

December 12, 2015

ADDITIONAL OBSERVATIONS FROM AUTISME FRANCE ADDRESSED TO THE COMMITTEE FOR CHILDREN'S RIGHTS

Following its alternative report and the French government responses to a list of points regarding the fifth French periodical report requested by the committee for children's rights from October 15, 2015.

After acknowledging some issues expressed by the committee for children's rights towards France, as well as some of the country's responses, Autisme France is submitting some additional observations regarding autism and the answers expressed by France to the UN questions.

Question N°6. Please supply information about legal charges pressed against people responsible for inhumane and degrading treatments inflicted to disabled children in specialized institutions and about the given sentences. Also, give some precisions about the measures taken so that such situations do not occur again and about measures to control those institutions in an effective and regular manner.

Lastly, indicate the measures taken to put an immediate end to the treatments inflicted to children with Autism Spectrum Disorder such as Le Packing, therapeutic wadding-pool or even over-medication.

Answer from France on october 15, 2015:

France answers that some Autism good practices guidelines have been created since 2012; that they constitute a frame of reference imposed to all professionals as well as an external tool for assessing all institutions when renewing their license.

France claims that the therapeutic wadding-pool practice is banned. Regarding Le Packing, however, France as well as the HAS and ANESM merely keep repeating that they have been formally opposed to this practice since March 2012.

Over-medication is qualified as "bad practice" and France highlights a program to train health professionals.

Last, France reminds that in Autism plan 3, an adult training program is planned for hospital staff.

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Remarks from Autisme France:

Good practices guidelines are not enforceable on professionals: no psychiatrists unions in France have supported those guidelines, no health professionals unions either. The guidelines are not enforceable on medical-social professionals for external or internal assessments; however, regional health agencies have no use for those assessments.

Besides, very few institutions have an autism agreement (an agreement that is not regulatively defined) and most autistic people are committed to institutions not dedicated to autism, without a formed diagnosis (60% of children haven't received a diagnosis). Thus, it is merely an illusion to try and enforce anything on any institutions.

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

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

This practice is still taught and even passed on in Autism resources centers:

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

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

Le Packing is also taught by the psycho-motor professionals union. We can find videos online as well as books and articles dealing with it. In one of those books edited by M. Delion, we can read that Le Packing is used to recreated erogenous zones. Those perverse tendencies, borderline pedophile, can be found in an online video:

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

We invite international experts to appreciate what this doctor says, breaching medical ethics by claiming that it is normal to start with worsening a patient's state to reach a goal. We also invite them to appreciate the sexualization of the practice and its scandalous aspect.

A journalist who put her son in a day hospital where Le Packing is a common practice, made a newspaper front-page:

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

Several IME of the Rhône-Alpes region as well as from other regions give training for practicing Le Packing. They acknowledge that fact themselves:

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

Psycho-motor professionals who contribute to continuing professional development (they are now entitled to do so) only teach psycho-analysis, Wadding-pool, Le Packing:

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

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As far as inhumane and degrading treatments go, we have learnt about electroshock therapy inflicted to autistic teenagers at la Pitié Salpêtrière.

Recommendation 1: enforce the autistic guidelines within a legal framework.

Recommendation 2: review all basic, care and medico-social trainings to integrate up-to-date knowledge about autism. This work promised years ago, is still to be carried out since nobody in France dares going against the psycho-analytical lobby which supervises all trainings and all services.

Recommendation 3: ban wadding-pool, Le Packing, electroshock therapy.

Question N°9. Please indicate whether the member State committed to a policy of desinstitutionalization and if yes, what the deadline is. Also, indicate the ongoing developments following the concerns expressed by the special Rapporteur on the rights of disabled people regarding the institutionalization of Timothée D. and the measures taken to prevent this institutionalization. Please comment on the information relating that many parents lost custody of their children after demanding that they were included in mainstream schools and after refusing inadequate treatments in institutions.

Answer from France:

France answers that the law from 2007 supports home-placements and educational measures to avoid institutionalization.

France has started a consultation with different organizations denouncing abusive placements of autistic children.

France claims that legally-motivated placements are only decided when keeping a child at home is impossible but are never based on divergences regarding the care process. Judges can demand independent and multidisciplinary assessment measures of the social services that carried out the request for placement and for the medical and psychological evaluation.

France also claims that a procedure brought forward to a judge for children is subjected to the contradictory principle, that parents and children, capable of discernment, have access to their file and can be assisted by a lawyer.

Remarks from Autisme France:

France contradicts itself by saying that the law from 2007 supports home-placements and educational measures when the answer to question 10 is: “a decision made to place children out of their home is mainly a legally-based one at 87%”.

Home-placements and educational measures remain the exception: France acknowledges that half of the children subjected to an “Aide Sociale à l’Enfance” procedure will be institutionalized. Granted, under the pressure of some associations’ outrage, a consultation is under way to try and draw up a plan of action in order to solve the dysfunction of the ASE when it comes to autism. However, nothing concrete has come from that and in any case, the supervision of the ASE is given to the various French Departments, which carry out their own agenda and don’t really answer to anyone.

Regarding Timothée Dincher, the answers from the French authorities are not satisfying: a teenager was committed to a medical-educational institution against his will and his

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mother's will. Moreover, this institution was inadequate and abusive and sent the child to a psychiatric hospital for adults where he was restrained and over-medicated.

The claims about legally-motivated placements are at least a lie by omission: indeed, the audiences in front of a judge for children are never contradictory procedures, the ASE is judge and jury since it makes the assessments itself or outsource them to associations without any control, it also manages the institutions and foster families or outsources this management to association that it funds. Judges often ban families from accessing the files.

Most of the time, judges follow the requests from the ASE which never has an unbiased vision of the situations since it is guided by psychoanalysis. So, it is, in fact, a divergence in the care process, contrary to what France claims that justifies autistic children's placements.

A mother in Isère lost custody of her 3 children because she wanted them diagnosed: she was accused of medical nomadism by the hospital services and the ASE. They said that she wanted her children to be disabled and that she was creating their troubles.

Recommendation 4: Take into account the report on ASE by Autisme France and follow all of its recommendations: autistic children are victims of abuse, deprived of their family, deprived of the care necessary to their handicap, forced to live in a modified environment without any preparation and subjected to incompetent educators solely guided by psychoanalysis.

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

The human rights defender produced a report on Children and Disability protection that shows how disabled children are invisible to the ASE.

http://www.defenseurdesdroits.fr/sites/default/files/atoms/files/20151120-cp-ddd_-_rapport_enfants_2015_-_handicap_et_protection_de_lenfance.pdf

Recommendation 5: ban the ASE system and reorganize endangered child protection services. 10 billion Euros are used every year in an inadequate and often outrageous manner to give abusive treatments to children, to deprive them of their fundamental rights (to live with their family, for example) and to fuel a perverted and incompetent system.

Immediately stop the ASE from stealing autistic children from their family out of ideological reasons.

Recommendation 6: open a conference on desinstitutionalization.

Question N°10. Please indicate the measures taken to ensure every child's right to be properly informed, to express her/his opinion and the right for this opinion to be taken into account regarding a placement outside of the family sphere and to ensure the continuity in the child's educational and relational points of reference.

Please comment on the information relating that 80% of children institutionalized in structures supervised by the ASE are placed because of their parents' poverty. Please

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provide details on how the systematic nomination of administrators - ad hoc – is ensured to guarantee the right of children being placed to be represented and assisted within the framework of educational assistance, legal, administrative and jurisdictional procedures.

Answer from France:

France answers that France now has a package ensuring that each child is properly informed, that each child can express an opinion to be taken into account in the decision to place the child outside of the family sphere – a decision that is mostly legally-based in 87% of cases. France explains that a law about child protection is being examined at the Parliament. France claims that the hosting facility and the parents' right to visit and exchange must be determined according to the child's best interest in order to facilitate these links, including the links with siblings. France claims that the placement decision lies on an assessment process taking into account the age of the minor, his/her ability to live within a community. France maintains that poverty is not a major reason for placement but contradicts itself by saying that fighting poverty can contribute to making a hazardous situation disappear.

Remarks from Autisme France:

The word of the child is never taken into account: in the case of the Isère mother whose autistic children were taken away from her, the children never asked to be separated from their mother.

The law reforming child protection reforms almost nothing. It hasn't been voted yet and it won't be enforced just like the 2007 law isn't.

The children from Isère are separated; they see their mother one hour every 15 days and don't have the right to see their grand-parents. We hold this family's file available for UN experts.

An expert in autism wrote in a medical certificate that the 3 children, suffering from autism, shouldn't be institutionalized since they were too vulnerable to live in a hosting community: the judge didn't take this certificate into account.

As far as autism is concerned, many families pursued by the ASE are single-parent families living with minimum allowances. These families are never helped or supported: they are being punished by having their children taken away.

Recommendation 7: demand that France ensure the children's right of expression and their fundamental rights.

Question N°12. Please indicate the measures taken to implement the injunctions of the Council of Europe and of the European Committee for social rights stating that children with ASD should get an appropriate screening and early educational and behavioral intervention with professionals trained in methods recommended by the Haute Autorité de Santé since 2002.

Indicate the measures taken to ban inappropriate and not scientifically-approved care, to reinforce the skills and competences of professionals, in particular in mainstream schools, to implement support and training programs for parents and to ensure that children's and parents' opinions are heard and respected.

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Answer from France:

France explains that the diagnosis and early interventions are a priority in Autism plan 3. France highlights a national training program for families' assistants, an assessment of experimental structures, various actions to encourage a shift in practices that should gradually put an end to inappropriate and not-scientifically-approved practices, the creation of a quality frame of reference, some measures to reinforce the efficiency of the plan announced on April 16, 2015.

Remarks from Autisme France:

On the French territory with the exception of Limousin, there aren't any local diagnosis teams or early interventions services.

The program for families' assistant hasn't covered the entire territory and the trainings aren't always adequate.

Given that experimental facilities – usually praised by families – have been assessed, why not assessing care facilities that refuse to shift practices, forcing families to accept the wadding-pool therapy, Le Packing, psychoanalysis. These facilities threaten families to report them to the ASE because they want to get away from those treatments. Why not assessing establishments and medico-social institutions funded with public money even though their competence and their efficiency are never evaluated and even though they are often abusive?

There haven't been any concrete measures to reinforce the plan yet. The plan has been delayed because the president of the national committee for autism hasn't been replaced yet: thus, the committee in charge of the follow-up of Autism Plan 3 hasn't met since April 2015. The project manager who left on September 30, 2015 was only replaced on December 9.

France seems to reckon that non-scientific and abusive practices will magically disappear on their own: to that end, France should actually adopt a real political will from both sides of the political spectrum. The dictatorship of psychoanalysis will then continue and autistic children will keep on being abused. Parents campaigning for a real diagnosis will continue to see their children being taken away from them by the ASE. There isn't any actual quality frame of reference or charter: a pseudo equivalent is now called guideline for the support of the medico-social offer and will never constitute an enforceable tool.

Recommendation 8: create the necessary diagnosis and early intervention services.

Recommendation 9: punish doctors who refuse to form a diagnosis of autism, control the quality of care and medico-social facilities hosting patients with autism and reallocate money given to care services to the national education ministry.

Recommendation 10: create a frame of reference about autism that could be enforceable to any institutions and staff and make sure that they abide by it.

Question N°13. Please explain how you translate in concrete terms the notion of “inclusive education” according to the law No. 2013-595 from July 8, 2013 and the concrete outcome of implementing such law regarding children excluded from mainstream classes, children who receive no education or children placed in specific systems such as CIS (classes for school inclusion) or UPI (inclusive educational units).

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Please supply detailed information concerning the measures implemented or considered to solve the issue of complete or partial exclusion of disabled children, of gypsies or migrants from mainstream schools, from educational activities or from extra-curricular and leisure activities.

Answer from France:

France claims that the rate of schooling of disabled children has increased by 121% since 2006. France highlights its guideline for assessing the compensation needs in terms of schooling. The country states that since the beginning of the school year 2014, the staff in charge of assisting disabled children can get permanent work contracts.

Remarks from Autisme France:

The rate of schooling of children with autism barely increases and they continue to suffer from discrimination in their access to education as highlighted by the Council of Europe, which sanctioned France 5 times for discrimination against autistic children and by the European commissioner for human rights.

The above-mentioned assessment guideline was drawn up without the concerned associations and is absolutely inadequate when it comes to detecting autistic children's needs.

Teachers aren't trained in autism: teachers training schools are independent and are not obliged to give any training sessions regarding disability.

There are twice as many assistants and care staff on short-term, precarious contracts or state-subsidized jobs without proper training than those on permanent contracts.

Educational units in kindergarten are a proper effort towards schooling young autistic children within a school with an educational support within the classroom. However, it remains difficult to fill those classes since, in many departments (Loire, Territoire de Belfort, Vosges...), day hospitals prevent children from leaving said-hospitals.

Recommendation 11: train teachers and assisting staff in autism.

Recommendation 12: rewrite the guideline for assessing the compensation needs in terms of schooling.

Recommendation 13: open a dedicated phone-line to report a school when they refuse to enroll a disabled child and to report discrimination. Create a cell to help parents find solutions.

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