**Submission on the draft Guidelines on deinstitutionalisation,   
including in emergencies[[1]](#footnote-2)**

Inclusion Europe is a disabled persons’ organisation representing 20 million Europeans with intellectual disabilities and their families.[[2]](#footnote-3)

This submission is based on:

* A consultation with our members;
* A consultation with the European Platform of Self-Advocates[[3]](#footnote-4);
* Decades of experience advocating for, and implementing deinstitutionalisation[[4]](#footnote-5).

We welcome the Committee’s recognition of how bad institutionalisation is   
for people with disabilities.

Of the impact it has on people lives.

Of the urgent need to end segregation.

Ending segregation of people with intellectual disabilities once and for all  
is at the heart of all we do.[[5]](#footnote-6)

The Committee has rightly identified the State Parties’ need to have clear guidance on **how to** **do** deinstitutionalisation.

Many State Parties are trying to implement deinstitutionalisation,   
looking for the right ways to do it.

They often speak of the need for a practical guidance, examples worth following:

* Often, this is just an excuse from the State Party not to change anything.
* Many State Parties are genuinely looking for advice.

Unfortunately, the draft document misses the opportunity   
to provide this much needed guidance:

* To explain clearly the necessary steps;
* To provide examples of deinstitutionalisation from around the world;
* To recognise successful efforts, and to outline how to extend them  
  at a systemic level for the many people with disabilities who need it.

Some parts of the draft document may not benefit the cause   
of deinstitutionalisation.

**The draft guidelines need a thorough revision** to fulfil their stated purpose.

## Deinstitutionalisation now. There is no alternative.

The problems of institutionalisation have been well established decades ago.

At least 1,4 million children and adults still live in long-stay residential institutions in the EU.[[6]](#footnote-7)

* The number of people in institutions in the EU has not changed much over the past 10 years, despite a lot of deinstitutionalisation efforts.
* **People with intellectual disabilities and people with complex support needs are most likely to still live in institutional settings.**

Institutionalisation deprives people of:

* the right to decide about their own life,
* social roles and relations,
* the simplest things that are the human experience.[[7]](#footnote-8)

Despite their frequent claims of “providing safety and security”,   
residential institutions are a pressure cooker of problems and abuse.[[8]](#footnote-9);[[9]](#footnote-10)

## The draft document does not fulfil its stated purpose

The right to live independently and be included in the community is clear  
and non-negotiable.[[10]](#footnote-11)

General Comment number 5 provides a good understanding of it.[[11]](#footnote-12)

There is a wide range of methodologies, tools, and implementation practices   
to inform the State Parties on how to fulfil their obligations.[[12]](#footnote-13)

Rather than giving clear guidance, the draft is convoluted and confusing.

How can such text help State Parties understand and make necessary changes?

“Deinstitutionalisation means very big reform of social services systems.   
I don’t see how these guidelines can create such big reforms.”[[13]](#footnote-14)

## Is the CRPD not enough?

The frequent rephrasing of the CRPD and other legal obligations suggests   
these legal documents are not enough *per se*.

The CRPD is turned into advice.

This impression is even stronger with the frequent use of “should”[[14]](#footnote-15).

For example, what is the purpose of statements such as this?

* “Deinstitutionalization process should aim at ending all forms of institutionalization, isolation and segregation” (§11)
* “Deinstitutionalization comprises interconnected processes that should focus on restoring autonomy, choice and control to persons with disabilities about how, where and with whom they decide to live” (§17)
* “State Parties should ensure that intersectionality is considered” (§41)
* “Such programs should be brought in line with the Convention” (§43)
* “States Parties should fulfil their obligation” (§100)

## Does the document give clear guidance?

What is the reasoning behind having a definition of “Support services” (§73-80), and of “Individualized support services” (§81-82)?

Especially when §73 states: “support services should be […] in accordance   
with a human rights model that respect the will and preferences of persons”.

## Does it help to extend “deinstitutionalisation” to everything?

The draft goes beyond the issue of deinstitutionalisation for persons with disabilities, arguing it should apply in the same way to prisons (§14), and other.

Without commenting on the merit of such statement, or the Committee’s competence in this area, we are concerned about its possible impact.

We are concerned this would give opponents the opportunity to confuse   
and distract from what the issues are for people with disabilities.

Similarly, linking deinstitutionalisation to “crisis” and “emergency” seams counterproductive to convince people about the merits of the process.

Deinstitutionalisation is already criticised for “leading to homelessness”.[[15]](#footnote-16)

Tying it with “emergency” and “crisis” may allow opponents to divert,   
and distract the State Parties from actual issues, and actions.

It is not clear how the draft document imagines “no institutionalisation” (shelters, refugee centres etc.) during a crisis such as war, floods, or fires.[[16]](#footnote-17) (§105-112)

## How should it work?

It is unclear how would the drafted picture of support services work when it meets reality of most people with disabilities.

When there has been housing crisis in many countries –   
does “equal access to housing” help people to get out of institutions?

When there are no services for people with disabilities in many (parts of) countries, and support and care rely on family members –   
what will be the result of portraying almost all service models as bad for people with disabilities?

People with more complex disabilities will have to stay at home and parents as well, can’t work or earn money and would just be too many problems, there should be better support systems introduced to better support people with intellectual disabilities after they leave the institutions.[[17]](#footnote-18)

We are concerned some of the ideas around support are so far from achievable it makes them useless as a “guidance”.

The impact of this will be mostly on people with intellectual disabilities and complex support needs.

For example:

* the picture of residential services (§26, §32, §72) is not particularly clear.
* Similar questions apply to §72 and §76.

Spaces where people with disabilities might want to meet with their peers should not be considered as contrary to the CRPD.

People don’t have to live by themselves for it to be human right compliant.[[18]](#footnote-19)

## Families

The draft document paints a picture of families of people with disabilities which does not reflect nor support their role in ensuring inclusive future for people with disabilities.

Some family members treat their relatives with disabilities badly.  
Some even commit abuse and violence.

But, when State Parties fail to provide proper support to people with disabilities, it’s families who create solutions, based on their understanding and means.

Many families dedicate their lives to providing care and support.

In many countries, many (if not most) community-based services have been founded and run by family members.

It may be tempting to point the finger at families, but it is State Parties who bear the responsibility for fulfilling the rights of people with disabilities.

Family members have been also doing most of the advocacy for inclusion in schools, and in other aspects of life.

It is deeply unfair to treat families as a “barrier to deinstitutionalisation”,   
and to paint them with the same brush as (institutional) service providers.

## Some people need support that is more than “providing information”

The draft document mostly lacks attention to preventing institutionalisation   
of people with disabilities.

It also reduces support to “providing information” (§30; §50; §93f).

“*Accessible information*” or “*compensatory* *packages*” are not enough:

* to prevent institutionalisation of those at risk of it;
* to support those who spent substantial part of their live in an institution, without opportunity to learn about the world and how to function in it.

## What do the “guidelines” do for people with complex support needs?

People with complex support needs are mostly overlooked   
in deinstitutionalisation.[[19]](#footnote-20)

The draft document barely mentions them,   
or addresses in any way the discrimination they face in deinstitutionalisation.

A lot of the draft document reads as if it is done with a specific type of person with disabilities in mind:   
Someone who **already has** access to all kinds of information,   
**makes** their own decisions, and **manages** their daily affairs.

People who have been deprived of this knowledge and experience through institutionalisation (or other forms of segregation) need all kinds of different supports.

People with complex support needs especially are at risk of being left behind.

## Is it correct to call the drafting process “participatory”?

To start drafting such document during a major global crisis was questionable.

During the Covid-19 pandemic many people who live in institutions   
(the ones supposed to benefit from this document the most) \  
were locked up in isolation.

In some countries they were not allowed to leave their room in a residential institution.   
This lasted over a year for some people.

How were they to participate in drafting this document?[[20]](#footnote-21)

Online “consultations” in 2021 were not accessible.

There was little consideration for people who need support in communication.

* 2 minutes of speaking time for people who may have speech difficulties, or simply do not speak the language and rely on support/interpretation.
* Hundreds of speakers waiting without clear schedule and timeframe.
* Using very complex language.

The draft document is written in unnecessarily complicated language.[[21]](#footnote-22)

Easy to read versions of documents were not provided at the same time.

This deprives those who need them of the time afforded to others.[[22]](#footnote-23)

Easy read version of the draft gives information **about the existence** of it.

It does not give information about **its content**   
in a way that would allow people to understand it, and to form their own views.

We find it questionable the CRPD Committee calls the document   
a “result from a participatory process” (§3).

What impression does it give to State Parties on how participation   
of people with disabilities needs to be organised?

## In conclusion

The draft guidelines need a thorough revision to fulfil their stated purpose.

Guidelines need to help State Parties **do** what is expected of them.

* The CRPD provides the goal and direction.
* Guidelines need to provide practical steps to realise the journey.

Any guidelines need to be clear:

Clear in purpose:

* What are the guidelines trying to achieve?
* Who are the people that are to follow the guidelines?
* How do the guidelines help them to do what is asked of them?

Clear in language:

* Written in a way that makes them easy to understand   
  to anyone who should use the document.

1. [OHCHR | Call for submissions: Draft Guidelines on Deinstitutionalization, including in emergencies Committee on the Rights of Persons with Disabilities](https://www.ohchr.org/en/calls-for-input/calls-input/call-submissions-draft-guidelines-deinstitutionalization-including) [↑](#footnote-ref-2)
2. ¼ of our membership are self-advocacy groups and organisations. Self-advocates are directly represented in the Board of Inclusion Europe. ([About us - Inclusion Europe](https://www.inclusion-europe.eu/about-us/#mission)) The European Platform of Self-Advocates provides specific route of discussions, inclusion-oversight for the organisation. ([EPSA - Inclusion Europe](https://www.inclusion-europe.eu/european-platform-of-self-advocates-epsa/)) [↑](#footnote-ref-3)
3. Further conversation was organised earlier in the process to provide self-advocates’ input into the drafting process.   
   This was organised by Inclusion International, with Inclusion Europe contributing. [Empower Us DI report (.pdf)](https://s38312.pcdn.co/wp-content/uploads/Global-SA-Report-on-DI-and-Art-19_compressed-1.pdf) [↑](#footnote-ref-4)
4. [Independent living - Inclusion Europe](https://www.inclusion-europe.eu/independent-living/) [↑](#footnote-ref-5)
5. [End segregation - Inclusion Europe](https://www.inclusion-europe.eu/end-segregation/) [↑](#footnote-ref-6)
6. Jan Šiška and Julie Beadle-Brown, Report on the transition from institutional care to community-based services in 27 EU Member States. European Expert Group on the Transition from Institutional to Community-based Care. (2020) <https://www.inclusion-europe.eu/people-intellectual-disabilities-complex-needs-institutions-report/> [↑](#footnote-ref-7)
7. [www.inclusion-europe.eu/tag/survivors](http://www.inclusion-europe.eu/tag/survivors) [↑](#footnote-ref-8)
8. How COVID-19 affected the rights of people with intellectual disabilities and their families. Inclusion Europe, 2020 [https://www.inclusion-europe.eu/covid-report-2020/#more](https://www.inclusion-europe.eu/covid-report-2020/" \l "more) [↑](#footnote-ref-9)
9. Life After violence, a study on how women with intellectual disabilities cope with violence they experienced in institutions, Inclusion Europe, 2018 <https://www.inclusion-europe.eu/life-after-violence/#Outcomes> [↑](#footnote-ref-10)
10. Article 19 CRPD <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html> [↑](#footnote-ref-11)
11. [OHCHR | General comment No.5 on Article 19 - the right to live independently and be included in the community](https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live) [↑](#footnote-ref-12)
12. As one example: Šiška, Beadle-Brown: The Development, Conceptualisation and Implementation of Quality in Disability Support Services. Karolinum Press, 2021. [↑](#footnote-ref-13)
13. EPSA member during a consultation to write this submission [↑](#footnote-ref-14)
14. We understand one of the meanings of “should” is to express obligation, propriety, or expediency (Merriam-Webster). We doubt this is how most people, especially non-native English speakers, perceive it. [↑](#footnote-ref-15)
15. We don’t agree such criticism has merit in Europe. There were such cases in some of the processes decades ago; we haven’t seen any evidence of it happening recently. [↑](#footnote-ref-16)
16. Latest example in Europe being the immediate answer to refugees escaping the war in Ukraine. [↑](#footnote-ref-17)
17. EPSA member during consultation to draft this submission. [↑](#footnote-ref-18)
18. From consultation to draft this submission. [↑](#footnote-ref-19)
19. Šiška, Beadle-Brown, 2020 [↑](#footnote-ref-20)
20. We raised these concerns before [Soufiane El Amrani: Self-advocates tell the UN we want institutions closed](https://www.inclusion-europe.eu/soufiane-el-amrani-self-advocates-tell-the-un-we-want-institutions-closed/) [↑](#footnote-ref-21)
21. For example, we don’t understand what this means: “Persons leaving institutions require to experience a more robust vista of possibilities of daily living, life experiences and opportunities to thrive in the community.” (§97) [↑](#footnote-ref-22)
22. In this very consultation, easy to read version was made available on 16 June, depriving those relying on it of 3 weeks of the consultation, leaving only 2 weeks to respond.   
    Again: “People with intellectual disabilities and people with complex support needs are most likely to still live in institutional settings.” (Šiška, Beadle-Brown 2020) [↑](#footnote-ref-23)