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## **Input to report**

We thank Special Reporter for this important initiative and for the opportunity to bring the input about psychosocial dynamics conducive to torture and ill-treatment.

Francedisability (<https://francedisability.com/>) was created in April 2019 ; our activity aims towards an effective implementation of the Convention of Rights of Persons with Disabilities (CRPD) in France through advocacy, information and research. One of our main goals is a recognizing of the forced medical non life-saving treatment, including restrain and confinement, as torture and the substitutive decision making as a main cause leading to arbitrary deprivation of liberty and inhuman treatment of persons with disabilities.

## **French context**

Signing CRPD, France had made the declaration about its own interpretation of consent, distinct of that, developed by UN bodies, in particular by CRPD Committee. France allows a forced treatment of persons with psycho-social and intellectual impairments both on the ground of the consent given by person's guardian and during involuntary psychiatric confinement. The latter is a subject to a juridicial revision but the judges always rely on the psychiatrist's opinion and outpatient forced treatment is very common practice. In the same time, the detention in care homes of persons with disabilities and elderly persons with intellectual impairments are not recognized as deprivation of liberty and virtually often happens by simple decision of guardian, escaping from legal proceeding. This is also the case for the medical treatments and interventions.

According to last statistics from January 2019 there was about 21 741 residential homes across the State, 877 146 places for older persons and 494 000 for persons with disabilities. This number has increased by 51% since 2007.<sup>1</sup>

The existence of segregated settings and the arbitrary deprivation of liberty based on disability violates the articles 12, 14 and 19 of CRPD. The absence of close monitoring of the conditions of detention in those settings leads to invisibility of the persons who are detained.

### **Example of individual case**

The case of Tom (name modified) a 21-year-old autistic adult, is a typical example of ill-treatment practices amounting to torture, following the detention of autistic adults under guardianship in residential settings in France<sup>2</sup>. Starting from this typical situation, we can observe the processes of acceptance and concealment of this ill-treatment in French society.

Tom, diagnosed with moderate autism, was placed, the year of his majority (2017) under the guardianship of a professional guardianship organization GRIM (real name, situated 317 rue Garibaldi, 69007 Lyon), by Court, following an alleged psychiatric expertise establishing his 'lack of discernment'. As often happens in these cases, Tom was not present neither represented in Court.

The placement under guardianship is unavoidable in France from the moment that the individual's 'normality' is questioned. The exact number of persons under guardianship is unknown but there is a firm ground to believe it overpasses a million.

The guardian, who met Tom only twice, availing himself of an 'orientation' decided by the *MDPH* (Regional Welfare Office specially dedicated to the PwD), places him in a residential segregated setting for some 30 adults with autism (MAS Michel Chapuis situated near Lyon) since November 2018. This decision is being carried out without seeking the consent of Tom, who lived until 18 years old in his maternal family, did his scholarship in mainstream school, reads, plays piano, used enjoy sports. But it was before.

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1 Caisse Nationale de Solidarité pour l'Autonomie (CNSA) <<https://www.cnsa.fr/outils-methodes-et-territoires-organisation-de-loffre/programmation-et-creation-de-places-en-etablissement-ou-service/le-bilan-des-plans>> accessed the 9<sup>th</sup> Juin 2020

2 See our article about this particular situation <<https://enil.eu/news/the-invisible-half-citizens-in-the-country-of-the-human-rights-declaration/>>

As he disagreed with this forced placement, the heavy and always increasing neuroleptic treatment (currently including 9 drugs) is administered to him, contributing to his 'acceptance' of the detention. Apart from very few and strictly supervised activities, he has no possibility of going out other than every other weekend to his father's house. Outings with his maternal family, or with long-time friends, are forbidden by the guardianship.

The constraints of the institution's life further reduce Tom's freedom and choices, including:

- room locked at night with a bathroom locked at all times, except for toilet time, under supervision; this may require Tom to relieve himself on the floor of his room;
- clothes locked in a cupboard, without free access to them;
- deprivation of the majority of his belongings, his iPad – the support of his daily occupation - disappears forever and his CD player is also regularly confiscated; these are apparently minor material deprivations that lead to a bigger frustration as there are the ultimate choices he would expect to have.

At the end of July 2019, while Tom protests against the situation by disruptive behavior, he is sent for a stay of a little more than a week in a psychiatric hospital in a strictly closed ward.

On three occasions, in November and December 2019, then in January 2020, (friends and relatives, during duly scheduled visits, discover that he is locked up in a small dark room called the '*salle de répit*', under the pretext of 'bad behavior'. He could be observed through a glass opening, banging his head against the door, or urinating on the floor in protest. This leads eventually to a new confinement in January 2020 in the psychiatric hospital, for a stay of more than three weeks. The number of drugs is increased and the side effects (bad sleep, problematic transit, apathy to name only these ones) influence further appearance of disruptive behavior. He is increasingly the subject to constrain, both chemical and mechanic.

All tentatives of his mother to stop the detention failed as in absence a clear framework of care placement, there is no legal proceeding accessible. The complains to the prosecutor are refused as only the guardian is allowed to legally represent 'protected person': Tom's guardian, GRIM, refused to answer to all communications about the issue.

Recently, a shocking video showing an autistic man in the courtyard of the same care home where Tom is detained, barefoot, eating a tree bark until bleeding from his mouth, was recorded by an occasional bystander and diffused on Facebook. We can hear the answers of police and emergency service called by the man with a demand of help: realizing that the man eating the bark is an autist, they refuse to come and are even joking. The individual who published the video online was threatened by the direction of OVE charity which runs the care home and was obliged to delete it. The parents of the autistic man, informed about this incident, did not complain about ill-treatment, to our knowledge.

### **Acceptation of ill-treatment**

The forced placement of PwD is a widely accepted practice in France: the common question to the parents of child with disability is 'have you already found a *place* for him/her'? The idea that there is a *special place* somewhere that allows to the persons to discharge themselves from the challenging mission of inclusion of the difference and adaptation to it. The distributive welfare logic and *rights* articulated as benefits (in french, the same word *droits* means the 'rights' and the 'allowances') creates passivity, isolation and self-persuasion that 'somebody takes care' of the PwD and that their rights are insured by the existence of costly care homes funded by the governmental budget (taxes); an amount of money spent on disability discharges from the feeling of personal and society responsibility.

It needs to be highlighted that both professional guardianship and residential homes are the sources of huge private profits<sup>3</sup>. Moreover, as the care homes for PwD are mostly run by charities founded by the families which advocated in the aftermath of Second world war for the solutions outside of asylums, giving them legitimacy of obtained 'right'.

There is a kind of repression of French society's knowledge about what happens in those care homes. The sporadic revelations of ill-treatment, abuse, 'accidental' death in those places never reach the national media, so as generally the topic of mental/learning disability<sup>4</sup>. It seems like the hidden reality is too abject to be known and doesn't match with an image of the 'country of human rights'.

3 *La protection juridique des majeurs: Une réforme ambitieuse, une mise en œuvre défailante*, Rapport Court des Comptes, Communication à la Commission des finances, de l'économie générale et du contrôle budgétaire de l'Assemblée nationale (2016), 11

4 See the dataviz of comparative study about visibility of the topic in French and UK media : <https://francedisability.com/articles.html> accessed the 9<sup>th</sup> Juin 2020

Families fight to obtain a 'place' for their child, given the absence of alternative solutions of independent living and the persistent scarcity of 'places'<sup>5</sup>, and, once given it, avoid any open criticism and even prefer not to know what is really going on there.

The care homes are often insulated from the city (Michel Chapuis MAS is situated far from all residential settings, on a no-man's land of an ancient factory) which makes it impossible for any inclusion projects to thrive. Hidden from exterior contacts and monitoring (the care homes are only controlled by pricing commission which evaluate the prices of provided 'services') those places of exception/exclusion become the ground of the chain of 'exceptional' measures often leading to the tortures (punishment by seclusion) neglecting, locking in the room without access to the bathroom for long hours, physical and chemical restrain.

A specific language made of euphemisms is established to speak about reality of residential settings. For example, by the name 'respite room', which can be read on the door of the room where the residents are locked up when they engage in 'undesirable' behavior. The idea of a 'well-treatment' (*bientraitance*) appeared recently as a pretended possibility of 'torture free' segregated settings but it is not clear how it is ideal, which is likely to be a self-deception strategy, will be reachable.

People who witness the ill-treatments refuse to testify formally, despite the empathy they show to the person subjected to ill-treatment. The reason, which is difficult to express, would be that one should not aggravate the situation and risk having one's access to the abused person restricted by denouncing the situation: the visits to the residents can be restricted by the decision of the guardian.

The system is very strong, the prosecution for 'defamation' is a frequently used weapon against whistleblowers and everybody believes that it is pointless to expose oneself to opposing it: a waste of energy, and fatalism dressed up in a constructive discourse. A problematic improvement is referred to a temporality that is beyond us. The common position is 'I'm against institutionalization but there is no alternative'.

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5 It is a reason why around 8000 French citizens are sent to the residential homes in french speaking part of Belgium : <<https://handicap.gouv.fr/presse/communiqués-de-presse/article/maitrise-des-departs-vers-la-belgique-et-renforcement-de-la-qualite-de-l>>

The organizations whose official goal is disability rights prefer rather than fighting head-on against the power of the institutional lobby, to spend their energy to obtain more funding for themselves and their activities or for disabled persons: welfare rather than fundamental rights. Official speeches, with their soothing vocabulary on inclusion, achieve the impasse of inaction.

### **Recommended measures of prevention**

The main obstacle to the preventing of torture is the outdated understanding of 'consent' on the basis of french guardianship system and the absence of any allusion on supported decision making in french legal framework. While the need of this framework is obvious, the recent project for the reform of guardianship presented to the French Parliament a year ago doesn't contain it.

The absence and urgent need of a mental health law was pointed recently by the General Controller of places of deprivation of liberty (National Monitoring Body under OPCAT) which can visit psychiatric closed units but not care homes. The recognition of latter as places of detention and their independent monitoring along with creation of legal framework to prevent arbitrary detention are thus crucial at this stage.

From another side, the embedded understanding of 'rights' as benefits makes very difficult all evocation of civil rights, before Courts but also in public debate. The strong safeguard of those rights are absent from French law and need to be urgently and clearly introduced.

The (in)visibility of disability remains a main self-perpetuating problem within French society because of ongoing segregation and stopping it is a most important and challenging goal today.