



**Autistan
Diplomatic
Organization**

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Dialogue with the public authorities in charge of the Autistic People Exposed to Disabling Situations (APEDS) in France

For the attention of Mr Christophe BRES, Head of Cabinet, Interministerial Delegation of Neurodevelopmental Disorders (DI-TND), French Government

18/12/2023

Mr Head of Cabinet

Thank you for your email of 25/10/2023 in kind reply to our first contact, in which we mentioned :

- **Our proposal for a dialogue** useful for public policies concerning autistic people in France, thanks to the provision of additional information made possible by our concept.
- As a crucial example, the lack of specific policies and standards on **accessibility for disabled autistic people**.



Autistan *The world of autistic people*

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Hereby :

- We would like to try and **clarify the main elements of our proposal**, with the hope that you find it suitable.
- You will find four **simple requests for information**, referenced **A, B, C and D** highlighted in yellow, in the hope that you will be able to provide them, as well as an indirect proposal for a meeting **E**.

N.B. Any replies will be published in the section corresponding to your Delegation

(<https://autistan.fr/category/reactions-diplomatiques/autorites-publiques-autisme-s005213-fr/>) and will be readable in several languages in order to inform at the international level, particularly your counterparts in certain countries.

Contents

1. Some useful information about our organisation and our approach	3
2. Misunderstandings and difficulties relating to dialogue and accessibility	4
2.1. Predictability and prevention of barriers	4
2.2. Apparent misunderstanding with our proposal for dialogue	4
2.3. Possible confusion regarding our reference to "accessibility"	4
2.4. The Inter-Ministerial Accessibility Delegation	5
2.4.1. How to access it?	5
2.4.2. Little visibility of any relevance in the decree	6
2.4.3. Notice of non-competence issued by the Ministerial Delegation for Accessibility	6
2.4.4. No mention of accessibility for autistic people in a recent CNCPH round table	7
2.4.5. Perplexity about any consideration of the concept of accessibility for Autistic People Exposed to Disabling Situations (APEDS) in France	7
3. Accessibility for Autistic People Exposed to Disabling Situations (APEDS)	8
4. Dialogue on all other useful subjects relating to autism	10
Appendices	12
Appendix 1: Brief presentation about Autism, the Autistan Diplomatic Organization, and the difficulties and needs of autistic people	12
Appendix 2: Common barriers to communication and collaboration	14
Appendix 3: A few points to help you understand the concept of "Accessibility for Autistic People Exposed to Disabling Situations (ASEHP)", and why it is so essential	15



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1. Some useful information about our organisation and our approach

The Autistan Diplomatic Organization has no desire (nor even any right) to make requests or demands (other than for information), nor any form of "external interference".

Our main objective is to **provide information** to the public authorities in the various countries, to enable them to better understand the real difficulties and needs of Autistic People Exposed to Disabling Situations (APEDS), so that they can optimise their public policies.

We know that our approach and the uniqueness of our concept can effectively **provide additional elements** to those already available to the entities concerned.

In particular, the possibility of **comparing** policies in different countries, and the **vast and diverse nature** of our resources (not limited to a single country) are undeniable assets.

Thanks to our neutrality, we can also **reduce or resolve conflicts** between government authorities and the organisations concerned.

We have found that **our information has been appreciated in various countries**, and there does not seem to be any reason why it should be irrelevant or useless in France. Indeed, **when we provide 'missing pieces of the puzzle', it is always beneficial**, so we cannot imagine that it would not be with you.

→ You can find out more - in brief - in **Appendix 1**.

("Appendix 1: Brief presentation about Autistan, the Autistan Diplomatic Organization, and the difficulties and needs of autistic people")



2. Misunderstandings and difficulties relating to dialogue and accessibility

2.1. Predictability and prevention of barriers

When you are autistic (even 'high functioning'), it is perfectly **logical and to be expected** to encounter **difficulties in communication** and interpersonal relationships, i.e. - in this case - between you and us.

If you bear this in mind, it helps to avoid 'automatically' falling into traps, misunderstandings and friction that can quickly lead to blockages.

➔ To do this, you might want to find a brief list of "classic" barriers in **Appendix 2. ("Appendix 2: Common barriers to communication and collaboration")**.

The simple fact of reading it should help to "immunise" you a little - so to speak - against these problems.

2.2. Apparent misunderstanding with our proposal for dialogue

Our previous and first e-mail proposed a useful dialogue not only on the theme of accessibility, which - although crucial - was cited only as a simple example (*cf. next chapter*), but you did not reply to us about a dialogue with your Delegation: on the contrary, you only directed us to the Inter-Ministerial Accessibility Delegation, which - assuming it includes autism - obviously cannot deal with the many aspects relating to autism other than accessibility, which are within your remit.

Therefore, we would like to ask you to forgive the lack of clarity in our initial writing, in the hope that this misunderstanding will now be cleared up.

2.3. Possible confusion regarding our reference to "accessibility".

The only sentence in our previous e-mail mentioning the word 'accessibility' ("*(...) especially if we judge, once again, by the absence of an accessibility policy (...)*") did not explicitly include the expression "*for Autistic People Exposed to Disabling Situations (APEDS)*", as this seemed obvious to us in the context.

What is more, our letter was originally intended for the Secretary General of your Delegation, who has already been informed on several occasions of the "*need for an accessibility policy (and*



corresponding concrete measures) for Autistic People Exposed to Disabling Situations (APEDS)" by a national association of autistic people.

We regret that we did not make it clearer that **our focus on accessibility concerns Autistic People Exposed to Disabling Situations (APEDS), which we feel falls within the remit of your Delegation.**

A→ You may wish to confirm or deny, in other words, help us to better understand to what extent your Delegation is concerned - or not - by this issue of accessibility for disabled autistic people, or whether it is entirely managed by the other government bodies in charge of accessibility (which - moreover - is not easy for us, as there are at least three of them).

2.4. The Inter-Ministerial Accessibility Delegation

Be that as it may, you were kind enough to point out the existence of the "*Délégation Interministérielle à l'Accessibilité*" (Inter-Ministerial Accessibility Delegation) and the decree establishing it (<https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000046751691>), and to suggest that we should approach it, in a way that seemed to refer exclusively to it (i.e. by suggesting that the subject of accessibility (for autistic people) would not in any way fall within the remit of your Delegation (?)).

We would like to thank you for this and we intend to do so as soon as we know how to proceed. However, we would like to submit the following questions and comments for your consideration.

2.4.1. How to access it?

B→ Could you please tell us how to contact this Delegation? (e-mail...)

Indeed, its official presentation page does not mention any way of contacting it (which makes it rather... inaccessible).



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The e-mail address isabelle.saurat@pm.gouv.fr may not be the right one, as five e-mails sent to her by an association of autistic people (on 23/01, 18/04, 22/06, 24/09 and 01/10/2023) did not produce a reply.

2.4.2. Little visibility of any relevance in the decree

The decree no. 2022-1578 of 16 December 2022 instituting an interministerial delegate for accessibility (<https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000046751691>) states:

- "The interministerial delegate will be responsible for coordinating and monitoring, particularly at territorial level, the actions of public and private stakeholders in the field of **physical and digital accessibility** and for promoting accessibility issues in the design and implementation of public policies".
- "The Interministerial Delegate for Accessibility coordinates, promotes and monitors the implementation and evaluation of actions prescribed by all the ministries in terms of **physical and digital accessibility**".

This decree therefore focuses mainly on certain aspects of accessibility, in particular "physical and digital" issues.

However, it seems to us that **the challenges faced by autistic people differ significantly from these aspects**, so a misunderstanding seems to exist.

Note: Clearly, this decree did not take into consideration the requests and explanations previously put forward (for more than a year) by at least one association of autistic people.

2.4.3. Notice of non-competence issued by the Ministerial Delegation for Accessibility

It is perhaps worth noting that the Ministerial Delegation for Accessibility (a different one, then), depending of the Ministry of the Environment and headed by Mrs Carole Guéchi, had already been consulted on this issue a few years ago.

At that time, this Delegation :

- a) Had expressed some displeasure at the "tone" of this request for information, which may indicate a lack of awareness about accessibility in relation to autism (*which we can explain*);
- b) Explained their main focus on physical barriers (using the expression "*concrete-bitumen*");
- c) Had indicated that for autistic people, the concern was more related to a question of "*human posture*" (in their words), which seems to us to be very correct and in line with the notion of "attitudinal barriers" present in the disability laws of some other countries;
- d) Concluded by advising them to contact the Secretary of State for Persons with Disabilities (Mrs Cluzel at the time);
- e) Had no longer replied to emails explaining that this Secretary of State never replied, whether on accessibility or other subjects.



(Note: These attitudes of non-acceptance and non-response appear to be unfavourable examples of accessibility, reinforcing the idea that there is a need to raise awareness in this area).

2.4.4. No mention of accessibility for autistic people in a recent CNCPH round table

During a recent CNCPH "round table" entitled "*L'accessibilité dans tous ses états*" (Accessibility in all its forms) (<https://youtu.be/Wa2CJJ2C3NY?t=4895>), careful listening to the debates failed to identify any elements relating to Autistic People Exposed to Disabling Situations (APEDES), particularly with regard to "attitudinal barriers" and what we call "Socio-generated disturbances (sensory, mental or other)".

2.4.5. Perplexity about any consideration of the concept of accessibility for Autistic People Exposed to Disabling Situations (APEDES) in France

These findings could perhaps raise **questions about the recognition or understanding of the "notion of accessibility for Autistic People Exposed to Disabling Situations (APEDES)" by the public authorities in France.**



3. Accessibility for Autistic People Exposed to Disabling Situations (APEDS)

As with any other type of disability or handicap, those that specifically affect autistic people obviously need to be reduced or avoided. This can be done through a variety of measures, including making the socio-administrative system (i.e. society) more accessible.

When an autistic person cannot access a swimming pool, school, shop, train or even a station, which almost always stems from "socio-generated disturbances (sensory or mental)", it is clear that this has nothing to do with 'physical' or material issues (*and even less with 'digital' issues, except when the handicap - i.e. the impediment or disadvantage - results from a lack of clarity of information*).

The handicaps, impediments and barriers concerning autism are - obviously - related to the characteristics of autism and "autism disorders", which correspond:

- To questions of "**communication and interpersonal relations**" (*which has nothing to do with the "physical", and very little to do with the digital*);
- Questions of "**sensoriality**" (*which could sometimes be improved by a better "physical" design, but the responses from the Delegations theoretically concerned do not seem encouraging in this respect*).

C→ It would be really useful to learn about your Delegation's position on this issue. Could you please inform about it?

Indeed, we believe in the need for an **accessibility policy for Disabled autistic people that is comprehensive and complete, i.e. not limited to physical and digital barriers.**

This policy should stipulate binding standards, as it does for other disabilities, and not make do with scattered measures and arrangements that may benefit only a small fraction of autistic people, and that are not mandatory, leaving the way open for arbitrariness and the usual injustices and rejection.



Accessibility for autistic people aims to facilitate effective access to services and to society in general by eliminating barriers to the full exercise of rights, **especially in terms of social relations and socio-administrative and sensory adjustments.**

Achieving accessibility for autistic people is based on the "**Prise En Compte Correcte de l'Autisme Partout (PECCAP)**" (*in the words of a French association of autistic people*) (i.e. "**Correct Consideration of Autism Everywhere**")

By creating an accessible environment (particularly in terms of attitudes and "social adjustments"), we encourage places, services or situations that are not mistreating. This reduces the difficulties of access for autistic people, and therefore enables their inclusion, and therefore "a better life, freer, fairer, more fulfilled, more dignified, in a word happier", which is the aim of our organisation.

In other words, **accessibility for autistic people with disabilities should be aimed at everyday life, everywhere and all the time** (and not "by areas or periods to be found"), so that society is accessible to them on an equal footing in all situations, which **would make it possible to start reducing exclusion (or self-exclusion, including suicide), confinement, segregation etc., in other words general mistreating** (institutional and social).

→ To find out more, you may wish to read **Annex 3: Some useful elements for understanding the concept of "Accessibility for Autistic People Exposed to Disabling Situations (APEDS)"**, and its **overriding necessity.**



4. Dialogue on all other useful subjects relating to autism

While the theme of accessibility for Autistic People Exposed to Disabling Situations (APEDS) is in our view the most important for reducing discomfort and suffering (*and therefore for reducing stigmatisation, harassment, depression, isolation and suicide*), the fact remains that there are **many other important subjects - most of which you address with your Delegation.**

We can therefore - here too - offer our additional information and points of view, which are certainly useful.

But for that to happen, **we need to find a way to engage in a genuine, sincere and constructive dialogue, which seems difficult to do when the conditions necessary for accessibility are little understood and therefore little present, even within your Delegation** and despite all its goodwill, skills and efforts.

We believe that if something has not planned or designed (in this case, accessibility), then it will not appear "by magic", especially in an age when "everything that is not planned has become impossible".

And this seems to be confirmed by your initial response, which (unless misunderstanding) did not seem to imagine a concept of accessibility (for autistic people) within your Delegation.

As ever, these observations bring us back to square one: the priority of accessibility for Autistic People Exposed to Disabling Situations (APEDS).

D→ Would you be so kind as to let us know your Delegation's position on our proposal for dialogue (in particular so that we can offer you some useful "puzzle pieces"), now that you have been able to take note of these clarifications, please?



E→ In particular, it is important to note that **audio-video meetings** make it possible to eliminate almost all misunderstandings (which seem inevitable in writing, given the "distance" between "Autistan" and "Non-Autistan"). This makes it much less uneasy to understand each other, this avoids or corrects 'friction', and saves an enormous amount of time compared with the written word.

We would like to ask you to forgive any inappropriateness or annoyance (*which would be an example of the reciprocal efforts needed to ensure accessibility for autistic people*).

Hoping to read your comments, and thanking you for them, please be assured, Mr. Head of Cabinet, of our respectful consideration.

The Ambassador of Autistan to France,

Alistair R.



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Appendices

Appendix 1: Brief presentation about Autism, the Autistan Diplomatic Organization, and the difficulties and needs of autistic people

-  **1. Autistan** is the “world of the autistic people”: in short, it refers to **everything that characterises autism and autistic people.**
-  **2.** The main goal of the **Autistan Diplomatic Organization** is to **inform the public authorities** of the countries, so that they better understand the needs and difficulties of autistic people, with the aim of a “**Correct Consideration of Autism Everywhere**” allowing “**Accessibility for Autistic People Exposed to Disabling Situations**“, in order to reduce “**Socio-Generated Disturbances**” (sensory, mental or other).
Our organization is “extra-national”, it does not “interfere from outside”, it proposes complementary contributions thanks to a very broad, diverse, different approach, which allows comparisons and reflections very useful to improve public policies.
-  **3. Autistic people do not suffer “from autism”:** they suffer from the consequences of the absence of **Correct Consideration of Autism Everywhere**, and therefore from the absence of public policies and measures enabling accessibility through the reduction of those external disturbances.
-  **4.** To achieve this, it is essential to begin by understanding that “**autism**” (*which is a human difference with many qualities*) **is something different from “autism disorders”** (*which are merely problems, objective or subjective*).
-  **5.** Autistic people must be able to “**learn about non-autism**” in order to adapt to it, **BUT without conforming to it**, i.e. without being “obliged to become non-autistic”, because the qualities specific to autism must be preserved, and the many dangerous social flaws and traps must be avoided, in particular the one that consists of creating self-esteem through “possible judgement by strangers”, which forces a kind of “dictatorship of social image” obliging people to “shine” (which is absurd, superficial and particularly toxic for autistic people).





- **6.** It is imperative that autistic people are not hindered in their interests or undertakings (apart from the minimum rules of conduct), that they are **not exposed to restrictions, over-protection or deprivation of freedom because of their autism.**

This is unfair and, above all, it prevents any positive development.

The positive development of autistic people is only possible if they can follow “their own path in life”, which is necessarily not ordinary, and which will be encouraged by **an unlimited multitude of possibilities, choices, chances, experiences, encounters, adventures, journeys, etc.**, and not by the opposite: the restriction and aridity of a life that is even more limited and restricted than that of most non-autistic people (which is very “standardised and robotic”).

For this reason, **it is imperative and essential that the PARENTS of autistic people be ” educated about autism “.**



- **7.** **Freedom and experimentation are therefore essential**, and an understanding of these principles (among many others that we can explain and demonstrate in detail) is essential for society to enable **a better life for autistic people: freer, fairer, more fulfilled, with the same level of opportunities and chances as non-autistic people, in other words a “real life”, dignified and happy.**



- **8.** This would be possible if the autistic people who can explain these things were *listened to attentively*, and if the public authorities made an effort and understood that the necessary changes are not abusive: **they are corrections that are beneficial to society as a whole.**

Trying to raise attention, and to explain these things convincingly with real life examples and evidence: that is the sole aim of our organization.

Learn more: [Autistan.org](https://www.autistan.org)



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Appendix 2: Common barriers to communication and collaboration

It would take too long to describe **the barriers to communication with public authorities** (and their solutions) in detail here, but simply bearing them in mind is useful to avoid falling quickly into certain traps without realising it.

Here are a few examples of problems that often make collaboration difficult, especially at the beginning.

Real-time verbal dialogue and patience help to overcome them.

- In general, questions of **goodwill** and **acceptance**.
- **Credibility** issues.
- Questions of **legitimacy** (*this is a "false problem", of the "social" or "bureaucratic" type, because when a person or organisation contributes useful things and helps to solve problems, the question of their "legitimacy" is in fact very secondary or unimportant*).
- The **length** of the texts (and videos) and the **lack of time**.
- **Confusion** and **misunderstandings** (*inevitable if you do "business as usual" without taking care to understand the nuances and avoid the classic pitfalls*).
- **Automatic thinking**" (*such as the idea that one needs to have qualifications or be "famous" to prove their competence and relevance*).
- **Administrative barriers**.
- Sometimes, perplexity about the fact that we "don't look autistic" (*it is a difficult subject, but it can be explained*).
- Doubts (*about hidden intentions, for example, while everything is sincere and explained from the outset*).
- Fears (*for example, of a "sectarian" or "supremacist" characteristic or something else negative*).
- The barriers that you see but that we do not (*hence the importance of dialogue in overcoming them*).
- Barriers that neither you nor we are aware of yet, and which may arise in the course of a collaboration or dialogue (*this is not a problem for us because we are used to having to overcome these inconveniences, which is often possible, and which is very interesting and instructive*).



Appendix 3: A few points to help you understand the concept of "Accessibility for Autistic People Exposed to Disabling Situations (ASEHP)", and why it is so essential

Summary of the points made by an association of autistic people :

(with a few corrections on our part (words crossed out))

1. Accessibility for autistic people aims to ensure effective access to services and to society in general, by eliminating barriers linked to autism, particularly in the areas of social relations and socio-administrative adjustments.
2. At present, these attitudinal barriers, which are unfortunately widespread, often take the form of difficult experiences and attitudes of rejection, contempt or mockery, creating inequalities in the exercise of rights, causing suffering and leading to the exclusion or even self-exclusion of autistic people. These attitudes correspond to the notion of "attitudinal barriers" (mentioned in the [Brazilian disability law](#)).
3. Physical barriers, particularly sensory barriers, also exist and are the result of socio-administrative factors.
4. In order for society to become truly accessible to autistic people, it is essential to adopt Proper Autism Consideration Everywhere ("*Prise En Compte Correcte de l'Autisme Partout* " (PECCAP)). Unfortunately, this demand is sometimes not sufficiently taken into consideration by public authorities, which can complicate their own accessibility.
5. Accessibility and abuse are two sides of the same coin: an inaccessible society and services contribute to a form of abuse, whether due to difficulties of access or to exclusion itself.
6. To remedy this situation, it is imperative to put in place an accessibility policy specifically adapted to autistic people with disabilities, accompanied by standards, regulations and practical implementation measures.



Further details:

- a) Accessibility for people with autism aims to make so-called "ordinary" society accessible to all, guaranteeing equal access with non-disabled people.
- b) Autistic disabilities, from our perspective, result from disharmonies and inconsistencies in the social environment, generating communication difficulties, sensory and mental suffering, and other problems characteristic of autism.
- c) Achieving freedom and a standard of living comparable to those of non-autistic people requires adjustments to the socio-administrative system to make it accessible to autistic people.
- d) Accessibility for autistic people involves general improvements based on universal design rather than individual assistance.
- e) It requires changes in attitudes, systems and administrative procedures.
- f) This accessibility encompasses more than sensory aspects. Although physical improvements are important, they must be accompanied by human accessibility aimed at correcting the shortcomings of the current social system.
- g) Accessibility for autistic people with disabilities implies the reduction of social or socio-generated problems, which would benefit society as a whole.
- h) To achieve this, concrete public policies and measures, integrated into regulation, are needed to reduce autistic disabilities resulting from the lack of Proper Autism Consideration Everywhere (*"Prise En Compte Correcte de l'Autisme Partout" (PECCAP)*).
- i) If the French authorities were to pay close attention, we would be happy to explain these needs in detail.
- j) Unlike other disabilities, there are currently no accessibility policies specific to autism-related disabilities.
- k) Autistic people often suffer and exclude themselves because of the almost total lack of accessibility, which can sometimes lead to tragedies such as suicide.
- l) Inclusion is impossible without accessibility.
- m) Justifying segregated institutions in the name of "freedom of choice" is questionable and hinders accessibility.
- n) The current lack of an accessibility policy in France is partly due to the delegation of disability management to private associations.
- o) Despite explanations to the CRPD Committee in 2021, the problem seems to persist.
- p) The measures needed are mainly "passive" and have a minimal cost, but they need to be improved in France.



- q) If society were accessible, it would be difficult to justify medical and social establishments, and people with disabilities would be able to lead lives equivalent to those of others.
- r) The predominant influence of the medico-social sector contributes to the distancing and isolation of autistic people in France, hindering their accessibility.
- s) The French authorities do not seem to be fully prepared to tackle the issue of accessibility for autistic people, partly because of the perfectible nature of their degree of accessibility to autism.
- t) This situation seems difficult to reconcile with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and human rights principles.
- u) The French State, notably because of its lack of accessibility to autism, remains unresponsive to calls from autistic people for accessibility.
- v) The question that arises is the following: would someone in the French government or administration be willing and able to engage in constructive dialogue with autistic people and autistic associations, particularly on the issue of accessibility in relation to autism?

