**Submissions on the Draft Guidelines on Deinstitutionalization, including in emergencies**

# Summary

The Deputy of the Public Defender of Rights of the Czech Republic hereby takes the liberty to provide submissions and suggestions for supplementing the Draft Guidelines on Deinstitutionalization, including in emergencies, which are based on her experience in protection of persons with disabilities.

According to the Deputy of the Public Defender, the Committee should consider supplementing the wording of the draft in the following aspects:

1. It would be desirable if the introduction to the Guidelines emphasised that states should not only focus on *deinstitutionalisation* (the return of people from institutions to life in the community) but also on the prevention of institutionalisation (the transition of people from the community to institutions).[[1]](#footnote-1) [[2]](#footnote-2)
2. It is essential to clearly define a residential service that complies with the Convention [(see para. 14 and para. 15 (in relation to each other)].
3. I recommend to redefine the characteristics of the institution relating to the psychiatric or medical care facilities (see para. 15).
4. It is necessary to further clarify the obligation of States Parties to provide an automatic compensation to survivors of institutionalization set out in part IX. (Remedies, reparations, redress) of the Guidelines.
5. In the future, it would be greatly appreciated if the topic of *affordability of support services in the community* mentioned in these Guidelines (see para. 23) were addressed in more detail by the Committee, as clarification of this issue may contribute to the completion of the deinstitutionalisation process.
6. For some paragraphs, I recommend relaxing the stringency of the requirements or softening the language of the Guidelines. I believe this will contribute to better acceptance and greater effectiveness of the Guidelines (see para. 3, para. 6, para. 13, para. 40).
7. For the other paragraphs of the Guidelines, I recommend individual partial changes. The nature of these changes cannot be characterised in general terms due to their completely different nature [e.g. deleting part of a paragraph due to illogical content (para. 63) or adding more detail to the paragraph to explain what situations it applies to (para. 18) etc.]

# Role of the Public Defender of Rights

The Public Defender of Rights protects persons against the conduct by authorities and other institutions if such conduct is contrary to the law, does not correspond to the principles of democratic rule of law and good governance, or in case the authorities fail to act. In addition, as the National Preventive Mechanism under the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment of Punishment, the Defender also performs preventive systematic visits to places where freedom of persons could be restricted and seeks to promote respect for their fundamental rights. The Defender also contributes to the enforcement of the right to equal treatment and protection against discrimination.

As from the 1 January 2018, the Public Defender of Rights will have competence in the area of monitoring the implementation of the Convention on the Rights of Persons with Disabilities pursuant to Article 33 (2) of the Convention (hereinafter referred to as the “*Convention*”).

# Specific submissions regarding the Draft

Paragraph 3:

The term “*survivors of institutionalization*“ is used very often throughout all the document (e. g. par. 3, 33, 51, 66). This term is strongly emotionally tinged and can be perceived very radically by the recipients of these Guidelines. **For this reason, I suggest that the use of this term should be better justified at the outset of the guidelines.**A qualified explanation of the used terminology may help to facilitate acceptance of the ideas of the Guidelines. Alternatively, the term “*survivors of institutionalization*“ may be replaced by an alternative, such as “persons with experience of living in an institution“.

It is also not clear from the text of the paragraph, why a group of persons with albinism is specifically named. No other group of people with disabilities is highlighted in this way, so **I suggest deleting the phrase “persons with albinism“ from the sentence.**

Paragraph 6:

The third sentences of that paragraph describes without compromise that institutionalization “*exposes persons with disabilities to forced medical intervention with psychotropic medications“* etc. The fourth sentence goes on to state that the “*institutionalization exposes persons with disabilities to administration of drugs and other interventions without the free, prior, and informed consent…*“ Although I am fully aware that institutionalization can have a very negative impact on people with disabilities, it is not true that every person living in an institution has experienced these undesirable phenomena (such as forced medication). **Here I recommend replacing the words “*it exposes*“ at the beginning of both sentences with “*it might expose*“.**

Paragraph 13, first sentence:

While this paragraph encourages“*to take immediate action by providing individuals with opportunities to leave institutions“*, it is clear that immediate exit from institutions for all people with disabilities is not possible. Unrealistic requirements may diminish the desired effect of the Guidelines. **For this reason, I suggest that the Guidelines should generally push states parties rather to “*immediately initiate a proces“* towards the exit of all people with disabilities from institutions.**

Paragraph 14 and 15 (in relation to each other):

It is not clear from the content of paragraph 14 and paragraph 15 how they are interrelated. Paragraph 14 (in the second sentence) lists, by way of example, the types of services that are institutions (social care institutions, psychiatric institutions, long-stay hospitals etc.). It is not clear here, whether each of these services is to be considered as an institution without more, or whether each type of services listed is to be assessed separately to determine whether it fulfils the characteristics of an institution from paragraph 15. **Please, it is necessary to explain the interrelation of the sections concerned.**

I also recommend that paragraph 15 be placed before paragraph 14. Both paragraphs (or any newly added paragraph relating to the definition of institution) should be included in the second part of the Guidelines (Duty to end institutionalization), as the definition of institution and institutionalization must be clearly defined at the outset of the Guidelines.

For this reason, I find it helpful to arrange the paragraphs in the second part of the Guidelines (Duty to end institutionalization) in the following order (paragraphs are in order of current numbering): para. 4, para. 5, par. 15, para. 14, para. 7, par. 6, para. 8, para. 9, para. 10, para. 11., para. 12 etc.

To fully understand what constitutes an institution and institutionalisation, **it is essential to clearly define a residential service that complies with the Convention**. The guidelines as currently drafted state in paragraph 26 that group homes cannot meet the definition of community-based services automatically, without any other conditions. According to the draft (paragraph 16), „homes where the same service provider packages housing and support together“ cannot be designated as a community residential service. Is this always the case, regardless of other facts?**[[3]](#footnote-3)** **Please add a definition of residential service, which is in line with the Convention, to the introduction of the Guidelines**.

Paragraph 14 (without reference to paragraph 15):

**I suggest deleting the last sentence completely, as in my opinion the facilities in question do not fall under the issue of deinstitutionalisation.** This concerns prisons in particular, where general issues of prison reform do not fall within the scope of the Convention. Alternatively, I recommend elaborating on the content of the last sentence; in particular, it is necessary to clarify how deinstitutionalisation relates to the types of facilities in question, such as prisons, refugee camps, migrant shelters etc.

Paragraph 15 (without reference to paragraph 14):

The paragraph contains definitional features of an institution relating to the manner in which the service is provided. In my view, however, these definitional features cannot[[4]](#footnote-4) be fully applied to facilities[[5]](#footnote-5) where medical or psychiatric care is provided.

For instance, according to this paragraph one of the characteristics of an institution is “*no or limited influence over whom one has to accept assistance from*“. Patients in psychiatric or medical care facilities can usually never choose from which health care staff they will receive the support they need (for example, patients cannot decide when a staff member will be available to them, as staff work on designated shifts). Under this characteristic would then mean that every facility providing medical or psychiatric care is an institution, because patients cannot determine, who specifically will provide them with support.

For facilities providing psychiatric or medical care, it may also be important to consider the attribute of *longevity* as one of the characteristics of the institution. For example, an acute psychiatric care facility[[6]](#footnote-6) cannot be considered as an institution, if it provides a person with a disability with *immediate* specialist health care, that cannot be provided in his or her home. On the contrary, if a person no longer needs such acute psychiatric care and yet remains in such a facility *for a long time* (the facility replaces his or her home and community life), we can speak of an institution.

**For the reasons stated above, it is necessary to redefine the characteristics of the institution relating to the psychiatric or medical care facilities.**

Paragraph 18:

Here it is provided that “*processes of deinstitutionalization* ***should not be led*** *by management or those involved in the maintenance of institutions“.* However, such exclusion of the management of institutions makes sense only at the state level. At the level of the transformation of a particular institution, the management of the institution cannot in practice be excluded from this process.[[7]](#footnote-7) **It is therefore necessary to specify to which level (state level x transformation of a specific institution) the paragraph refers.**

Paragraph 23:

According to this article, the support services should be affordable. Ensuring the affordability of support services is a direct obligation for States Parties.[[8]](#footnote-8) **For this reason, it would be helpful if the Guidelines addressed the topic of affordability in much more detail.** For example, I would suggest defining more precisely what it means by “*support that cover disability related costs.*“ [[9]](#footnote-9)It would also be very much appreciated if the Committee would issue a commentary on Article 28 of the Convention.

Paragraph 31:

I suggest adding the phrase at the end of the second sentence: “*on an equal basis with others.*“

Paragraph 33, last sentence:

The essence of this sentence is that all “*those with financial or other interests in* *in keeping institutions open*“ should be prevented from influencing decision-making processes related to deinstitutionalization. The other stakeholders mentioned (such as service providers, charities etc), on the other hand, can sometimes have a positive influence on deinstitutionalisation, so they cannot be automatically excluded from the process. **I therefore recommend that the first part of the sentence should be deleted.**[[10]](#footnote-10)

Paragraph 36:

**I suggest that the sentence be reworded here.** It would be good to say that all people with disabilities should have the opportunity to transition from the institution to the community. However, as part of the deinstitutionalisation process, it is permissible to have selection processes about who leaves institutions earlier, as each person with a disability may need a different amount of time to get back in a community.[[11]](#footnote-11)

Paragraph 40:

The wording of the first sentence is too strict. Not every girl and woman with a disability has experienced multiple discrimination on the grounds of gender and disability. It will be better if **the words “*are subject to multiple discrimination* " are replaced by the words “*might be a subject to multiple discrimination*“.**

The third sentence provides that girl and woman with a disability “*are denied the right to legal capacity more often than men with disabilities*“. **There is necessary to add a source of this statement.**

Paragraph 62, first sentence:

According to this paragraph, “*existing* ***community-based*** *services*“ should be mapped and only then it should be assessed whether or not it is indeed a community type of service in accordance with the Convention. For this reason, **I suggest deleting the word** “**community“ from the first sentence and leaving only** “**existing services“.** A service can then be designated as community after the mapping process has been completed if it really meets the defined characteristics.

Paragraph 63, second sentence:

I disagree that medical professionals should be completely excluded from the development of new tools for assessing the needs of people with disabilities. Collaboration between professionals from different disciplines and a multidisciplinary approach is important. **I therefore suggest that the last part of the second sentence concerning medical professionals should be deleted.**

Paragraph 64:

The content of the third and fourth sentences is not thematically related to the issue of workforce analysis. I recommend the issue of the need to provide services under the direct control of a person with a disability and the licensing of new services **put in another section of the guidance.**

Paragraph 65, first sentence:

I recommend that a detailed plan of action should **also identify *the authority responsible for the deinstitutionalisation proces.***

Paragraph 117, second sentence:

The Guidelines here commit states to a serious obligation to provide an **automatic** compensation to survivors of institutionalization. However, this obligation is not sufficiently clarified here. Specifically, **I suggest that the paragraph in question must address the issue of:**

* does a person with a disability, who has entered into a contract for the provision of a social service in an institution on a completely voluntary basis, have a right to compensation.
* does a person with a disability, who has a compelling need for psychiatric care and voluntarily undergoes a medical treatment in mental health care institutions, have a right to compensation.
* is everyone really entitled to compensation automatically, without having to meet other conditions, such as living in an institution for a certain minimum number of days, etc.
* which authority or body should decide on the disabled person's entitlement to compensation (e.g. a general court or a special body should be set up due to the possible number of compensation cases).
* at what point does a person with a disability become entitled to compensation (e.g. when they leave the institution or even if they remain in the institution).
* at what point the wording of this paragraph relating to entitlement to compensation becomes effective; here it is specifically necessary to define, whether persons with disabilities, who joined the institution or who left the institution before the Convention on the Rights of Persons with Disabilities came into force, will be also entitled to compensation.[[12]](#footnote-12)

Paragraph 134, first sentence:

Here a problem arises, according to the law rules, providers of social or health services are usually obliged to keep records of a person with a disability even after his or her release from the institution.[[13]](#footnote-13) Providers also have a duty of confidentiality, which would ensure the protection of people with disabilities.[[14]](#footnote-14) For this reason, I recommend that the **first sentence should be deleted or at least it should be specified more precisely what kind of records of persons with disabilities the first sentence refers to**.

1. If, for example, a person with a disability can no longer be supported by their informal carers or the person with a disability no longer wishes to be supported this way. [↑](#footnote-ref-1)
2. This recommendation is not further elaborated in the text below. [↑](#footnote-ref-2)
3. In the Czech Republic, for example, a typical residential service for people with disabilities is the so-called home for people with disabilities. It provides clients with accommodation, food, assistance in managing the usual tasks of caring for their own person, social therapy activities, and more. The Ministry of Labour and Social Affairs has issued criteria for community services, which define for residential services both how they are to provide support in accordance with the Convention and at the same time define the material and technical requirements for accommodation. Accommodation requirements include:

   “*The household is located in a family house or small apartment building structurally adapted to the target population. This family house or apartment building must be in a conventional residential or mixed-use development occupied by conventional households, shall not be in the immediate vicinity of a similar house orother social care service facility. It shall not create an excluded locality or segregated enclave occupied by social services clients.“*

   *„No more than 12 users of social services live in one family or apartment house long-term residential care, if they are people with low or medium level of support (adults). No more than 18 service users living in one family or residential home social care services associated with long-term residence, if they are people with a need for a high level of support (adults)….“*

   The criteria for community services issued by the Czech Ministry of Labour and Social Affairs are available here: <https://www.mpsv.cz/kriteria-socialnich-sluzeb-komunitniho-charakteru-a-kriteria-transformace-a-deinstitucionalizace>. [↑](#footnote-ref-3)
4. Such as obligatory sharing of assistants with others, isolation and segregation from independent life in the community; lack of control over day-to-day decisions etc. [↑](#footnote-ref-4)
5. Long-stay hospitals, nursing homes etc. [↑](#footnote-ref-5)
6. The same applies, for example, to intensive care units as medical facilities. [↑](#footnote-ref-6)
7. Management has relevant information and experience in running the facility. [↑](#footnote-ref-7)
8. Deinstitutionalisation can never be completed without fulfilling this commitment. [↑](#footnote-ref-8)
9. See para. 86 of Guidelines. [↑](#footnote-ref-9)
10. The proposed sentence reads: *“Those with financial or other interests in keeping institutions open, should be prevented from influencing decision-making processes related to deinstitutionalization.“* [↑](#footnote-ref-10)
11. The first sentence could read, for example: *“All persons with disabilities have the right to live in the community and to leave the institutions. It is allowed if certain people with disabilities leave the institution later than others, if this is justified by their needs.*“ [↑](#footnote-ref-11)
12. In this respect, it should be added that retroactivity significantly undermines the legal certainty of the addressees of the legal norm. [↑](#footnote-ref-12)
13. The reason for keeping the records may be an inspection by the health insurance company, the founder, court proceedings etc. [↑](#footnote-ref-13)
14. Paragraph 100 (1) of the Law 108/2006 Coll. Social Services Act. [↑](#footnote-ref-14)