interactions and exchanges with children without such disabilities. The efficiency of inclusion is evidenced by several scientific studies when comparing current approaches to autistic disabilities<sup>56</sup>.

Yet, in France, most autistic children are “schooled” in medical establishments known as day-hospital units, where the autistic child is most of the time simply “kept an eye on”. In these units, no one keeps the child from self-

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<sup>56</sup> « [A review of the quality of behaviorally-based intervention research to improve social interaction skills of children with ASD in inclusive settings](#) », Camargo SP, 2014.

stimulating and no means of communication is taught to these children, nor are they given the opportunity to interact with non-handicapped children.

These children then develop behavioral problems which are mainly caused by an inability to communicate, aggravated by their isolation. These disorders are often handled with neuroleptic drugs, rather than behavioural therapy.

This situation hinders their emotional growth, and damages the development of their physical and mental abilities.

## **II- Recommendations**

Inclusion is an important tool against the development of secondary handicaps, particularly psychological problems worsened by segregated education and lack of peer interaction with ordinary children.

We recommend that school assistants be named not only to work in the classroom, but also to facilitate interaction during mealtime and extra-curricular activities.

### Rest, play, leisure, recreation and cultural and artistic activities (art. 31)

#### ***CRC Article 31***

*1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.*

*2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.*

## **I- Current Situation**

Several cases of discrimination exist, mainly because adequate personnel are not available to accompany the child, a requirement of certain municipal activity centres. However, this excuse is not valid according to the law.

### • Example<sup>57</sup>

An autistic child was active in his local activity centre from 2007 to 2010. In 2010, the parents were informed that the child would no longer be allowed to attend this centre because the personnel were unqualified to deal with the disabled. The parents appealed and won their case.

Concerning after-school activities, autistic students are often excluded for the same reasons as given by the municipal activity centres. When a school assistant is named by the Departmental Centre for Persons with Disabilities (MDPH), the hours are currently only allotted for class time.

## **I- The reasons behind the current situation**

French society is not inclusive towards handicapped individuals. Autistic children have been concentrated in medical establishments, and municipal activity centres do not often welcome them or do anything to prepare for inclusion. Generally, these centres are convinced that autistic children need special education professionals in order to be included, which is not true most of the time. They therefore put up barriers themselves, which are mainly due to their misconceptions of autism.

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<sup>57</sup> « [Sport, handicaps et discriminations](#) », Ministry of sports and youth, p. 2

It is easier for these centres to justify their refusal to the parents by claiming a lack of qualified personnel rather than doing the necessary to ensure that the child can be welcomed under good conditions. The families, already quite fragile from the battles they face, often accept this refusal without a fight.

In general, parents are not sufficiently informed of their rights, and often don't realize that they are facing a situation of discrimination. It is necessary that they fight for their rights and the rights of their child.

With regard to after-school activities at school, these periods are organised and staffed by the municipal activity centre personnel, but take place at school. However, these personnel are not invited to the Educational Team meetings (Individual Education Plan meetings, composed of school officials, teachers, health professionals and parents) where the objective is to identify, evaluate and agree to the child's needs, which are then transmitted to the regional authority (MDPH) for funding.

Consequently, the child's needs for the after-school periods are not included in the request to the MDPH, and the allocations of education assistance hours allocated do not include these needs.

## II- Recommendations

We recommend:

- that municipal activity centre personnel be included in the Educational Team meeting, and that these meetings include an evaluation of the child's needs for extra-curricular activities and communicated to the regional authority (MDPH) for funding;
- that disability awareness programmes be organised within municipal activity centres and information sessions on the human, financial and material means which can be put in place to promote integration.

## Conclusion

205 million Euros over 4 years (2013 – 2017) have been allocated to the third Autism Plan. That is clearly inadequate in view of the number of autistic persons in France, which is estimated to 600,000. In reality, the budget should be at least 1 billion Euros.

But the problem is not the lack of money. Indeed, billions of euros are wasted now by specialized institutions and psychiatric hospitals, in a complete opacity on what this public money is spent on.

Health professionals, medico-social structures and psychiatric day hospitals' administrators openly reject recommended best professional practices published by High Health Authority (HAS), because those recommendations disavow psychoanalysis. They got themselves organized publicly and legally<sup>58</sup> for the withdrawal of these guidelines. They have a very strong influence and lots of power over agencies that fund institutions and over policy makers.

The chairman of the Autism Studies Parliamentary Group (Mr. Deputy Fasquelle) made in 2012 a budget projection that estimated the potential cost saving around 13 billion Euros, over the total lifetime of the 8,000 autistic children born each year, if the 25 hours of adapted assistance per week for 16 years (from 2 to 18 year old)<sup>59</sup> were reimbursed.

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<sup>58</sup> « Autism : Council of state is saying no to psychoanalysts », [Vivre FM](#), décembre 2014.

<sup>59</sup> “ How to improve caring of autistic persons ”, [Le Parisien](#), octobre 2012



The Government must stop subsidising erroneous content training, and has to put in place significant number of training leading to a diploma, responding to the recommended best professional practices published by High Health Authority (HAS).

In 2010, the Council of Europe published a recommendation supporting de-institutionalisation<sup>60</sup>. France assisted the European Expert Group in the publication of European guidelines<sup>61</sup> to establish a transition from institutional to community-based care (2012). But in fact the government doesn't follow these guidelines.

The 67th WHO World Health Assembly<sup>62</sup> (WHA), in May 2014, urged Member States, including France, "to shift systematically the focus of care away from long-stay health facilities towards community-based, non-residential services."

Nowadays, all countries agree that autistic children have to be included in society. Such an inclusion implies a major social change, for which France is not yet ready.

Autism Plans and law on inclusive schooling can't achieve change : only material and human resources can help to really apply the law. This probably begins by raising awareness about inclusion in education sector and recreation centres.

It is necessary to reallocate funds captured by psychiatry, in order to concretely put in place inclusive education of autistic children.

But first of all, France needs to recognize the existence of a special type of disability specific to autism, which is not the case. Autism doesn't appear in the Guide for Persons with Disabilities, for use by the public services. Autism doesn't appear in evaluation grids used by French Departmental Units for Persons with disabilities' unit (MDPH) to cover their needs. Autism doesn't appear in the National Education nomenclature<sup>63</sup>. For a person with autism, a choice must be made between cognitive and psychic disability, or multiple disabilities.

This "oversight" is highly revealing about the way the country treats autistic persons: burying its head in the sand.

## General recommendations

### We recommend :

- Government should stop funding training institutions providing courses which content does not conform to High Health Authority (HAS) guidelines. Government should use those credits more efficiently to promote recommended and scientifically evidence-based best practices. This can be done if this vocational training is no longer considered as in-service training (DPC), whose financing is assumed by the employing organization.
- Healthcare professionals and social workers should have specialized training relating to autism, with up-to-date knowledge, so they get ready to interact with a fragile and vulnerable public, with special needs.
- Coercive measures should be taken by the Government against the universities that provide training courses that are not in compliance with the current state of knowledge on autism.
- Government should develop autism training for staff in French Departmental Units for Persons with Disabilities (MDPH).

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<sup>60</sup> [Recommendation](#) CM/Rec(2010)2 of the European Council Committee of Ministers to member states on deinstitutionalisation

<sup>61</sup> Common European [Guideline](#) on the Transition from Institutional to Community-based Care, 2012.

<sup>62</sup> [WHA67.8](#), 24 may 2014

<sup>63</sup> « [Autisme, overview 2014](#) », Autism France Association

- Parents should be better informed about their rights, for example by offering them training about rights of persons with disabilities, or about how to complete an application file to the French Departmental Units for Persons with Disabilities (MDPH).
- French Departmental Units for Persons with Disabilities (MDPH) should respect the time limit for processing applications (maximum 4 months).
- Compensatory disability benefit (PCH) should be allocated not only to support autistic children independence but also to ensure educational and psycho-educational needs.
- Parents appeals when school assistant (AVS) is not assigned should be promptly dealt with and acted upon.
- Needs assessment criteria should be adapted to autism, and should be competency-based to allow the child progression.
- Magistrates should have to appoint an expert psychiatrist with up-to-date knowledge about autism.
- France should concretely follow European guidelines<sup>64</sup> for the purpose of progressive de-institutionalisation, in order to stop segregation.
- Existing establishments should be really and regularly controlled by external bodies, to check whether the type of support is consistent with recommended best professional practices.
- Pricing in day psychiatric hospital units should be related to acts instead of being a daily rate.
- Screening centres should be independent of local hospitals, where psychoanalysis influence is powerful.
- Structures applying recommended best professional practices should be developed to replace establishments where the children do not have the possibility to progress.
- 2013 French School Reorientation Act, based on inclusive school principle (child-friendly school, adaptation to child's needs), should be concretely applied: all the teaching personnel must be trained in inclusive teaching, to promote inclusion and understand how it benefits child, themselves and other pupils.
- Special education and regular education should be de-compartmentalised.
- Human and material resources (specialised teachers, adapted teaching material...) should be made available.
- Teachers schooling an autistic pupil in their classrooms should be recognized and be supported by their hierarchy.
- School psychologists and doctors should receive up-to-date training.
- Teachers should be adequately trained on the specificities of autism and the required education strategies.
- School assistants (AVS) should receive specific training about autism, and their status should be revalued.
- The number of places in special education and home care services (SESSAD), intervening in school to support teachers and propose adjustments, should be increased – the number of places announced by the third Autism Plan is clearly insufficient.
- School assistants (AVS) should be assigned too for the extracurricular activities and the midday meal.
- The number of hours of school assistant (AVS) intervention during school time should be increased.
- Recreation centres' animators should participate in the educational team meetings, which assesses the child's needs and transmits it to the French Departmental Units for Persons with Disabilities (MDPH).
- Awareness campaigns concerning disability should be conducted in recreation centres, and also information campaigns concerning material, human and financial means that can be put in place.

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<sup>64</sup> Common European [Guideline](#) on the Transition from Institutional to Community-based Care, 2012.

## Appendix

### I – Appendix: About the psycho-analytic approach of autism

In the psycho-analytic approach, autism is considered as a psychosis provoked by a poor relationship with their mother; autistic children are considered as children who have chosen to hide in their own personal world to protect themselves from a traumatising maternal environment.<sup>65</sup>

The professionals consider that they must heal the mother in order to heal the child.

The "therapy" (acknowledged and funded by the state without any control) consists of waiting for the child to want to leave the world in which they are hiding.

Concretely this consists of observing the child without interaction, interpreting their gestures and emotions on the basis of psycho-analytic theories.

In consequence, they learn no means of communication, no learning objectives are fixed, and they learn nothing. This is damaging for the child because when an autistic child is left to their own devices they indulge in repetitive behaviours which become invasive and block their development.

Because they do not know how to communicate their most basic needs, their state (for example, "I want to eat, I am tired, I am sad, I want to go outside, I don't want to do that, I don't want to do this..."), they express themselves how they can, screaming, with anxiety crises, with panic which are interpreted by these professionals as an expression of their psychological suffering due to their autism (a psychosis according to them).

*« The worst abuse that you can do to an autistic person is to deny her education and to let her languish in her autism »,*

*Stanislas Tomkiewicz, psychiatrist (non-psychoanalyst)*

### II – Appendix: About the Article L246-1 of the Social Welfare Code (pursuant to Chossy's law)

It must be pointed that there is an article within the French legislation aimed at autists and people with multiple disabilities: the Article L.246-1 of the Social Welfare Code stipulates that: "Any person with a disability resulting from autistic syndrome or related disorders, regardless of their age, shall benefit from multidisciplinary provision catering for his or her specific needs and difficulties. Such provision shall be adapted to the condition and age of the individual. It may be educational, instructional, therapeutic or social. It is the same for people with multiple disabilities."

To these days, the vast number of autistic children gets concentrated within institutes or day-hospital units proposing at best occupational past-times without taking in account neither these children's needs nor their specific difficulties. Thereof these children are deprived of an adapted care programme that would allow them to increase

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<sup>65</sup> *The Wall ; psycho-analysis put to the test for autism* (documentary available in various languages)

their competences in areas like communication, social interaction and autonomy, and would support them with their difficulties related to autism.

The others, who are attending school, are either in specialised classes mixing different types of disability, void of specific and adapted teaching objectives, and with teachers not trained in adapted strategies for education with autistic children, or in mainstream classes but with part-time schooling, due to the insufficient number of hours for individual school assistants, hence adding another difficulty to the disabled child.

It is clear that this article is almost never applied. Some parents may know its existence but the difficulty lies in enforcing its application, since they would have to lodge an individual complaint against the French State, the proceedings being a several years lengthy one, expensive on financial and human costs, ending, in case of success, with a financial compensation that can hardly amend for problems resulting from the lack of proper adapted care programme at an earlier stage of development.

To conclude, the main article from the legislation useful to autistic children is nor or under applied, by large not well-know, and we need it to be enforced.

### III – Appendix: our synthesis about the Report<sup>66</sup> established in december 2014 by the inspectors of the National Education Service , Social and Health Affairs and and Financial services on “Teaching units in medico-social and health institutions”

This document definitely ascertains the terrible actual school conditions disabled children suffer from, when they are supposed to be offered school education in Institutions and Day-Care Psychiatric Hospitals.

In fact, “15% of children in IME (special needs institutions) receive no general education, that means 6600 between 6 and 16 years old”(p.18) and these figures do not include the teenagers over 16 years old who are definitely out of the scholar system.

- Concerning the increasing number of disabled children included in general education schools

The document mentions that the increased number is only due to the integration in the disabled field, of children who weren't counted before (particularly those with language problems).

Those who could have benefited of inclusion in ordinary schools stayed in specialized institutions, despite the recommendation of the law on Equality of Chance -dated 2005- and the law of orientation and program of the Republic's School - dated July 8<sup>th</sup> 2013- which replaces in the Education Code the fundamental principal of including all the children.

- Concerning the school in Institutions or Day Care Hospital

Schoolchildren do not study in good conditions, as the lines below testimony:

“The arrival of a pupil in a medico-social or sanitary institution, means generally saying, an interruption of his studies whatever. If this interruption is sometimes presented by the professional team as something positive for the child,

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<sup>66</sup> This report was published on April 2015, available on

[http://cache.media.education.gouv.fr/file/2015/29/4/2014-046R - Unites d enseignement etablissements medico-sociaux\\_411294.pdf](http://cache.media.education.gouv.fr/file/2015/29/4/2014-046R - Unites d enseignement etablissements medico-sociaux_411294.pdf)

and being a possibility for him to quit a painful school experience, it is also, the facts tell us that, a definitive stop in his studies which had been started years ago and often followed up to secondary school.” (p.53)

Though teacher ratios are superior to those of “special” classes in general education schools, these “classes” in institutions concern in fact groups of 2 or 3 schoolchildren (sometimes only one), taking pretext of the severity of the disability and the necessity of individualizing the pedagogic practice: this is the reason why they offer only a very short time of study from a few hours to a few half days. On the other hand, the class is given mainly by primary school teachers which can be a problem when taking in charge teenagers (see proposition 3d in the report, p.97).

The weekly studying volume, which is already quite low, diminishes as the child grows and leads to no-studies at all after 16 years of age. “The directors in the institutions often declare that their goal is to offer studies to the youngest to whom they grant a maximum of school classes” (but never over 12 hours, as we have seen). Some even consider that after a certain age it is impossible to teach them anything -or that their mission stops here”. (p.60)

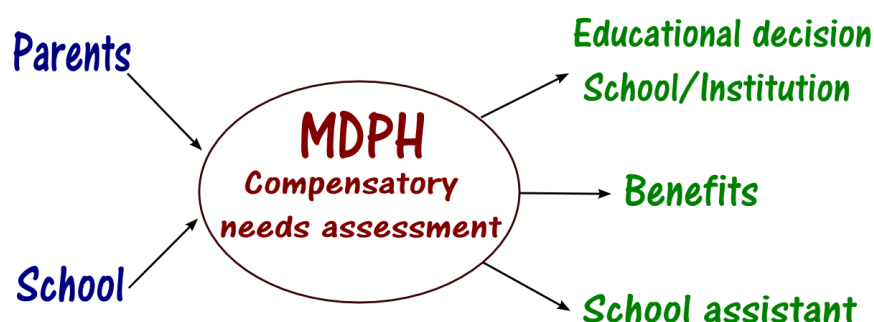
- Concerning access to Professional Training

Only 38,9 % of students having followed their education in an institution have access to professional training when 77 % of the students coming from inclusive classes in a general education school do; though, as it is specified in the report, the abilities of the students are similar. (p.67)

- Principal Recommendation of this Report

As a first step towards inclusion, this report recommends that classes be externalized from specialized institutions to general education schools. Following this document, it is: a first step towards inclusion”. (p42sq)

#### IV – Appendix: testimonies<sup>67</sup> illustrating the institutional dysfunctions that prevent or hinder the implementation of certain rights mentioned in the Convention on the Rights of Children



Reminder : the MDPH plays a central role, of which the general dysfunction is illustrated by the examples below

<sup>67</sup> These testimonials are examples among thousands

- SAFAA K., 6 years old

Currently in pre-school in poor conditions, with a significant turnover of school assistants, interrupted by deschooling periods (in the absence of school assistant).

K. is set apart from her class. No activity is proposed to her. The Departmental Units for the Disabled (MDPH) has decided upon request from her mother on an orientation to an institution meeting the recommendations from the High Health Authority (HAS), in which there is no place for her (on a waiting list for 5 years).

- LORET Axel, 7 years old

Previously schooled in poor conditions, one let him stagnate for 4 years in the same class, with a turnover of school assistants, interrupted by deschooling periods (in the absence of school assistants). His parents were under pressure from the teaching staff to deschool him (« He does not fit in at school ») and also from the MDPH concerning an orientation to an unsuitable institution (a kind of nursery which does not meet recommendations), which his parents turned down.

Currently cared for 20 hours a week by an educational center, which meets the recommendations from the High Health Authority, financed and managed by parents without any public support.

Requests to the MDPH:

- technical aid to finance an iPad (a means of communication for Axel): rejected on the grounds that this communication tool comes under education, not autonomy
- financial aid for transport: rejected on the grounds that the place of care does not come under the medical field
- financial aid for the care proposed by the center: rejected on the grounds that the MDPH must not favor any method

- ILINARES CRUZ Loïc, 6 years old

He is attending school 7 hours a week with a school assistant available 12 hours a week. The school refused to school him for more time. With an untrained school assistant, Loïc spends most of his time in the schoolyard or the corridors. Last year, a request for institutional care was sent to the MDPH. No answer from the MDPH

- JOUY Cyriac, 5 years old

School attendance for 45 minutes, 3 times a week

His mother is under pressure from the school: if she refuses to place him in a day care center on a half-time basis, he will be deschooled.

- PAON Antonin, 7 years old

School attendance in poor conditions (turnover of untrained school assistants often on sick leave). Experiences discrimination: no school attendance in the absence of school assistants, no extracurricular activities on the grounds that there is no school assistant during those activities.

In the same time, he is placed in an institution which does not meet the recommendations of the High Health Authority.

Request to the MDPH: school assistant for the 2015-2016 year, orientation to a suitable institution (far from home, but his mother accepts to move).

Mrs Paon raises her child alone and has not been working: the allowance paid by the MDPH is not enough to compensate pay losses and disability-related expenses.

- PEDROTTI Axel, 9 years old

Private care, attends school in a mainstream class (1<sup>st</sup> grade) with a school assistant in a termination period. The academic management refuses to renew his contract.

Request to the MDPH: orientation to a special education and home care service (SESSAD) visiting at his home or his school. Allowance to finance private care.

The MDPH decided on his orientation to a SESSAD, but he has been on a waiting list for 5 years. The allowance granted does not compensate the costs of care.

- YVON Maïwenn, 13 years old, deschooling period

Family's wishes: retention in a special education class specialized in autism inside the junior high school (1<sup>st</sup> choice), special education class in the upper level (2<sup>nd</sup> choice), institution meeting the recommendations of High Health Authority (3<sup>rd</sup> choice).

The academic management rejected his retention in a special education class specialized in autism.

The MDPH rejected the orientation to a special education class and accepted institutional care. But the institution rejected the choice due to lack of places.

- YASAR Gulcan, 15 years old

Her mother withdrew her from an institution which proposed no educative care, only recreational care (like a nursery); suspected sexual abuse on her daughter.

She spends her time at home every day. Three professionals take care of her every day during her mother's working time.

She receives no public support to pay the professionals involved.

- BREARD Arthur, 17 years old

Previously attended junior high school in a special education class, his mother wanted him to go on with a vocational training: the headmaster rejected the idea and did not complete the necessary formalities.

Requests to the MDPH: orientation to a vocational training, disability benefits (PCH), mileage allowance, sessions with the special education teacher with an estimate, sessions with a psychologist with an estimate, school assistant for the vocational training 34 hours a week

Occupational guidance and disability benefits refused, help from a school assistant accepted (12 hours a week).

Faced with those refusals, Arthur receives distance learning.

- PEDRON Erwann, 14 years old.

He previously received unsuitable institutional care (for children with multiple disabilities), his mother withdrew him, as she was under pressure from the staff for him to take neuroleptics.

Erwann is currently living with his mother at home, with a help of a professional 6 hours a week

He displays severe autism and needs external assistance 24 hours a day.

Request to the MDPH accepted: renewal of disability benefits (PCH)

- LAGO Mélina, 17 years old

Institutional care since he was 5 years old. It concretely consisted in childcare. No school attendance, no suitable care. She lost the autonomy she had before integrating the institution. She experienced physical and psychological abuse. Now she is 17, she is receiving care in the same institution, which wants to expel her (following a child abuse report from her mother).

The MDPH proposes institutional care for autistic adults.

- BADAoui Lina, 8 years old

Institutional care (9 hours a week). The institution is not conducive to autonomy, community participation, the development of mental and physical gifts and abilities, no school attendance.

Few or no access to interventions recommended by the High Health Authority (HAS) by lack of skilled professionals in the field, she receives speech therapy (only twice a week)

Her mother wants her to get more sessions with skilled professionals, at home.

- BEVERLY Guillaume, 18 years old

Cared for in Belgium for 5 years, in the absence of adapted care in France

- RAHMANI Anissa, 12 years old

She previously received psychoanalytic care in a day care center, which deschooled her at 8 for a so-called school attendance in an hospital, which has never taken place.

She is been attending a mainstream school with a special education class since 2014.

Her institutional care is being put to an end by the hospital (age limit to be schooled in that class).

Requests to the MDPH: the family is under pressure from the hospital staff for institutional care, which her parents finally requested before changing their mind with retention in the special education class and private care meeting the recommendations of the High Health Authority

The French National Education staff rejects that change and retention in the special education class.

The MDPH decided on institutional care.

- KHEDARI Ryan, 14 years old

He previously attended mainstream school in a special education class on a half-time basis, and received psychoanalytic care in a day care center until 12 (age limit to be schooled in that class).

The family is under pressure from the hospital staff for institutional care. His mother refused to place him in an institution, as Ryan had a very negative reaction during the visit.

The social worker living in her town refused to inform her of a possible placement in a recreation center and blamed her for rejecting institutional care.

His mother takes care of him on a full-time basis, without any solution, and wants him to be placed in a special education class for pupils aged 12 to 16.

- DRESSI Medhi and Leïla

Mehdi, 3 years old, diagnosed with severe autism in 2014 by a Ph.D in psychopathology, who made the diagnosis on the basis of the results in the standardized assessments recommended by the High Health Authority.

Leïla Drissi, 4 years old, diagnosed autistic in 2013, moderated mild confirmed by medical diagnosis in 2014

June 26<sup>th</sup> 2014: a child abuse report against them was launched by the public social service along with a summons before the children's judge with a view to placing her two children in a host family or a shelter.

During the hearing, the mother could read and take notes of the youth welfare office report intended for the judge.

The notes read:

*"Her children's health and development are heavily compromised. We are worried about their health and development in the mother's home because of the "autism spectrum disorders" she transmits to her children. – "Mrs. X is convinced that they both display autism spectrum disorders, forgets to treat them as children. – Mrs. X also rejects any support in contradiction with her certainty that her children are autistic. Her children's disorders are increasing, Medhi is rejected by her mother, who shows no affection to him. Mrs. X imprisons her children in a disease by transmitting "autism spectrum disorders" to them – Mrs. X needs to control and decide upon her children's life without considering a more favourable evolution outside the family context.*

During the hearing, the judge did not decide upon the daughter's placement and gave extra time to decide upon the son's one: he asked for a second confirmed diagnosis from the autism screening center.



However, the child psychiatrist in the screening center rejected the diagnosis of autism for a diagnosis of "evolutive disharmony" (based on the French classification, not recommended by the High Health Authority (HAS)). Moreover, they phoned her son's speech therapist (only care) to tell him not to listen to this mother, as he is not autistic. The assessment carried out by this center did not take place in the planned conditions. In the summary record of the diagnostic analysis, 4 pages out of 5 describe the mother's health in detail (she has autism and Crohn's disease), which proves irrelevant.

The child psychiatrist of this center sent the diagnosis of "evolutive disharmony" directly to the MDPH without his mother's approval to bias his MDPH file to be compiled: indeed, this diagnosis cannot be considered by the MDPH, as it is not found in the international classification of mental disorders.

In the meantime, her son is receiving care only 30 minutes a week, as she has no means of compiling a file intended for the MDPH; the mother is completely deadlocked.