

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

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Comments and recommendations

about the **answer¹ by the French government** (dated October 15, 2015) concerning the **list of issues²** released on July 23, 2015 by the **UN Committee on the Rights of Child** in relation to the examination of France's fifth periodic report

Issue 1

The main problem being mischannelled funds (towards health rather than education), the Committee starts by questioning the government 's national strategy about its impact assessments and fiscal adjustment steps. This is severely harming the inclusion of children with disabilities, and more specifically autistic children (since they cannot learn how to engage in social life within closed artificial environment).

This preposterous situation is so nonsensical that it causes most of the blockings : These are due to the pernicious effect of the excesses of thoughtless and inappropriate public funding (of the medico-social lobbies by the national social security authority) : the situation is so critical and the scandal runs so deep that this government can harldy do anything else but go on ignoring the facts :

- Hardly any active measures are taken, carried through or considered in terms of their results.
- As a consequence, any answers given to the Committee's crucial question concerning the mismanagement
 of funds remains irrelevant i.e. a vague "bill" which "proposes" to set up a "high council" which would
 receive "special training" in order to give an "opinion". These are all very hypothetical things, diametrically
 opposed to the concept of results of actions undertaken.

Regarding the arrangements about monitoring the **uniform application** of the Convention by the State, France sidesteps the question by simply saying that information is passed on whenever the child moves to another department.

However, this problem which affects the disabled, is a crucial one (see Issue 12): The fact is that the MDPH³ is managed by the departmental councils. Now, these are the places where the orientations of the children are

¹ Available here :

http://d3n8a8pro7vhmx.cloudfront.net/childrightsconnect/mailings/212/attachments/original/R%C3%A9ponses%C3%A9critesFrance.pdf?14453 25410

² Available here : <u>http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G15/162/95/PDF/G1516295.pdf</u>

³ Maison Départementale des Personnes Handicapées (one in each department)

decided, and these decisions are usually based on the best interests of the medico-social institutions managing foundations (see our comments in Issue 12). In addition, there is a huge disparity among departments in granting allowances and benefits, as if each MDPH was acting as they see fit, without regard to regulations. In concrete terms, few parents will appeal to the court, due to lack of information and lack of experience in defending themselves. Moreover, when the court (TCI : Disability Litigation Court) proves the parents are right, the MDPH is not sanctioned.

The same goes with the Regional Health Agencies (ARS) who are normally expected to comply with public health policies, but the fact is that agencies act in the interest of the medical lobby i.e. medical and medico-social professionals who put pressure on them.

The government has announced that € 10 billion is spent yearly on child protection, without specifying the impact on children's rights. This money can be misspent, and we condemn this at the same time as the excessive placements in foster care (Issue 9)).

Issue 3

The response of the government mentions all kinds of discrimination (gender, racism, etc.) but - even here- wishes to address separately the issue of the discrimination against the disabled (which is a discriminating way of thinking against the disabled, illustrating the general state of mind).

While this answer to the issue 3 makes a very large room for discrimination in the educational context, the latter is not at all mentioned anymore where the writer decided to answer about disabled children (i.e., in issues not related to school discrimination), which enables him to avoid a very embarrassing topic, and which allows us to measure how deeply school and disability cannot be thought of together in France, not even in such a text.

Issue 6

Regarding **criminal prosecution in case of ill-treatment**, the answer does not provide any concrete and real cases which would illustrate the kind of prosecution available for such an offense; besides, does such a concrete case even exist ?

In reality, very very few criminal proceedings (if any) are undertaken when parents lodge a complaint against a person responsible for inhuman or degrading treatment such as "packing" (called "therapeutic moist wrap"), the "therapeutic puddle", over-medication and physical restraint (called "therapeutic retention") which is applied sometimes for long periods (more than a week, 24/24).

Indeed, such practices are common and accepted, even encouraged in health institutions, since they are considered as a therapeutic treatment (intended as a cure), and therefore not as an inhuman or degrading treatment.

Concretely:

 In case of child abuse reported to the Regional Health Agency (ARS), this agency will generally be sympathetic towards the institution involved ; it is the same for a complaint to the Medical Association (Order of the Physicians), which covers for the doctor. At best, the ARS may temporarily bring the establishment under guardianship, which does not necessarily fix the problem⁴;

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⁴For example: the IME (Institut Médico-Educatif) Moussaron, whose agreement has been renewed after a temporary guardianship measure by the State.

- Complaints of abuse against an institution are almost always closed without follow-up⁵;
- Any qualified professional denouncing an abuse is faced in all likelihood with dismissal and exposed to charges of allegations of defamation⁶ in all.

The recommendations are not "mandatory rules" among professionals: they are only recommendations and have no legal value: no criminal proceedings may be initiated against professionals who do not follow them.

As example of this is the symposium⁷ "Children with mental disabilities" which took place in March 2015. It focused on practices not recommended by the HAS (High Health Authority), in spite of the fact that this conference is acknowledged by the Government, as having the Continuous Professional Development (DPC) label.

During a meeting with the President of the Republic's Counsellor for Health and Welfare – which took place in the presence of 2 other organisations – we were told that fighting against "**the reluctance of professionals**" is hard in practice. This, it was added, is due to lack of resources both to control institutions and to "*monitor compliance with the recommendations*", which "*would require thousands of people*".

And when we asked for effective coercive and deterrent measures which would be suited to an understaffed environment, she changed the subject.

This Advisor was accompanied by her counterpart working for to the Prime Minister, who told us the same thing: to sum up: "We have neither the means to control nor the means to compel professionals and institutions who do not comply with good practice recommendations, which, additionnaly, are not actually legally enforceable".

ANESM (national agency for assessment of medico-social institutions and services) conducts **external assessments** of socio-medical institutions every seven years, which is too long a time period. The assessment was expected to be carried out before 2009, but it was postponed to December 2014.

As ANESM is partly piloted by the institutions it assesses, one might raise the question about its independence⁸.

In practice, **most institutions do not take into account the recommendations concerning autism**; yet **their overall assessment is consistently positive** which allows the renewal of their contracts (to make sure there is always a place for disabled children).

Extract 1 :

Extract 2 :

 ⁵ <u>http://www.la-croix.com/Actualite/France/Les-plaintes-contre-l-institut-Moussaron-presque-toutes-classees-2015-04-22-1305100</u>
 ⁶ For example :

⁷ <u>http://www.afar.fr/afar-colloques/colloques_2016/colloque_ENFANTS_151104.pdf</u>

⁸ Voir le discours d'inauguration de l'ANESM :

 $http://www.anesm.sante.gouv.fr/IMG/pdf/discours_inauguration_didier_charlanne_directeur_anesm.pdf$

[&]quot;Two months, too, to **develop with all the medical and social sector actors** a scheme that allows the Agency to take over the national social and medico Evaluation Council.

Because the Agency is the result of extensive consultation. The federations of institutions and services have been associated with all steps of the drafting of the statutes. This is essential because the Agency must be their agency. It was up to the State to manage the organization of this new entity to give it the means of its action and ambition. The actors of the sector must participate in the work of the Agency and provide the same material recommendations, standards and best practice guidelines to be developed."

[&]quot;Second instance, the Strategic Policy Committee has a more operational role: it is tasked with discussing the draft recommendations and to set the annual program of the Agency course, professional representatives participating in the Committee and this is essential. " On the other hand, there is no mention of user participation (for which this agency is supposed to work) ...

The "**therapeutic puddle**", an actually outdated method, is certainly - in theory- "proscribed in the field of autism spectrum disorders", but in reality workshops on this method, subsidized in part by the government, are still being held⁹. Those who practice it are not penalised. A book explaining the practice (extracts of which were quoted in the alternative report of Alliance Autiste) is among the CRA resource materials (CRA Bourgogne¹⁰). And some reflections about the practice were implemented by the CRA Rhône-Alpes¹¹.

<u>Regarding the practice of "packing</u>", France merely points out the recommendations, which are only recommendations: in fact, health institutions can implement this practice without any sanction, which is the case in some psychiatric day hospitals.

As an example, hospital psychiatrist Dr. Thierry Albernhe, who was invited on 8 October 2014 by the High School of Health in Vaud (Switzerland), spoke at length of the practice of packing in his service (psychiatric hospital Montfavet, Avignon), thereby promoting this "therapy"¹².

With regard to the measures taken to prevent **ill-treatment**, these are limited to simple reports without any coercitive aspects whatsoever.

As shown in the link below, here is a common example of a certification report concerning France's most important psychiatric centre – the Vinatier Hospital - which was carried out by the HAS:

http://www.has-sante.fr/portail/plugins/ModuleXitiKLEE/types/FileDocument/doXiti.jsp?id=c_1268507¹³

In most of the cases posing problems such as treatment related damage, one can read negative comments and a lack of involvment and cooperation from the staff¹⁴.

In practical terms, this report has no measurable impact on child maltreatment prevention nor can it stop it. The problem is put off again and again to the next appointment. Some experts do not take the trouble to reply, so it is merely written down as a bureaucratic measure.

http://www.crabourgogne.org/biblio/opac_css/index.php?lvl=author_see&id=485
 http://www.cra-rhone-alpes.org/IMG/pdf_CR-Psychomot-02-07-12.pdf

- "The school project is being developed. To date, the cases of child abuse reporting procedures are not defined. However, doctors and social workers provide a number of reports to the Attorney General Council (concern information). The procedures of internal and external specific reports do not exist. The adverse event profile that does not include specific items can be used to report cases of abuse but does not encourage reporting. There is no good treatment charter drafted."

Note: here, there are cases of abuse which are EXTERNAL to the institution (family etc.). (It is possible that in general the institutions themselves think that they give positive treatment.)

Extracts 2 :

- Etc.

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⁹ "Liste noire des formations" (black lit of the trainings) :

http://allianceautiste.org/wp/wp-content/uploads/2015/04/AA_Formations-non-conformes-reco-HAS_2014-2015.pdf

 ¹² "Journées d'étude 2014 - Le pack en institution psychiatrique" :

⁻ Video footage with english subtitles) : https://www.youtube.com/watch?v=65a40ICC-sk ("intimacy", "eroticism", "fantasy", etc.)

⁻ PDF : <u>http://www.hesav.ch/docs/default-source/recherche-et-developpement-docs/Pack/programme_pack.pdf?sfvrsn=0</u>

¹³ <u>Rapport de certification V2010-7347 (</u> 1,25 Mo) - july 2012 - avalaible on this page on the HAS website <u>http://www.has-sante.fr/portail/jcms/c 262203/fr/centre-hospitalier-le-vinatier</u>

¹⁴ Extracts 1 :

^{- &}quot;The conclusions of a first working group on the prevention of child abuse did not generate any particular action. This important topic was not shared by the entire healthcare community. The promotion of good treatment is a priority issue for the new CSIRMT. "

^{- &}quot;Some situations are discussed in CRUQ, eg contention, the isolation room. A status report to identify situations, risks and abuse of factors is not made. In the recommendations of the CRUQ for this year, 2012, we find the theme "Ensuring respect for patient rights and freedoms."

^{- &}quot;There has been no assessment of actions [for the prevention of child abuse and promote positive treatment]."

^{- &}quot;There is no definition or procedure in institution of a structured approach to inform to patient in case of damage related to care."

^{- &}quot;In actions for improvement of this criterion was proposed "the establishment of an awareness of professionals to patient information for

damage related to care," the timing is not determined, the actions have not been implemented to date."

^{- &}quot;There is no evaluation or improvement. [about the process to inform the patient in case of damage related to care]

With regard to urgent measures taken to halt **over-medication**, France replies that professional training have been planned, but fails to offer any further details. This measure is not efficient and does not yield quick results : if what is "planned" is put into practice, then in a few years professionals will be able, if they so wish, to reduce the medication.

Issue 9

Concerning **de-institutionalisation policy**, France notes reservedly that it is a "principle" which does not include the institutionalisation of disabled children but solely ASE¹⁵'s foster care placements. The Committee asked "if the answer is yes, how soon": there is no answer ... simply because there is no "affirmative" answer (for a concrete application), thus nor timescale.

With regard to **Timothée D.**, France did not provide any answer to the Committee's question, given that they mentioned, by way of answer, a letter sent on 27 March 2015 which could not take into account the child's personal

and evolving situation. The juvenile court judge ordered parental custody to be given to the father so that he could handle his son's placement in a residential care institution (this reason is made explicit in the judgement). As things did not go well, he was confined in a psychiatric hospital, where he was kept tied on a bed, four days in a row, under heavy neuroleptics medication. Thereafter, the judge confirmed the decision in spite of the fact that a statement¹⁶ was issued by the Special Rapporteurs Rights of persons with Disability and Wellbeing.

Since then, his mother has had no alternative but to leave the country to protect her son from a court order that would clearly put into jeopardy his mental and physical wellbeing. She fled with him to Ireland on 28 September 2015. Her husband and daughter joined her a few days later, following a heavy police intervention at their home where police forces searched the house from top to bottom in search of Timothée.

This is a family which has dared to fight, without respite, against the absurdity and unfairness of a system. A system which has no alternative other than to attack the family and make them a dissuasive example for other parents.

Last news (January 3)

The mother of Timothée was arrested December 17 by the Irish police, pursuant to a European arrest warrant issued by the France, and held in a jail in Dublin (Dochas Center).

The alleged legal grounds of this arrest are "child abduction" and failure to present the child to his father, the latter having been entrusted the child's custody since march 2015 by judicial decision. Timothée and his sister Daria have been hosted by the neighborhood since her arrest.

On December 11, her husband went back to France for a few days to settle some business. He was arrested on Monday, December 14, held in police custody for 48 hours and heard by a judge. He put him under investigation for complicity of legal grounds against his wife. He then placed him under judicial supervision, depriving him of his personal computer and his passport, with the obligation to go every day to the police station which is located 18 km away from their home.

He has been released from judicial supervision from December 29 until January 31, on bail of € 25,000.

Timothée's mother was held in a jail in Dublin from 17 until December 21 and was heard by the High Court on December 21: the judge accepted a release on bail until the next hearing to be held on January 11, 2016.

The bail was set at EUR 75,000 in immediate availability.

¹⁵ ASE: Child Welfare Service

¹⁶ <u>http://www.un.org/apps/newsFr/storyF.asp?NewsID=35577#.VIGMFXYvfIW</u>

That's the <u>real</u> answers of France! The total disregard of autistic persons, persons with disability, families, the UN ... This is the reality, the facts, in flagrant contradiction to government statements.

Concerning judiciary placement, the recent 2015 report¹⁷ by the National Federation of Associations for Pupils with Disabilities (the FNASEPH), on disabled children and childhood protection, mentions many problems which contradict the reassuring statements made by the government¹⁸.

Some recommandations:

We recommend a serious and thorough training on autism for all those professionals who deal with children (childcare professionals, expert psychiatrists)

We welcome the following recommandations FNASEPH makes:

- observe the development, the nature and the origin of the alarming reports thanks to the creation of a complete statistic tool for the follow-up of alarming reports, and the precise study of the origin of alarming reports, structure by structure and person by person, so that the structures managed by the department (the CRIP) may warn overzealous whistleblowers about the risks of excess;
- reduce abusive transmissions of alarming reports by providing for penalties or warnings;
- ensure that the National Education reviews their practices regarding the transmission of alarming reports;
- enable families to ensure their defense in compliance with the adversarial principle;
- review the usefulness of educational assistance measures in the case of disabled children, and favor the support of professionals usually close to the children¹⁹;
- encourage placement with reputable third parties²⁰.

In view of court rulings which are often ill-suited and "institutionalising", we insist that **in the absence of medical experts specialised in autism and duly approved by the scientific community and the users, this court ruling is not sufficiently substantiated and represents a high risk of error.** Autism, including both the behaviour and the needs of an autistic child, is hard to understand and neither a judge, nor even a psychiatrist with no expertise in autism, can encompass what is at stake. They can only "believe they understand", which the worst of all²¹.

Issue 12

We know that the Government **focuses on training courses which follows the** recommendations of High Health Authority ; however **the actions planned are not enough important compared to the issue, and the third autism**

¹⁷ <u>http://www.fnaseph.fr/images/actufnaseph/Rapport_Defenseur_des_Droits_FNASEPH_protection_enfance_version_.pdf</u>

¹⁸ - alarming rise of "Concern Information" (IP), especially made by schools;

⁻ the definition of the concept of "Concern Information" can cause unwarranted abuse;

⁻ abusive Information Concern, and impunity for whistleblowers;

⁻ more reports on families with a disabled child, desptite the fact that no serious study shows a correlation between the risk of a family abuse and disability (moreover, institutional abuse can occur when the child is in an institution);

⁻ educational assistance measures unsuitable in the context of disability;

⁻education professionals' ignorance of disability, whether they specialize in early childhood or social welfare. They don't know how to interpret symptoms of certain cognitive disabilities, such as those related to autism or ADDH, and think family education is at stake..

¹⁹ Explanation: In general, these placement measures cover parents who want, for example, out of the medico-psychological center and ask for a private care with competent professionals: which is enough for the ASE to send an alarming report ... So 'the support of professionals who provide care for the child' refers to those that the parents are wishing for their child.

²⁰ Such as the grand-parents.

²¹ Note that in the case of Timothée, Dr. Thierry Albernhe, defender of "packing" hostile to the HAS (see above video), and thus example of non-consensual psychiatrist, was appointed by that the Justice of Lyon to write a psychiatric report on Timothée and his parents (he works in the south of France, at 230 km of Lyon). This again shows the bad faith, bad will and cynicism of the "vulnerable children jailers caste".

plan underestimates changes needed: formulations and contents are approximate, with a lack of overall consistency, which were already present in previous Autism Plans, failed to change practices.

The **childcare** social workers and professionnals are among the first practitionners met by the families when they suspect their child to be autistic. However, their training will be focused only on the perspective of a warning information network: it is is highly insufficient to compensate their outdated knowledge with dramatic consequences (very often: a child considered as with a psychotic disorder, caused by a bad relationship with the mother).

Moreover, the Secretary of State of Children and Youth just appointed (in June 2015) as <u>task officer for early</u> <u>childhood</u>²² **a Lacanian psychoanalyst** whose writings can be read on the Ministry <u>website</u>²³ : *"In childcare facilities, to consider a child as a subject, an infant as a speaking being, to acknowledge infantile sexuality and the unconscious dimension in individuals, families and institutional relations requires subjective, substantive and long-term work".*

The alternative report²⁴ by Alliance Autiste clearly identifies **the omnipresence of psychoanalysis as a major obstacle** to the implementation of the Convention on the Rights of the Child in relation to autistic children. We wonder therefore how professional training can evolve with the appointment of a Lacanian Pyschoanalyst as Task Officer of Early Childhood.

Furthermore, these efforts alone do not allow targetting **the crux of the matter**, which is basically a conflict of interests.

Currently, the benefit for psychiatric hospitals (which concentrate most of autistic both children and adults) do not lie in their patients' progress, but in the major financial return they can easily yield, since standard hospital fees are only fixed daily, and not fee-for-service. Thus, a patient receiving for example 1 hour of "care" (psychoanalytic psychotherapy, "packing", "therapeutic meal", "storytelling workshops"...) will be charged a complete day, e.g. between 700 and $1000 \, \ell^{25}$.

This source of income with little investment or involvment is a powerful motivation for hospitals, which seek to maximize the number of autistic patients, and put pressure on Regional Health Agencies to influence them in this direction. Psychiatrists are not held accountable for the self-fulfilment and progress of the patients. It is a similar issue with "institutions" (such as as IME, medico-social institutions), who offer more placements, but this time for a lower fee. Everything is "well organised" by and for this system to maximise placements²⁶.

Some recommendations :

- Psychiatrists working within a hospital setting must be accountable.
- We recommend a **fee-for-service**, as it is the case with other medical practices.
- We ask for a redistribution of budgets from the health ministry to National Education Ministry : the proper place for disabled children is at school, not in psychiatric day hospitals (or other "centres").

France has reacted neither about the measures supposed to ban inadapted and scientifically non-validated care, support professionals' skills and abilities, especially in mainstream schools, implement training and support

²² <u>http://www.social-sante.gouv.fr/actualite-presse,42/breves,2325/mission-de-sylviane-giampino,18041.html</u>

²³ http://www.sante.gouv.fr/spip.php?page=ipb_new_article&id_article=14622&id_rubrique=2065&id_branche=2063¤t=2061&rub_cour

²⁴ <u>http://allianceautiste.org/wp/2015/03/rapport-alternatif-alliance-autiste-comite-droits-enfant-onu/</u>

²⁵ (which is actually an indecent and indefensible amount, even when the "patient" stays during 24 hours, not to mention uselessness, suffering, deprivation of liberty, etc.)

²⁶ A "placement" of patients is comparable to a financial investment ... ("investment" can also be translated by "placement" in french)

programs for parents, nor to ensure that children's and families' are considered and observed. No measure has been actually taken, on the contrary.

The Commission on rights and autonomy of persons with disabilities CDAPH²⁷ decides upon choosing a mainstream school or a medico-social institution (outside mental hospitals, until recently (cf. article 21 bis of the Health law below) for children with disabilities).

In that commission, there are among others representatives from:

- associations (of parents) managing institutions;
- the National Education (EN);
- the Departmental Council.

When a parent wants mainstream schooling for the child, he/she requests a school assistant (AVS), who is actually paid by the EN: this request does not support EN representatives, who want to spend as least money as possible.

Moreover, it does not support representatives of "institution" managing associations aiming to ensure their continuity and economic development, financed (generously and automatically, in line with the number of "hosted" persons) by the French Social Security (CPAM²⁸), which – so conveniently – is not represented in those commissions and cannot go against the future cost of institutionalization.

A placement decision in one of their establishments, on **waiting list**, is profitable for them. Indeed, the more children are on a waiting list, the more the managing association has odds to get (from the Regional Health Agency, ARS) an authorization for a new establishment, which would increase its economic development.

As for the representatives of the **Departmental Council, institutionalization would also be profitable, as it would not have to pay parents a compensation allowance**. A child's "institutionalization" is fully assumed by the Social Security, and not by the Departmental Council.

Any parent attending the commission's meeting has to face these representatives, each defending his own budget²⁹ : the parent's opinion does not weigh much.

As a result, decisions taken depending on the child's higher interest are inevitably rare, and other stakeholders' interests and contributory capacities are prioritized.³⁰

Up to now, a decision against the child's higher interest was actionable. However, far from having parents' opinions considered and the child's higher interest prioritized, the government has enforced a law article (article 21 bis of Health Act) which has the opposite effect.

With reference to this article, the French Departmental Units for Persons with disabilities (MDPH) do not have to decide on the person's needs only anymore, but can elaborate a "Global Accompaniment Plan" (PAG) offering a **placement by default "by lack of unavailable or inadapted known answers"; so, it depends on available ressources.**³¹

²⁷ Commission for the rights of disabled persons to independence, one for each department.

²⁸ Local Healthcare insurance office

²⁹ They all have a convergent interest, i.e. a lucrative, easy and "arranging" placement.

³⁰ Again, we cannot fail to see how the system is organized "by and for" establishments thriving via people with disabilities, especially children, and who do not intend to see "their daily bread fend for itself".

³¹ Certainly not at school or in the "free society", as almost nothing fosters inclusion (so "unavailable") and, on the contrary, the whole system "manages" people with disabilities with a view to keeping its "golden goose".

As part of the PAG, the placement by default includes "therapeutical interventions": so, one can imagine a PAG with a follow-up in a Medico-Psychological Center (very influenced by psychoanalysis) or in a psychiatric day hospital.

Moreover, the government declines any responsibility for inadapted care, as a proposal will have been included via this 2nd plan: a placement decision against the child's interest is legal and unactionable and eliminates families' only recourse today: actions for damages against the State (very difficult, but possible in theory).

Recommendation

We request that commissions (CDAPH) be *really* independent and no conflict of interest interfere with children's higher interest (in other words, that today's system be entirely changed).

Issue 13

Following France's replies concerning the practical application requested by the Committee³²:

- France says that the schooling of disabled pupils in a standard environment has increased by 121% since 2006, but without any further details concerning this figure, it is both difficult to assess the duration of schooling and to know whether it is carried out in a standard environment or a specialised³³ one; moreover, France provides no details as to the source.
- In spite of this lack of precision, we would like to comment on this figure : such an increase can be explained, at least partly, by the fact that the figure takes into account pupils who are now considered disabled, which was not the case before. (such as those affected by dys-type problems.)
 Alongside these figures, we ask ourselves whether the number of pupils enrolled in institutions has gone down. It would make sense if they had, but what is the case in reality ?
- We wish to point out that except for the figure of 121% (debatable and theoretical), there are no other concrete field test results i.e. no signs of any effective inclusion is provided.
- With regard to the compensation needs assessment guide for the purposes of school enrolment (GEVA-Sco program), we had pointed out in our report the fact that it is not suited for the autism disability, that parents are not consulted (only the teacher fills in the form), and that it is not inclusive: the fact that the teacher has to refer to the abilities and skills of an ordinary child of similar age when ticking boxes in the assessment guide is a problem, because there is a risk of showing a gap with the norm, which would lead to concluding that the child cannot be integrated into mainstream education.
- Although it is interesting to include a teacher against the multidisciplinary team, the problem remains that teachers are usually against mainstream schooling. This is either due to the ongoing mentality in France which sees non-disabled pupils in standard schools and the others in specialised institutions, or because his hierarchy (i.e. the inspector) is not willing to financially support too many AVSs (School Assistants). The National Education is the main employer and income provider of school assistants.
- We are glad to read that disabled pupils are «entitled» to be granted access to extracurricular activities, however, the problem is that time alloted to AVSs (schooling assistants) all goes to normal lesson hours, which takes into account neither extracurricular time (TAP) nor school canteen time. This penalises the pupils whose access to TAP or canteen is refused on the ground that there are no assistants available during these hours.

Consequently, this "entitlement" remains usually limited to... a theoretical entitlement.

³² (The wording of this issue implies that, according to the Committee, special classes, even inside regular schools, are not considered as inclusive education).

³³ (In France, a specialized class in a mainstream school is considered "mainstream schooling")

- Concerning «measures to address the full or partial exclusion of disabled children and Roma», the government contests that this exclusion exists for the Roma, but does not contest it for the disabled. This would suggest that the government recognises that disabled children are partially excluded.
- The government added that Roma cases of both discrimination and exclusion fall under the penal code framework. Why not mentioning that also for the disabled children ?...

Some recommendations

- GEVA-Sco is an educational tool but, in concrete terms, it is used by the MDPH, which are related to the medico-social sector : the needs assessment concerning schooling, therefore, depends on the board which takes placement decisions. In order to ensure neutrality, we encourage the creation, within the MDPH, of an educational committee (i.e. National Education field), which would be responsible for all matters related to scolarisation and independent from any medico-social lobby. We request that a dialogue between the teaching staff and the familly be developed, and that this guide be filled in another manner than just ticking boxes *or, that it be adapted to autism in one way or another* since the current approach does not provide the MDPH with the necessary data on which to establish suitable educational arrangements.
- In order to ensure that feedback is provided to the MDPH on the needs concerning AVS and TAP, we recommend that an extracurricular activity coordinator (TAP) be included in teams concerned with school attendance and whose mission is to oversee educational arrangements.

Comments about a new relevant element related to the present review of France, because of the major role of the Human Rights Defender:

The <u>report</u>³⁴ (20/11/2015) "Handicap et protection de l'enfance : des droits pour les enfants invisibles" (Disability and child care: rights for invisible children) by the Human Rights Defender ("Défendeur des Droits") (or ombudsman for France) also points out to the difficulty of having different services and specialists work together in relation to a child, which recalls the compartmentalisation of services. The Defender acknowledges the lack of training of judges in the area of disability in general, which leads them to mistakes in the judgment and appraisal of situations.

In spite of some positive points in his report, we regret that we cannot approve the recommendation of the Human Rights Defender regarding the proposition of communication forms between social services (ASE) and the MDPH, and in particular of an ASE referent inside of the MDPH: the agents of social services are imbued with psychoanalytic theories, which lead to abusive institutionalizations, and we fear this recommendation could impact even further the bad knowledge of the agents of MDPH, who already tend to direct children massively to medico-social services. On the contrary, we think that this recommendation reinforces this trend.

We are absolutely against the recommendation of creating more places in institutions, as this goes against the need of deinstitutionalisation and inclusion into society.

We feel offended that according to the Defender, placing children in a "specialized" institution is considered as the ultimate goal, enabling the access to the rights of children and ending any kind of danger in his regard.

Besides, we note that the report doesn't denounce unjustified admissions and states instead, in order to justify the existence of alarming reports ("Informations Préoccupantes"), that a diagnosis of a disability can fragilise families and endanger the child; letting believe that a link exists between disability and risk of mistreatment, while no serious study has been carried out (studies don't distinguish family and institutional mistreatments).

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³⁴ <u>http://www.defenseurdesdroits.fr/fr/publications/rapports/rapports-annuels-droit-de-lenfant/handicap-et-protection-de-lenfance-des</u>

We totally disagree with the Defender who regrets a lack of pedopsychiatric caring services³⁵: actually, pedopsychiatrists are imbued with pyschoanalysis, and relate the child's difficulties to a bad relationship with his mother. In a general way, we deplore the gripping influence of psychiatry on disability.

Our conclusion

The government replies with very little relevance to the concerns of the Committee (when it does reply...), and pretends to handle them on paper, in the same way as it pretends to handle them on the field. The action of our government consists mainly in saving face, with various "smoke screens", because anyway it has no means (and doesn't give itself the means) to face the supremacy of the medico-social "lobby", which institutionalises and excludes, thriving to the detriment of most vulnerable people (namely disabled children), all of which relying on the uncontrolled opportunity of social security funds. In the meanwhile the population approves passively, unaware of the situation of disabled people (and kept ignorant and mistrustful towards autistic people) because of the segregation organised by this system, encouraged by psychiatrists and other "professionals" and "establishments" whose interests are surely in maintaining their dogmatic, obscurantist totalitarism... remarkably organised and profitable.³⁶

Lastly, we wonder how France could set up an efficient public health strategy in the field of autism while it can't even provide up-to-date statistical data for the last three years, regarding the number of children with special needs, in particular children with autistic spectrum disorders.

France is able to provide this kind of data for the cases of influenza for example... but not for autism (which prevalence rate is estimated between 1/100 and 1/150).

December 15, 2015, for Alliance Autiste, Magali PIGNARD Eric LUCAS

- families: manipulated, frightened, destroyed, in debts, etc.;

- teachers, who don't get enough means to ensure a mainstreamed education, which thus does not look desirable to them;

³⁵ Page 24 of the report's synthesis: "Moreover, whereas it could be expected that the diagnosis signs the start of a planified, organized care, it can rather be a moment of breaking off in families that besides, get fragilised. In this area, the lack of health care in pedopsychiatry together with the diminution of prevention actions must be particularly regretted."

³⁶ In this absurd and cynical system, everybody loses (except the exploiting caste):

⁻ **disabled children**: exploited and whose chances of autonomy are sacrificied to keep the provisioning (and expansion!) of concentration centres which can only keep them in an artificial "under-life";

⁻ **taxpayers** (since one day spent in a "medico-social" service is far more expensive than mainstreaming adaptations, and because there are neither controls nor results expected, which means: no limit) ;

⁻ carers, in collusion, against their own will, with the acts of the "lobbies" employing them;

⁻ **the government**, who **doesn't dare to face this enormous nonsense**, **but just pretends to do it and pretends to reply when asked to account for its actions**, like here **(QED 1)**, while giving away some very little measures so that it can't be said that they don't do anything (QED 2), and hoping that this scandal stays stifled, under control and constraint, disregarded... like autistic people (QED 3).