



**Alliance Autiste**

Autistic persons' NGO  
for the freedom and defence of autistic persons  
and for the implementation of the [CRPD](#) in France

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Mr. Secretary of the Committee  
**Committee on the Rights of  
Persons with Disabilities**  
UNOG-OHCHR  
CH-1211 Geneva 10 (Switzerland)

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Submission about deinstitutionalization in France

## Submission for the UN CRPD Committee about deinstitutionalisation in France

in the framework of the online regional consultations with persons with disabilities and  
their representative organizations in May 2021

12/05/2021

Dear Mr. Secretary of the Committee

We thank you for your kind clarifications and for the accommodations provided, and we thank the Committee for the possibilities of consultation and participation it offers us, which is not at all the case from the French public authorities, who despise the CRPD and especially deinstitutionalization (a taboo word for them), as much as they despise our autistic persons' organization (which very rarely gets the information and clarifications it asks for, on the basis of General Comment N°7).

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Even the French Ombudsman ("*Défenseur des Droits*") does not provide any of the written information we have been politely requesting for one year, and they barely respond to us.

Although the French State is obviously not interested in their full compliance, the Convention and its General Comments provide very important arguments in our attempts to make the rights, needs and difficulties of handicapped autistic persons heard by the French public authorities.

While waiting for the day when France will hopefully consent to put into practice the Liberty, Equality and Fraternity that it so falsely proclaims, please kindly find enclosed our offline contribution to the current consultation, wishing the best of success and remaining at your disposal to continue participating in the elaboration of the "Guidelines on Deinstitutionalisation" document.

Please be assured, Mr. Secretary of the Committee, of our most respectful consideration.

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# Submission for the UN CRPD Committee about deinstitutionalisation in France

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- May 12, 2021 -

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## **1. Problems**

**1.1. The often-lifelong institutionalisation or hospitalisation of persons with disabilities, with no possibility of choice as there are no alternatives**

**1.2. The poor physical accessibility, and lack of human accessibility**

**1.3. The lack of support services in the community (at home or nearby)**

**1.4. The lack of remote support services (accessible for all disabilities)**

**1.5. The refusal to try to make adaptation efforts on the part of non-disabled people**

## 2. Causes

### 2.1. The delegation of the public service to private entities

The French system is almost entirely privatised, by means of associations managing establishments. This does not guarantee that the requirements of 'public service' and respect for human rights are sought and applied, and it generates situations of conflicts of interests.

### 2.2. The perversion by the economic considerations of the "medico-social" and medical systems

Medico-social establishments, with their buildings, their parks, their administration and their numerous staff, are very expensive and they receive much more money (about 300 € / day) when they house people, than when they provide services outside their walls.

The managing associations support an important economic sector, with many secondary jobs (related to accommodation) which would no longer be necessary if people could live in freedom.

The price of a day in a public psychiatric hospital (where many autistic people live for years) is about 1000 € / day, which is unbelievable and indecent as there is almost nothing going on there. Since this has been continuing for decades, there must be an economic interest somewhere.

All this money is automatically paid to the establishments or hospitals by the social security and by the departments.

It is taken from the taxpayer, who cannot object to it and who, moreover, believes that these measures are beneficial.

If there were much less money circulating when people are institutionalized, then there would be fewer obstacles to de-institutionalization on the part of those living off institutionalization.

### 2.3. Private lobbying, proximity and complicity of public authorities

Most of the private entities involved in public decisions are the associations that manage institutions. They are rich (thanks to all the "easy money" that circulates) and powerful (by invoking the risk of job cuts).

They are united in opposing any form of real deinstitutionalization (which would remove any 'compulsory' link between them and people who would have become entirely free to choose their place of life and their service providers).

The word 'deinstitutionalization' is literally taboo, and it is a subject they do not want to hear about, or which they sometimes 'reinvent' in their own way, i.e. in ways that allow them to keep their hold (and their income).

They do not receive any objections from the public authorities in charge of disability, since anyway their officials often come from the medico-social sector.

All this is greatly facilitated by Article 1 of the 2005 law, drafted under the preponderant influence of these lobbies, which straightaway presents these associations as "representative" of the persons that they accommodate (and who are virtually their - obliged - clients), which constitutes an obvious conflict of interest:

*"In all national or territorial bodies that issue an opinion or adopt decisions concerning the policy in favour of persons with disabilities, the representatives of persons with disabilities are appointed on the proposal of their representative associations, ensuring the simultaneous presence of associations participating in the management of the social and medico-social establishments and services mentioned in 2°, 3°, 5° and 7° of the I of Article L. 312-1 and of associations not participating in them."*

## **2.4. The incompatibility of private financial considerations with the pursuit of autonomy, freedom and respect for human rights in an equal manner**

The more people with disabilities become autonomous and live outside the control of lobbies, then the fewer people they have to accommodate and the less money they receive.

The autonomy of people cannot be the priority of associations that live mainly from accommodation.

Conversely, if these establishments were run by the State, it would be in the State's interest to keep people there as little as possible, in order to reduce public expenses.

An autonomous person costs less to the State, but this is not the concern of associations that live off the lack of autonomy, which they contribute to maintain through institutionalization.

## **2.5. The reluctance of public authorities**

The public authorities are not making any significant effort to support a genuine deinstitutionalization, since in reality they originate mainly from the lobbies, or are strongly influenced by them.

## **2.6. The refusal by public authorities to listen to persons with disabilities in their diversity**

The public authorities in charge of disability despise very powerfully our association of autistic persons (and many other ones), and they never answer our requests for information about deinstitutionalization since they know that this is our main objective and since this subject is taboo (or to be avoided as much as possible) in the French Administration.

(The word "deinstitutionalization" does not appear in official texts for the French public, but only in those for international organizations).

## **2.7. The French State's deep and sovereign disregard for the CRPD, and the art of pretending to respect it**

The French state, characterised by its polite arrogance, likes to lecture the rest of the world but does not accept to be lectured.

The contempt for the Convention is obvious when one analyses the facts.

It makes it very difficult to fully implement the Convention and to respect human rights, in a country that presents itself as the "cradle of Human Rights" (or, should we say, of the "Rights of the normal human" ("*Droits de l'homme normal*")).

The public authorities are often much more concerned with circumventing their obligations and using tricks to make it look like they are respecting them, rather than actually implementing them (since this is not compatible with the "institutionalizing" system that has been in place for decades and since it is not possible to "move up" in the Administration if one wants to oppose it).

## **2.8. The ableist and segregating biases**

French society generally considers that persons with disabilities, who are automatically considered "inferior" (or regarded condescendingly), should live "in places made for them", and that they are happy there.

Because of institutionalisation, one does not meet many disabled people "in freedom", and this increases the stigma and a sense of superiority.

Indeed, since people with disabilities have visibly less freedom and are segregated, and since this seems fair to public authorities, then it generates the general idea that these people are "other citizens", "a little less equal" (or "inferior"), and with fewer rights.

The "normal" or "normalitarian" or "ableist" way of thinking considers that disabled people are "defective" and therefore "cannot" enjoy as many rights as "normal" people.

# **3. Solutions**

## **3.1. Legislative or systemic transformations**

The State must commit to matching the following obligations and prohibitions with real and effective sanctions, and to apply them "for real".

- We need a law which completely prohibits institutionalization and orders the abolition of all such segregated accommodations, as in Italy for children since 1977: we ask the "Land of Enlightenment" to reach at least the level of Italy in 1977.
- Remove the associations managing establishments (and services) from article 1 of the 2005 law.
- Legally prevent so-called " associations of persons with disabilities " which directly or indirectly manage establishments with accommodation (or who otherwise violate the CRPD) from being "representative".
- Enable representative organisations to obtain the removal of any entity that has violated the CRPD from any public consultation committee or group.

- Effective legal obligation to fully comply with Articles 4.3 and 33.3 and General Comment No. 7, including the provision of human assistance, and the provision of information and clarification of public policies when requested.
- Legal obligation for full and permanent transparency of establishments, and for accountability to taxpayers.
- Legal obligation to provide persons with freedom of choice of residence, with a legal obligation to provide sufficient options, on an equal basis with non-disabled people (i.e. not just in places provided by lobbies).
- The state must be obliged to allocate funds solely for services, and/or drastically reduce daily allowances when a person is accommodated in an establishment.
- Legal obligation of training about autism (and psycho-social difficulties) for all civil servants who have to meet the public.
- Legal obligation of real CRPD awareness campaigns reaching the whole population, with a commitment from the State to pay penalties to disabled people (and their organisations) when this is not done.
- Following the example of point 66 of General Comment No. 7, allow the person with disability to easily have a decision (including a court decision) overturned if the Administration cannot prove that it has taken his or her disability into account and respected the CRPD (including Article 4.3) in its decision.
- To avoid abusive hospitalisation and "life" in hospital, Law 2011-803 must be reformed and real possibilities for systematic recourse to justice and real equitable respect of human rights must be ensured. In particular, the obligation to provide evidence of "dangerousness" (very often used as a pretext for locking up), and evidence that restrictive measures are absolutely necessary and proportionate must be guaranteed.  
A simple certificate from one or more doctors is not proof.
- In housing, legislative measures with financial incentives should give priority (or a "reservation") of ground floor dwellings to wheelchair users, which would solve the problem of lifts. (Indeed, it seems absurd to require lifts in all new residential buildings, since it is sufficient to live on the first floor. Those who do not wish to do so will always find enough higher buildings which necessarily have lifts).
- Stigmatising, devaluing or negative statements or publications about disability and disabled people by entities linked to the "public service" should be made illegal and punished financially.

## **3.2. Concrete measures for people**

*Note: In France, there is not much point in proposing concrete measures, since anyway this is opposed to the current "disability exploitation system", which has the political levers to do what it wants, in a country which despises and violates the CRPD, and which subtly manages to make it look like it respects it.*

### **3.2.1. Freedom and full equality in the choice of housing**



People should be able to live in any type of residence (within their means) and in any neighbourhood, like other people.

Support and care services should be available in their homes and/or in their neighbourhoods (without the need for expensive buildings and administration).

People who do not wish to live in collective housing should not be forced to do so.

People should not be subject to any constraints, problems or authority from care service providers, and in particular they should not be penalised by financial considerations or restrictions due to the mutualisation of services, which should be adapted to the person and not vice versa.

### **3.2.2. Accessibility for all, including autistic persons**

Universal design and universal accessibility must be implemented for all types of disabilities, including psychosocial and autism-related disabilities, in particular through "passive" or "active" (human) adaptations to be provided by the socio-administrative system and by any public or private entity.

Autistic persons and their organisations must be consulted in order to understand what accessibility measures they need (e.g. autism-friendly forms or formalities, use of specialised facilitators in case of communication difficulties and social problems, refuge places or other arrangements (including sensory) in establishments open to the public and in transport (including air travel), exemptions for protective items normally prohibited, accessibility in school, employment and housing by raising awareness of the social environment, autism training for doctors (including dentists), etc.).

It may take decades to make the whole "normal" system accessible, but in the meantime it would be very useful (and quite easy and quick) to create a concept of "Inclusive Neighbourhoods and Villages" (or "Inclusive Areas"), without reducing, elsewhere, any of the efforts due to the obligation of accessibility everywhere.

These areas, self-designated on a voluntary basis, would include all necessary adaptations for one or more types of disability.

In particular, with regard to autism and psycho-social disability, the entire population of the area (shops, public services, schools, industries, residents, etc.) must be made aware of how autism functions, especially in order to prevent mocking, rejection or condescension.

In this way, autistic persons having chosen those places would feel much more at ease, would be less handicapped, would suffer less and would (finally) be able to appreciate and to adapt to life in society.

After some trials, an increasing minimum rate of these areas could be made compulsory in each region and for each disability (e.g. 1% for autistic people, then 2% etc.).

In this way, persons with disabilities would have a choice between living "everywhere but with poor accessibility", and living "without difficulties in a sufficiently diverse selection of places".

The same principle can be applied for "Inclusive Buildings" (instead of clustering persons with disabilities together in housing controlled by the disability lobbies).

### **3.2.3. Direct personal allowance and freedom of choice for private personal assistance**

Each person with disability should be allocated financial means for the assistance he or she needs, the amount of which should depend solely on the disability and not on where they live. This includes 'physical' human support (including domestic help if needed), care or interventions, therapies or any other paid service provided by a private professional.

These funds should be paid directly to the disabled person, not to "institutions" or providers.

This way, the person finally has several possible options.

Since "institutions" (or hospitals) are inevitably much more expensive (because of their "walls" and administration) than care or assistance at home or nearby, then people would choose the cheapest, which is also the most respectful of their freedom.

Assistance services "in the community" could therefore finally be developed.

At present, very large sums (around €300/day) are paid directly to the institutions if the person lives there, but not if they live at home or with their family. This is illogical and prevents freedom of choice.

The same sums (or sometimes less) should be paid directly to the persons or their families, in the form of "assistance vouchers" (for example) which can only be used for the specific assistance services they need, in free competition and not by being the plaything of "markets" where everything is decided for them and which need to keep them within their walls to live and prosper.

### **3.2.4. Free, remotely available public assistance**

Deinstitutionalisation makes free, remotely accessible human assistance indispensable (by any means adapted to all disabilities, including real-time written, audio and video dialogue, and any form of Augmentative and Alternative Communication).

This assistance must be available to all persons with disabilities, considering all types of disabilities (through real consultation and participation of persons with disabilities), including psycho-social disabilities and autism-related disabilities.

In particular, it should be accessible and effective in case of crisis or "social friction", and it should be usable (and known, through cards, wristbands, information) by those present (such as security or emergency personnel).

This assistance should include the possibility of free consultations with psychologists, counsellors (including legal counsellors), doctors or others, free of charge, at a distance and without the need for registration or formalities other than those needed to prove one's disability and its nature.

### **3.2.5. Teaching autonomy and life in the community**

There is also a need to offer people with disabilities, free of charge and if necessary at a distance, specific training or education to learn how to live independently and better manage life in society, particularly in the case of autism or psycho-social disabilities.

It is necessary to create "Personal Autonomizers", i.e. personal assistants in charge of accompanying, at home and in the community, one or more autistic persons (or persons with psycho-social

disabilities) in the long run and in a consistent and persistent manner, in particular by coordinating the possible caregivers and therapists but without ever making decisions for the person, with the precise mission of ensuring that the person becomes completely autonomous.

### 3.3. Changing mindsets

Really motivating awareness campaigns are needed:

- With families, so that they understand that their disabled relative should live with them.
- By showing taxpayers that their money is being wasted and used to segregate and generate "loss of chances".
- By allowing the broadcasting, without fear of censorship or prosecution, of reports that show the "naked" truth, such as the shocking *Zone Interdite (Forbidden Area)* documentary on "centres which abuse disabled children", very strangely unfindable (but still visible for now [on AutiLeaks](#)).

### 3.4. Solutions through International Dishonour

Unfortunately, there are no legal coercive means to force France to fully and sincerely respect the CRPD. However, for a State which believes itself to be prestigious and which is very careful to maintain this illusion, "international shame" is a powerful lever.

Thus, the International Organisations and foreign countries (including the press) should strongly increase their denunciations.

It would also be useful to symbolically and publicly propose to France to leave the Convention, since they are incapable of respecting it despite their important means (which are often diverted by private interests).

### 3.5. Solutions through Subsidised Salutory Expatriation

Persons with disabilities should be allowed to live in another ("less handicapping") country while receiving their disability benefits, because among the advantages:

- They would no longer be exposed to the risk of institutionalisation and forced hospitalisation;
- For autistic people, in many countries there is much less socio-generated harm and therefore less disability and less need for support;
- The persons would be able to discover a "real life", more supportive and more human.

Depending on the cost of living in the country of expatriation, the financial allowance could be reduced (never increased), which would represent savings for the country of origin.

It would therefore be necessary to create agreements between countries for the preservation of financial allowances.

It would also be possible to consider the relocation or training of human assistance in these countries, for the benefit of those expatriates and perhaps also as examples in the framework of international cooperation.

## **4- Crisis situations and pandemics**

### **4.1. Some of the collateral benefits of the Covid-19 pandemic and containment**

- Liberation of many disabled people.
- Proof that it is possible to live in family, far from establishments.
- Some of the flaws of institutionalisation are highlighted.
- It gave non-disabled people the opportunity to experience being deprived of freedom and being placed under a paternalistic public authority.
- Social status or lack of disability does not protect against the virus.
- Improving solidarity in the realm of individualism.
- The French have finally been able to accept communication and work at a distance, instead of repeating that it is absolutely necessary to "see one another" in person, which penalises many persons with disabilities (including autistic persons).
- Masks force people to get used to communicating without facial expressions (often reproached to autistic persons).
- Autistic persons are less touched by others (physically) and are no longer criticised for their social distancing or aversion to "tactile politeness".
- The city is quieter and less crowded.
- "Normal people" realise that their superficial pleasures are not so necessary.
- And more...

### **4.2. Billing the families for "days of absence beyond the annual maximum allowed"**

As incredible as it may seem, there is a limitation in the number of "absence" days authorised by the (public) Departmental Councils, and they ask the families to pay for these days if the disabled person is not

in the establishment, which is the last straw...

[https://www.apf-francehandicap.org/sites/default/files/courrier\\_relance\\_absences\\_esms\\_se\\_ph.pdf](https://www.apf-francehandicap.org/sites/default/files/courrier_relance_absences_esms_se_ph.pdf)

This very unfair and indecent aberration (revealed thanks to the absences due to the pandemic) pushes families to send the disabled person back to the establishment (or forces them to pay - very expensively - for nothing); it clearly shows that there are "fixed costs" not related to assistance or care but due to the "walls", and that economic considerations take the lead in all this system (obligation to pay for an absence of service, and "punishment" if one is in liberty: the person is just an indispensable pawn).

One should pay according to the services obtained, and not according to the economic needs of the providers.

### **4.3. How to avoid re-institutionalization after a pandemic**

The only way to avoid institutional tragedies during pandemics, or the return to those establishments, is to close them.

## **5. Needs of the persons having been liberated or to be liberated**

### **5.1. Full freedom (on equal terms with others)**

Including the possibility (as seen above) to move to a Less Handicapping Country (especially for autistic people or other relevant cases).

### **5.2. Free public assistance for communication, decision making and discovery of freedom**

These persons need support to become accustomed to freedom and to the possibility of deciding on their lives:

- By all necessary assistance (which in France is rarely provided for autistic persons);
- By the support of organisations of persons with the same disability (organisations which should therefore receive the necessary assistance as well).

### **5.3. Psychological help**

If necessary, to overcome trauma.

### **5.4. Moral reparation**

The aim is to obtain "justice" (judicially), punishment and reparation, especially for persons who have "lived" in hospital.

## **5.5. Financial reparation**

Not for the institutions that have lost their income (as was the case with the abolition of slavery in 1823 and 1848), but for the people who have been deprived of freedom and of 'chances' for years.