



Alliance Autiste^{.org}

Autistic Alliance

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

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CRPD

Analysis of France's responses to some of the Committee's oral questions on 18/08/2021 (539th meeting of the CRPD)

in the framework of the **French State review**
at the **25th session of the**
Committee on the Rights of Persons with Disabilities

(16/08/2021 – 23/08/2021)

- Publication : 19/08/2021 -

French --- English

*As a reminder, links to **our Shadow Report:***

FULL REPORT (in French with automatic translation)

EXCERPTS (in French) --- **EXCERPTS** (in English)

Video recording of this meeting on UN Web TV:
<https://media.un.org/en/asset/k1b/k1bv5fepmw>

Introduction

*"I find that **article 1 of the 2005 law** is one of the keystones of the problem because it creates confusion and conflicts of interest between the managing associations of the medico-social sector and associations of people with disabilities, which allows the managing associations, and not the organisations representing people [with disabilities], to have a preponderant influence on [the] public policies on disability. "*

Mr Jonas Ruskus, opening statement, 539th meeting of the CRPD,
18/08/2021

<https://media.un.org/en/asset/k1b/k1bv5fepmw> (22'50")

(Thank you very much.)

- *Statements **not translated into French by the simultaneous translation** (which - therefore - are not heard by the French delegation) are with a **dark grey background**.*
- ***Badly translated** terms are shown with a **light grey background** (when this may change the meaning more or less).*
- *Elements **added by mistake** in the interpretation are with a **red background**.*



00h27'00" - 1 [CRPD] Questions from the Committee (Ms Amalia Gamio)

(...)

→ What steps are being taken to harmonise national legislation in practice with the provisions of the CRPD, and in particular with regard to de-institutionalisation, which is an extremely serious problem in France?

It seems that there has even been a backward step from a legal point of view with the decrease in the number of accessible housing units, the [decrease in income (problem of decrease in AAH depending on the spouse's income)], or [the fact that the] Oviedo protocol is maintained (...).

(...) [regarding the request to withdraw the interpretative declaration] (Article 15), you reply that you interpret the term "consent" in accordance with the European Convention on Biomedicine Rights and its additional protocol: this doubly violates the Convention on Articles 12 and 15, and it reinforces the medical approach, **it is a medical offence**, which is one of the most serious problems that exist in France, and it violates the Committee's declaration opposing the Oviedo additional protocol.

→ Can you give us your position on this?

(...)



00h31'09" - 2 [CRPD] Questions from the Committee (Ms Gerel Dondovdorj)

(...)

You have indicated that steps have been taken to harmonise all national laws and policies with the CRPD, and to mainstream the rights of persons with disabilities.

→ I would like you to provide information on the current status of the reform to abolish discriminatory legislation and decrees that allow hospitalisation and care without consent for people with psychosocial disabilities.

→ With regard to this legal harmonisation, how does France ensure its commitment to respect the CRPD, and also how is this reflected in the implementation of other instruments?

For example (...) the 2008 Convention on Vulnerable Adults, what are the measures in line with the CRPD and with the UN Council (...) (...) on the protection of vulnerable adults adopted in 2021.

→ (...) [About the functioning of the CNCPH], [my concern] is about the appointment of the members of this Council, which is made by a Government Ministry, so this [limits the capacity of participation] of people with disabilities.

In this regard, what about the budget, does it allow for the participation of people with disabilities?

Are there any measures and actions to remedy these problems and to improve real participation of people with disabilities in this council?

And is there any evaluation done by the French Government to check the effective participation of people with disabilities in their advisory council and in other committees.

(...)



00h35'46" - 3 [CRPD] Questions from the Committee (Mr Robert Martin)

(...)

I would also like to talk about the Advisory Council [(CNCPH)].

I would like to know to what extent people with disabilities can take part, or are they represented by their families, for example.

Families are important, but it is important that people with disabilities can express themselves.

→ Can you tell us to what extent disabled people are involved in the work of this council and to what extent they have access to legislative and policy decisions?

It has been brought to my attention that the CRPD and other human rights texts have not been translated into easily understandable language.

(...) This is not compatible with the Convention (...)

What steps have been taken to (...) dignity (...) rights (...) abortion for babies with Down syndrome?

(Question on Braille and audio formats)

(...)



00h39'19" - 4 [CRPD] Questions from the Committee (Mr Markus Schefer) *(in French)*

(...)

The 2016 Blatman Report deals in detail with the direct applicability of the Convention.

The exchanges with civil society show, however, that French jurisprudence is very restrained with regard to the direct applicability of CRPD rights in individual legal proceedings.

→ Could you describe the current practice, and how the rights of the CRPD are guaranteed in these proceedings?

According to information from associations of [disabled] people, there is a general ignorance of Convention rights in the courts and the administration.

There is also a lack of general coordination of these rights.

A proposal by the National Consultative Commission on Human Rights [(CNCDH)] along these lines was rejected by a Senate committee.

However, there has recently been a training package for the staff of the administration and judicial bodies.

→ How does France ensure that the rights of the Convention are effectively realised in court proceedings and administration, and in this context, could you please explain how the EU

Directive on victims' rights has been transposed and is being implemented to ensure that all rights are recognised and applied to victims with disabilities, also taking into account the EU Strategy for Victims' Rights from 2020 to 2025?

(...)



00h41'38" - 5 [CRPD] Questions from the Committee (Ms Gertrude Oforiwa Fefoame)

(...)

Measures regarding articles 6 and 9: is there a clear roadmap or programmes to take much more care (...) about women and girls with disabilities.

(Another issue concerning women and girls with disabilities)

→ Regarding Article 9, what measures are you taking for the accessibility of online platforms, private or public, websites, so that people with disabilities have equal access to information?

Example of an online forum on women's accessibility but without subtitles, so I think a lot of women and girls with disabilities have been excluded: what steps are you taking?



00h44'15" - 6 [CRPD] Questions from the Committee (Ms Odelia Fitoussi)

(...)

My questions are based on some alternative reports.

- **Regarding Article 7, I would like to know what measures (or aids?) are provided by the state for autistic people, which are not based on a medical approach, for inclusion in the family and in society.**

- **What is the policy on babies born with Down's syndrome, especially in the north of France, do they receive care in France, or are they transferred to Belgium?**
We heard that they would be transferred to Belgium.

- **If they are transferred [to Belgium], what are the reasons for transferring them?**

- **If not, do they receive care and education and assistance at home like other children?**
And why can't France take care of them?

- **Regarding Article 10, what are the policies to prevent the killing of autistic children by family, due to lack of knowledge, despair, or perception of (?) worthlessness, and to prevent the exodus (?).**

- **Are there any awareness-raising programmes (?) concerning the issue of autism?**

(...)



00h56'22" - 1[FR] Response from France (Ms Sophie Cluzel - Secretary of State for the Disabled)

Answer to the question by Ms Amalia Gamio on de-institutionalisation

Excerpts:

"France's choice of institutional model should not be understood in the light of institutionalisation or de-institutionalisation, it is the choice to go towards people, as close as possible to their life choices.. (incomprehensible) ("que des avancées"?). "

"To respect these life choices and to accompany them towards autonomy and self-determination, which is extremely important to me, the Departmental Houses for the Disabled [(MDPH)]..."



Comments from the AA

Sophie Cluzel's response: blah blah blah.

She uses the logic of "**life choice**" to avoid talking about de-institutionalisation.

But there can be no real possibility of "choice" when there is no inclusion in society, AND when people have been conditioned to live in institutions and know only that.

Moreover, it is often the parents who insist on sending their children to these institutions (imagining that it is beneficial) because the "system" as a whole is not designed for children (or adults) to live with their families (no autism education for the parents, no help in organising themselves at home, no "proper consideration of autism everywhere" (in society), etc.)

In a (single) meeting we had with the representative of the Collectif Handicap (i.e., more or less the medico-social lobby), he started by using this "people's choice" argument. Sophie Cluzel is doing exactly the same.

This is their common strategy (politicians and the medical-social sector), to avoid the difficult issue of de-institutionalisation.

Instead of using the fundamental principles and the CRPD, they prefer to use "people's choice".

It's very clever...

But as usual it's vicious because the whole system in France currently

forces one choice, and parents are so conditioned and believe in it that they themselves "cry" for more centres to be built.

The "best dictatorship" is when people themselves demand their own enslavement. (cf. <https://naturedefenders.org/about-the-obsolence-of-man/>) This problem is not only related to disability, it is general.

But disabled people themselves do not have and have never had the choice to make comparisons and therefore informed choices.

How can we choose freedom (something we can discover in other countries, such as Brazil), when we don't know what it is?

This "freedom of choice" strategy is in fact like in all semi-dictatorial countries, where the citizens elect their president, but everything has been done to eliminate the opposition, and finally they are given the "choice" to elect a single candidate.

It's a bit of the same deception.

(Explanations on MDPH...)

Blah, blah, blah... "life wishes"... "most appropriate solution"...

"It's the same logic", blah blah blah... "the most complex needs", blah blah, blah...

(...) "in autism, and severe autism" (...), "two initiatives..."

"Early identification..." (explanations)

"Interventions [that are done] well before the diagnosis..." [(??...)]

"The disabled person is not a spectator of his or her life but an actor in his or her life."

→ Typical example of useless theoretical statements and "incantations" of EYPD...

(Presentation of the concept of "360° platforms", in response to proximity").

"It is really a policy of territories: they are solutions of proximity, which **think about building** the policy with the person.

Life-course assistants... Life-course referents...

Help in expressing wishes... "The answers can be very technical, or simply an accompaniment in ordinary life..."

(At one point it says "for children, but not only", and the word "adults" is heard at the end of a short sentence).

"We are in the process of **deconstructing the monolithic response** (...) in order to have a **totally plural response**, with all the actors concerned, and no longer centred on the medical - as you have so often said - but on the social and the accompaniment in ordinary life (...).

- Regarding "no longer medically focused", it is not enough to move away from hospitals, it is also necessary to abandon the medical model of disability and the medical approach to autism. It is perfectly possible to do what she describes (which are physical and material measures), while keeping the medical approach (which is linked to a state of mind).

"A national telephone, and a territorial response



Comments from the AA

Sophie Cluzel spoke for many minutes about "territories" and "villages", but this is just blah blah.

And the "360° platform" is "nonsense", it's just a phone number that refers to MDPH, but it's very complicated to use! (and it is specialised on the coronavirus crisis).

What misery! And lies!

We set out all this in our report in

1a-5[AA(Com.)] AA comments on answer 5, here:

https://allianceautiste.org/docs/AA_OrgIntl/ONU-CDPH/Rapport_2021/20210805_Alliance-Autiste_Rapport-application-CDPH-France.htm#_Toc79074062

She talks all the time about policy "in the territories"...

But of course, that policies have to be applied at the level of where people live...

It seems that the French government, from its cloud, is starting to understand that its "policies" have to end up being usable and effective where people live...

"I salute the commitment of the **managing** associations who are totally transforming their model of response to people's needs."

- This is a message of support for the "friends" of the social care sector, who are concerned about this review by the CRPD Committee.
- There is no evidence of this transformation.
- If they were "totally transforming", there would be bed cuts. And if there were bed cuts, the French government would be sure to say so!
In the statistics, there are none.

"So it's really far from a caricature, our model is really focused on the development of services, and when you have the word 'facility', it's mostly the word 'service' (*sic - singular*), social and medico-social that are being developed."

- This is nonsense.
Establishments and services are two very different notions. That's why the notion of "services" exists: to make the difference with "institutions" (which manage "walls" and accommodation). They do everything to try to hide the problem of the institutions, by developing services (which is positive) but without removing anything from the "walls".
In fact, this system uses "services" to hide the problem, and to get extra (€€€) markets.
And she dares to try to deceive the Committee members by trying to confuse "facilities" and "services"...

The sentence would have been more correct in this way: "when you have the expression "establishments and services", it's mainly the "services", which are being developed", but anyway all these declarations, manoeuvres, and "services" don't change anything to the fact that there are still so many people living in establishments.

Explanation on "the third alternative with inclusive housing, according to the choice of the person, in shared accommodation if he/she wishes or not..." "... in the heart of the city, in the heart of the village...".

- This does not change the problem of institutionalisation. France has still not answered the question of how many people have been "taken out" of institutions to live in these "inclusive habitats".

The Coordination Handicap Accessibilité - Vie Autonome explained to us that, often, it is people who already live in an "ordinary environment" (e.g. with their parents) who choose to move to these "inclusive habitats", for various reasons.

So in these cases, it is not possible to "move people out" of institutions (with accommodation).

In fact, perhaps this should be banned, and "inclusive housing" should be reserved only for people currently living in institutions (as a transitional solution before real freedom).



01h01'35'' - 2[FR] Response from France (Mr Frank Bellivier - Ministerial Delegate for Mental Health and Psychiatry)



Note from the AA

- *For more than 6 minutes, the French governmental delegation tries to adjust its microphone, but cannot.*
- *You can even hear "C'est quoi ce bordel?!" from their side (which is translated into French Sign Language), and the UN person trying to help them (from a distance) cannot help but laugh.*
- *The French government doesn't even have the decency to do serious testing for such a high-level meeting, broadcast live on UN Web TV...*
- *At the end, the speaker can't even find the name of his colleague to whom he should pass the floor (and who is in the same room).*

- This is objectively pathetic...

And it is another proof of the difference between :

What is displayed (costumes, relative elegance at times, soft and gentle voices, reassuring speeches...);

and reality (incompetence, contempt, and rudeness when faced with the consequences of one's enlightened, thoughtless and wrongful short-sightedness).

P.S. We learn that this gentleman is a psychiatrist: so there is nothing surprising about what we see here.

He lives in his own world, disconnected from reality, and this is doubly so since he is at the same time a psychiatrist and in the French administration or political bureaucracy.

This pathetic sequence is one proof, among thousands of others.

But hundreds of thousands of people suffer in France, because of these "caricatures", because of these people who have an influence on their lives, when it is clear that they are not even capable of doing simple things and that they do not even understand that what they say is not adapted to reality.

It's a guilty behaviour, the whole system is rotten and guilty.

It's the French administration. On its high cloud.

The technical problem is not its fault, but it is a whole, they should have tested before and prepared better.

The whole performance is so **pitiful**, from beginning to end and on all aspects (content and form), that we give up trying to make an analysis of it, especially since some associations (such as Advocacy France or the Collectif pour l'Arrêt des Traitements Forcés) will certainly do it better than us.

However, we will make some brief comments below.

01h07'52"

Additional Protocol to the Oviedo Convention

"**involuntary treatment** of persons with mental disorders".

"**involuntary measures of treatment** or placement in the **exceptional cases** where these measures are implemented".

→ "involuntary": a euphemism for 'under duress'.

Grammatically, this is not even correct.

These treatments and measures are indeed "voluntary" because they are decided and imposed by the will of doctors.

→

How many tens of thousands of "exceptional cases" ?

It is clear that this gentleman has never been locked up in a psychiatric hospital.

"this project, this text, is not incompatible with existing law and in particular with the ICHRD"

→ All the opposition to this project, notably by the CRPD Committee, is not even mentioned. Mrs Gamio's question: we don't even know if this gentleman heard her.

He reads his text, prepared and printed a long time ago.

"France" imposes its theories and decisions, without listening, ignoring.

This gentleman does with Madame Gamio exactly what the French administration does with us.

They do not listen to us, there is no dialogue.

We are "served" texts and declarations, told that it is good and that everything is fine. And we have to believe it.

Can you imagine the degree of contempt of SEPH for us (and for our association), seeing that even a question of the CRPD Committee is ignored?

And many other questions have been ignored.

"which aims to define a binding regulatory framework for these practices".

→ "which aims to define a framework for framing"

But where did they find this person?

It's really pathetic.....

(France offers two concepts...)

"programme the extinction of these practices and therefore the implementation of alternative strategies to the use of care without consent, seclusion and restraint".

→ What is "programming"? And how? Evidence...

"the promotion of tools such as joint crisis plans or advance arrangements with people with mental disabilities

→ What is this "joint crisis plans" and "advance arrangements"? (it seems to be related to ageing)

Care without consent

"freedom is a constitutional principle in France".

→ Blah blah blah...

"in certain circumstances, however (and these are often situations that are temporary), the person's consent to care, and only if that care is urgent, cannot be obtained, because of a temporary clouding of judgment or a temporary inability to participate in the care decision"

→ What about all the non-emergency cases that last for years?

→ "temporary clouding of judgment"? Who knows? One can have different judgements and wishes than the psychiatrists' views! (and it's even preferable, especially when you see this...)

→ "temporary inability to participate in the decision"... This means that a doctor makes a decision about the person, and judges (himself, all by himself) that the person's judgement is too "clouded" for him to "participate", i.e. give his consent.....This is too easy!!!

"French law provides that in certain circumstances and under the control of the judge, freedom can be limited.

→ Fffff... What hypocrisy.... Novlangue.....

When you are locked up for years and in reality there is NO way out, and the despair is bottomless, and you are like being at the bottom of a 1000 km deep well, and only the public psychiatrist medesinge is the master and can decide whether our "judgement" is "clouded" or not

Strangely, he did not mention "dangerousness" or "supposed dangerousness", which is the classic excuse.

They must have felt that this "trick" was far too well known at the CRPD Committee level...

Perhaps the new trick is "clouded judgment"?

"these practices are strictly regulated by law

→ Blah blah blah - see contributions from Advocacy France, Collectif Arrêt des Traitements Forcés, France Disability, for example.

"Faced with the persistence of what is still considered to be too high a level of recourse to these practices, their supervision and control have just been strengthened at the beginning of this year, and will be further strengthened in the coming months, since France has made the extreme reduction of these practices a major objective of its strategy for mental health and psychiatry, and moreover the Constitutional Council has asked for a new amendment to guarantee effective control of these situations of deprivation of liberty by the liberty judge.

→ They themselves recognise that there is too much abuse.

→ He says that everything is getting better and better, citing vague reinforcement measures at the beginning of this year (what is that?), and that it will get even better soon, because :

"France is making the extreme reduction of these practices a major object of its strategy for mental health and psychiatry".

And because :

"The Constitutional Council has requested a new amendment

It is completely abstract and vague...

It is "the magic of France"...

Moreover, the word "control" is ambiguous. It is quite possible to control something without having any influence on it.

"uh, here goes..."

→ Pathetic... Not even able to adapt to a high-level international meeting...

It's

August, the French bureaucracy is on holiday (proof, by the way, that it is not so indispensable...)



01h12'10" - 3[FR] Response from France (Ms Carole Guechi - Ministerial Delegate for Accessibility)

(Loi Elan and accessibility of housing)



Comments from the AA

We cannot comment on these issues as they are not our speciality.

We wrote to this person, who replied that accessibility for autistic people was a question of "human posture" and that we should contact SEPH (who never replied).

After a second reply which showed that she did not understand our explanations (see below), she never replied to our other emails.

(The fact that it was done nicely does not solve the problem).

See more explanations and evidence (e.g. with the message from Service-Public.fr which itself admits its lack of accessibility for autism and "psychosocial"), in our (full) report, here (shortcut for direct access): https://allianceautiste.org/docs/AA_OrgIntl/ONU-CDPH/Rapport_2021/20210805_Alliance-Autiste_Rapport-application-CDPH-France.htm#_Toc79073929

Subject : Possible consideration of autism by the Ministerial Delegation for Accessibility
Date : Thu, 8 Apr 2021 23:06:35 -0300
From : > contact (via Internet)
<contact@allianceautiste.org>
Reply to : [contact](mailto:contact@allianceautiste.org) <contact@allianceautiste.org>
For : dma.sg@developpement-durable.gouv.fr

Madam Delegate

We would like to know whether your Delegation, in its work, considerations or decisions, takes into account autism and/or related disorders and/or disabilities, and if so to what extent.

Yours sincerely

Possible consideration of autism by the Ministerial Delegation for Accessibility



SG/DMA (Délégation ministérielle à l'accessibilité) issued by 9 Apr 2021,ent
- SG/DMA <Dma.Sg@developpement-durable.gouv.fr> 11:41

Hello ,

It is the responsibility of the Ministerial Delegation for Accessibility, which I head, to lead the public policy on accessibility of the Ministry of Ecological Transition (MTE) and the Ministry of Territorial Cohesion and Relations with Local Authorities (MCTRCT) with regard to the accessibility of the built environment, roads, public spaces and transport. I enclose a note on our remit for your full understanding.

But I would like to draw your attention to the fact that the delegation does not decide on the content of public policies. It participates in their legislative, regulatory or normative transcription and ensures that they are understood and applied by public and private actors according to their field of responsibility. From a political point of view, it seems to me that the government, and in particular Mrs Sophie Cluzel, Secretary of State for the Disabled, is conducting a proactive policy in terms of the recognition and inclusion of people with ASD.

However, if there are any clearly identified issues within the scope of the MTE and MCTRCT that require a meeting, please let us know.

Yours sincerely

Carole GUECHI

Ministerial Delegate for Accessibility

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**Ministry of Ecological Transition Ministry
of Territorial Cohesion and Relations with Local Authorities Ministry of
the Sea**

www.accessibilite.gouv.fr

11 April :

Madam Delegate

Thank you for your response and for the presentation note that specified it.

We would like to know whether your Delegation, in its work, considerations or decisions, specifically and explicitly takes into account autism and/or related disorders and/or disabilities, and if so to what extent.
(A priori, this is not the case, but it is not for us to say).

We are already in contact with SEPH and DISAND (Délégation Interministérielle Autisme).

It is precisely because these entities seem to be unfamiliar with the notion of accessibility (in the broadest sense of the term) and universal design in the field of autism, that we thought it might be useful to ask you some questions, as part of our efforts to identify possible traces or projects contributing to the said "accessibility".

In order to better understand our approach, we need to look at the characteristics of autistic disabilities.

The special measures that people with autism need to access services (especially) with less difficulty (or more equity) are forms of adaptation of the "socio-administrative system".

For example, for a "PRM", accessibility may mean ramps or avoiding the location of services on floors; for an autistic person it may mean, for example, more "accessible" administrative forms, more "accessible" (less abstract) pictograms, adapted queues, less absurd temperature settings (hot/cold), the provision of human assistance for communication or mediation, etc.

We can assure you that, for example, overheated shops, shopping centres or public transport in winter are completely inaccessible for many people with autism (as well as floors without lifts for PRM), and the list of examples would be long.

The benefits of "autism accessibility" are particularly interesting:

1- Firstly, they allow autistic people to have effective access to institutions, transport, but also to services or "abstract" things (such as technical or commercial assistance services at a distance, which are already very difficult for non-autistic people, and which are often inaccessible for us); even some procedures for obtaining aid are considered too difficult (inaccessible) by people with autism (due to the lack of human assistance and the lack of accessibility of procedures), who therefore do not carry them out and therefore do not access the aid they could benefit from;

2- Secondly, all citizens would benefit from this accessibility. Indeed, autistic people do not need "inhuman" or "superhuman" measures that others could not bear, on the contrary, autistic people need "more finesse in a world of brutes" (to sum up), and therefore the fact of refocusing and correcting what needs to be corrected, of moving towards more balance and harmony, not only cannot harm "ordinary" people, but it can only do them good.

For example, for temperatures, less extreme settings (such as 20-22°C in winter and 24-26°C in summer) will not bother anyone, and elderly or sensitive people will be relieved (it is quite often observed that they suffer as much as we do from overheating of public buildings). Most of the world's heating and air conditioning "managers" seem to ignore the principle of a thermostat and systematically set it to "full" (cf. "rough world").

3- Finally, not only do measures for the accessibility of autistic people cost almost nothing (since it is first and foremost a question of "optimising the systems"), but they also make it possible to make significant savings, which is easy to understand if we continue with the example of heating (and the "insane" and unnecessary temperatures of 28°C when it is zero outside). If the sensitivity of autistic people was duly taken into account (i.e. if accessibility, in the broadest sense of the term (including "intangible" accessibility (procedures)) took autism into account, then just with the heating issue (but there are many others) it would be possible to save tens of millions of euros each year (and incidentally to have a little less air to pretend that there is no money to help us, but that's another problem).

We hope that these few reflections will help us to better visualise what we are talking about, so that we can better answer our questions and, as far as possible, make them fruitful.

To achieve this, the most difficult thing is to understand what autistic people really need, but here again there are solutions: you have to start by consulting autistic people themselves (which by the way corresponds to article 4.3 of the CRPD), and not only "professionals" or "specialists" who do not live what they are talking about.

(We were part of the Steering Group of the HAS-ANESM Recommendation of good practice for adults with autism).

In the hope of receiving answers and useful consideration, and remaining at your disposal, please accept, Madam Delegate, the expression of our best wishes.

The Autism Alliance

From: **SG/DMA (Délégation ministérielle à l'accessibilité) emis par MOST Vincent - SG/DMA** <Dma.Sg@developpement-durable.gouv.fr>
Date: mon. 12 apr. 2021 at 08:15Subject
: Re: Possible consideration of autism by the Délégation Ministérielle à l'AccessibilitéTo
: contact <contact@allianceautiste.org>

Dear Alliance Autisme,

I took care to reply to your first rather inquisitive email with some elements of clarification that I thought necessary to set the framework of our action. You immediately conclude that none of our "work, considerations or decisions specifically and explicitly take into account autism and/or related disorders and/or disabilities".

I obviously cannot let you say that we exclude any disability family from our actions. Since the 2005 law, mental disability is taken into account as a disability in its own right and is no longer assimilated to mental disability.

For the areas that concern me: The DMA has drawn up a booklet on the various disabilities "A short memento on disabilities for people presumed to be able-bodied", which will be updated for the next Autonomic Paris exhibition on 12, 13 and 14 October. The revision will focus on mental disability, as much progress has been made in terms of knowledge of this disability since the first publication.

As your association points out, accessibility measures for autistic people are not "concrete-bitumen" adaptations, but rather accompaniment and human posture. This is therefore outside our regulatory framework. On the other hand, the principles we present in our guides for the reception of people with a mental or psychological disability partly meet these needs.

In the standardisation work that the DMA follows or initiates, mental disability is well taken into account, despite the absence of an association representative, particularly in terms of lighting, illumination, noise, and crowd movement such as fire evacuation, for example.

If in tourism and culture policies, the visual representation of mental disability remains associated with the pictogram of mental disability, it is for a simplification reason, as the Tourisme & Handicap and Destination pour tous representation is now well perceived by the general public. However, in all the criteria, mental disability is well taken into account (accessibility of websites, adapted visits to media libraries and museums, etc.).

These are some of the thoughts that come to me after reading your new e-mail. You can be sure that the DMA is driven by a constructive approach in favour of people with disabilities and that this motivates us on a daily basis.
Yours sincerely

Carole GUECHI
Ministerial Delegate for Accessibility
General SecretariatGrande
Arche- 92 055 La Défense CedexTel



01h16'30" - 4[FR] Response from France (Ms Sophie Cluzel - Secretary of State for the Disabled)

Answer to the question by Mrs Gerel Dondovdorj on the CNCPH

Excerpts:

"This Council is essential, it informs the government (...)"

"(...) body (...) associated with the implementation but also with the construction, it intervenes in the construction of the texts, and above all it follows their operability and it evaluates the application of these texts".

"co-construction", "participatory democracy"...

"operability

→ Is this word "accessible" and "easy to understand"?

"I wanted this CNCPH to be renovated in 2019 in order to improve the participation of people with disabilities and their power to act"

→ So we can see that it is under the influence of public authorities

"we have 6 colleges, the most important one (numerically) is the one representing associations of disabled people and their families; **we have another college which represents associations or managing bodies**, and which represents professionals who intervene in the field of disability" (and she quotes other "colleges").

→ **This is misleading or deceptive!**

Moreover, this 2nd college cannot represent management associations, since they themselves want to present themselves as associations of disabled people and families (thus 1st college).

It's really nonsense, she mixes everything up.

If it's intentional, it's serious, and if it's not intentional, it's also serious, when you are Secretary of State, to make such confusions.

Order of 8 February 2020 appointing members of the National Advisory Council of Disabled Persons

<https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000041850077>

1° College of representatives of associations of persons with disabilities or their families composed of a maximum of 65 members

2° College of representatives of associations or organisations representing professionals working in the field of disability, composed of a maximum of 35 members

Associations managing establishments and services are in the FIRST college (for example, APF France Handicap, UNAPEI, Fédération APAJH, Sésame Autisme, etc.), because they are considered to be "associations of people with disabilities or their families", and indeed they generally are, but it is important to distinguish between those managing establishments and services and those managing associations.), because they are considered as "associations of people with disabilities or their families", and indeed, in general they are, but a distinction must be made between those who manage establishments and services and the others, which are truly representative of the interests of people with disabilities, without the risk of influence by economic interests or by the 2 million people employed by the medico-social industry.

"Of course, these people are appointed under my signature, but the candidates are selected by an **independent committee...**"

→ What is this "independent committee" that selects candidates to be in the CNCPPH?

It's all cronyism...

"to examine each bill".

"to guarantee perfect accessibility from the outset of the CNCPH's productions, with the aim of enabling as many people with disabilities as possible to follow the work of the CNCPH

"it is an autonomous body



Comments from the AA

They try to make it look like this CNCPH is open to the participation of disabled people, but in fact, to participate, you have to be chosen "by the grace of the prince". There is not even a way to contact the CNCPH. The Secretariat General of the CIH never answered us (we don't want to be "part" of the CNCPH, but we want to participate in the decisions, it is not the same thing).

In fact, everything is protected.
You have to "be part" of the groups that are created by the government, and you have to please.
Otherwise, you are ignored.

The relationship between this CNCPH and disabled people (or "non-admitted" associations - and there is far too little room anyway), is one-way: we only have to be able to find out what they are doing. This is not open, broad and democratic consultation at all.

We have analysed these problems of representativeness of the CNCPH (and its subtleties and vices) in much more detail in our (full) Report, which can be found here (shortcut to this section): https://allianceautiste.org/docs/AA_OrgIntl/ONU-CDPH/Rapport_2021/20210805_Alliance-Autiste_Rapport-application-CDPH-France.htm#_Toc79073937



01h20'40" - 5[FR] Response from France (Ms Céline Poulet - Secretary General of the Interministerial Committee on Disability)

Answer to the question by Mrs Gerel Dondovdorj on the functioning of the CNCPH

Operating budget :

Travelling expenses, hotel expenses, translation expenses (into LSF, written subtitles), provision of rooms, training of members.

Team of 4 people in support.

Participation of people :

"A major effort has been made to ensure that people can express themselves, and we have developed training for members of the CNCPH on "Easy to Read and Understand" so that people can express themselves in this body in a sufficiently flexible way for all people to be able to give their opinion on the texts proposed to us. "

(Effort on easy to read and understand)

"The CNCPH participates in many projects, but people with disabilities themselves, even if they are not members of the CNCPH, can participate in other bodies in France, such as those related to the work of people with disabilities"

"The ICHRD is well translated in France into Easy to Read and Understand language".

"to promote all access to government communication, in Braille, in LSF, in Easy to Read and Understand... multimodal, to be able to reach all people with disabilities".

The benefits of transport, restaurant and hotel expenses for the "chosen elite" of the CNCPH are not useful for the representativeness of disabled people (except for the few "genuine" associations that are there).

Concerning participation, she said that a major effort had been made to ensure that people with disabilities could **express themselves**, mentioning FALC, but how could they express themselves if they were excluded?

In short, we are told that we cannot participate in the CNCPH, but that we can always try to participate elsewhere, at local level, for example in the field of employment...

And efforts are being made to ensure that we, 'la France d'en bas', the little people, have the chance to learn about work to which we have not been invited.

In 2021, there is no need for travel and hotel expenses.
And translations into FALC or LSF of the productions of the CNCPH, directed and chosen "from above", are not indispensable to us.

In 2021, it would be very easy to organise broad, open and democratic consultations (and above all decisions) via the Internet, but this would not help at all the affairs of this little world, which is gangrened by lobbying to the core.

This explains this protectionism and opacity (in which the government is an accomplice and even an actor).

We demonstrate in our report the problems of the CNCPH and its GREAT inaccessibility (they don't even have an email address) here:
https://allianceautiste.org/docs/AA_OrgIntl/ONU-CDPH/Rapport_2021/20210805_Alliance-Autiste_Rapport-application-CDPH-France.htm#_Toc79073937



01h23'40" - 6 [FR] Response from France (Ms Marine Boudeau - (Digital Accessibility))

Response to the question by Ms Oforiwa Fefoame on the accessibility of online platforms (websites)

New obligations for companies with a turnover of more than 250 million euros per year.

Access to law, online procedures... Observatory that lists the 250 most used procedures... (RGAA)

32 million investment to accelerate the improvement of accessibility for all

Raising awareness and skills in ministries

"Accessibility Commandos"...

"very aggressive objectives"...



Comments from the AA

In any case, the RGAA and digital accessibility do not take autism or psychosocial disability properly.

We explain this in detail in our (full) Report

See 7b: https://allianceautiste.org/docs/AA_OrgIntl/ONU-CDPH/Rapport_2021/20210805_Alliance-Autiste_Rapport-application-CDPH-France.htm#_Toc79074007



01h27'38" - 7[FR] Response from France (Mr Marc Salvini - Ministry of Justice)

"An international convention that has been duly ratified has **direct effect**, and the Cour de Cassation reminds courts that might tend to forget this. "

(Training)

"Educational kit (Droit Pluriel association): awareness-raising

Criminal procedure (for victims): **the integration of accessibility of disabled people is total** through, when necessary, integration in texts, specifications, for example for the legal protection of adults, for example for the deaf, aphasic, hard of hearing, with special considerations.

Protection is provided, either in the texts or in a general way, from the filing of a complaint to the judgment, and after the judgment, possibly civil compensation.

Victim support... Victim support associations (which the Ministry of Justice subsidises) are generalists, but also specialise in disability, and I welcome "Femmes en danger", "Femmes libres" (?)



Comments from the AA

→ On direct applicability :

- See the **Blatman Report on the direct effects of the Convention's provisions**, e.g. from page 200:

https://www.defenseurdesdroits.fr/sites/default/files/atoms/files/02_rapport_de_michel_blatman.pdf

However, this remains "theory", and we know that in France what is "on paper" can easily stay there...

This text talks a little about the problems of reluctance of judges:

<https://halshs.archives-ouvertes.fr/halshs-01889465/document>

Excerpts:

"The applicability of a text is a necessary condition for its effectiveness before the courts, or if one prefers, for its justiciability. It is not, however, a sufficient condition: a text may be considered applicable without being applied. But what are the legal conditions of applicability? Can it be justified that a text of positive law is not directly applicable? An answer is often given on the basis of the direct effect of a text, its legal scope, the possibility for individuals to invoke it before a court. Note that this last formula is misleading. A legal person will always be able to invoke a text - which is moreover valid in the internal legal order - before the courts. The problem is precisely that judges sometimes dismiss it as inapplicable. What considerations allow judges to reject the legitimate request of legal persons to invoke a rule of positive law? The solution differs according to whether the texts whose application is envisaged have an international or domestic origin. The current status of the jurisdictional application of the New York Convention on the Rights of the Child

"The avowed reasons for inapplicability can be reduced to three: the intention of the signatories of the treaty to have created obligations for States alone and not (to have opened up rights) for other legal persons; the lack of precision and imperative nature of certain provisions with insufficient normative content; the incomplete nature of international norms which must be clarified by domestic, i.e. State, norms in order to become applicable. The **unmentionable** reasons are, as is often the case, easier to understand: **the concern of governments to derive political benefit from the signing of international commitments without allowing citizens to derive rights from them; the reluctance of public authorities to make applicable a law of international origin; the prevalence among certain judges of a nationalist and sovereignist ideology which considers that positive law is primarily of internal origin, i.e., in their minds, State law.** "

" . However, the positivist approach attaches the greatest importance to the distinction between the legal value of a text (formal validity) and its application, including by the courts (effectiveness). A rule of positive law remains legally valid even if it is not effective and implemented by the courts. **The legal value of the fundamental rights recognised by the Constitution is not diminished by the reluctance of judges to make them produce all their consequences** (see on the right to obtain a job, E. Dockès, Valeurs de la démocratie, Dalloz, coll. Méthodes du droit, 2005, p. 28). A positive law text is therefore, by definition and unless it is impossible, directly applicable. "

"The general answer to the question posed is quite simple: **a text is directly applicable when it is considered as such by the authorised doctrine. It**

undoubtedly flatters the ego of the jurists from above with regard to the citizens below.

Democracy lies elsewhere: it requires that texts of positive law, whether of international or domestic origin, can be simply and usefully invoked by individuals before the courts. "

→ See the explanations of our colleagues from other associations

→ There are no associations or other things to assist with access to justice for autistic people.

The association Droit Pluriel seems interesting, but it just puts you in touch with lawyers, who are not autism sensitive.

There is no assistance adapted to autism, I have proof of this by my own example.

The lawyer told the association (and not even me) that I should look for a social worker (but they are not legally competent). All this is explained in detail in our (full) Report here :

https://allianceautiste.org/docs/AA_OrgIntl/ONU-CDPH/Rapport_2021/20210805_Alliance-Autiste_Rapport-application-CDPH-France.htm#_Toc79073963

and here :

→ On these legal issues, our colleagues from the Collectif pour l'Arrêt des Traitements Forcés (among others) will be able to provide more information.



01h30'40" - 8[FR] Response from France (Mr Jérôme Jumel - Deputy Director General, DGCS)

Parity (women / men) in consultative bodies

Search for free choice and self-determination (women - MDPH)

350 free choice facilitators

3919 helpline: accessibility

...

Instruction for institutions (ESMS)

Also in higher education - testimonies of women students with disabilities

Support to associations (e.g. "Women to say it, women to act")



01h35'30" - 9[FR] Response from France (Mr Philippe Romac - State Secretariat for Children)

Parenting support for people with disabilities



01h37'21" - 10[FR] Response from France (Ms Claire Compagnon - Déléguée Interministérielle Autisme et TND)

Answer to the question by Ms Odelia Fitoussi

Autism Strategy

Children :

- Schooling
- Early identification, diagnosis and intervention (children)

Rights-based approach...

Referral to specialised services that will give them all the guarantees of an intervention by competent professionals
Support for families, particularly in terms of parental guidance (although this aspect needs to be further developed)

Possibility of schooling in a "regular" school

More than 42,000 autistic children enrolled "in the school of the republic" (increase)

Coaching - consensus methods (Teach, ABA, Denver)

"And this allows these children to integrate into very inclusive arrangements since they are both taken care of in ordinary schools in specialised units with increasingly long periods of inclusion in their age group, to enable them to be in the same situation as all children taken care of in French schools. "



Draft comments

(impossible to finish this document in time, due to lack of sleep, need to sleep - no assistance - nightmare of France, lifelong administrative torture by this state of pathetic, bewildered and inhuman Tartuffes and Thénardiens - sorry, impossible to do more)

Claire Compagnon:

Reply to Odeli-a Fitoussi

- As usual, it is mainly with the management associations
- children... the usual blah blah blah, she doesn't answer questions
- support for families (parental guidance)... ok...
- 42,000 autistic children in mainstream schools - more support - increase in the number of - she quotes TEACH ABA Denver (this is debatable.....)
- she didn't say a word about parental murders!



01h42'20" - 11[FR] Response from France (Ms Marianne Cornu Pachet - (Belgium - ARS - DGCS))

Answer to the question by Ms Odelia Fitoussi

Departures to Belgium / children with Down syndrome

The dynamic is to focus on the development of solutions on our territory...

The reception of children in Belgium has been subject to a moratorium since 2015, which means that all the actors (...) have integrated the fact that there cannot be a systematic sending, and for this reason a strong mobilisation has taken place (bla bla bla....) Blah blah blah "contributes to the fact that children may not be subject to sudden departure"

We still have efforts to make on this subject to provide suitable living conditions [for these] children on our territory (blah blah blah, minister, president of the republic, blah blah...), it is a question today of putting an end to a situation for children and adults which is no longer tolerable and which consisted until now of financing places following commercial approaches by Walloon establishments, and therefore, um, the, um, the... It should be pointed out today that the orientation is now towards, um, being able to give means for, um, reception, for the return of people, [from] Belgium, and I will hand over to the Minister [= Secretary of State] on this subject.



Draft comments

(impossible to finish this document in time, due to lack of sleep, need to sleep - no assistance - nightmare of France, lifelong administrative torture by this state of pathetic, bewildered and inhuman Tartuffes and Thénardiens - sorry, impossible to do more)

Marianne

- departures to Belgium :

- moratorium since 2015: the associations (?) have integrated that there should not be any systematic sending to Belgium (incomprehensible remarks...)

then promises (blah blah blah president of the republic blah blah blah - it literally makes me want to vomit this blah blah really, I think I'm going to have to go to bed as I'm starting to feel sick - I don't usually listen to this crap



01h45'24" - 12[FR] Response from France (Ms Sophie Cluzel - Secretary of State for the Disabled)

(impossible to finish this document in time, due to lack of sleep, need to sleep - no assistance - nightmare of France, lifelong administrative torture by this state of pathetic, bewildered and inhuman Tartuffes and Thénardiens - sorry, impossible to do more)

- Cluzel promises no more "forced exile" in Belgium

- then she talks about Aide Sociale à l'Enfance - 25% of these 34,000 (350,000?) children are disabled

- platform for identifying autism in these children and parents, but the list of professionals she mentions, most of whom are psychoanalytically oriented

- senior officials in disability.... is vague, very vague...

48% more children in school than in 2017 - to be checked with Danièle Langlois

She says that 45% (?) of institutionalised children are now in "service" arrangements (?) but these seem to be services added as an "extra layer" but the children remain in residential care.....

Markus Schefer :

Very well, he used the expression "Travellers" (and Roma), to avoid the trap ("Roma")

This time, the State will not be able to avoid the question :-)

Sorry, can't do more, terrible need to sleep

But you can ask your questions at contact@allianceautiste.org