



**Written Submission  
to the UN Committee on the Rights of Persons with Disabilities**

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

Submitted by:

**a woman diagnosed with intellectual disability**

With the support of

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I am a woman diagnosed with an intellectual disability. I lived in institution for 5 years. I have been living in my own apartment since May 2022.

After going through the guidelines, I have the following remarks.

- The guidelines are very good and quite specific.
- I recognise the part of moving/transiting from institution to the community as a crucial point.
- The idea about the transitional package is great.
- For a clearer picture, the guidelines could be **organised** according to **stages**:
  - 1- before moving out (in the institution; What does a country have to do? What does the institution have to do for the person with a disability? What do the outside service providers do? etc.)
  - 2- transition
  - 3- living in the community.
- **Caution** should be applied when delegating the power (mostly) to the representative organisations.<sup>1</sup> How to make sure that a country does not take the status of representative as given, giving the "power" to lead the DI processes to a representative organization regardless of their views, leadership, etc.? A similar problem might arise with other "types" of disabilities. Shouldn't there be a clearer, more sensible guideline on this, so it is not taken too literally by a country and indirectly possibly exclude people with

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<sup>1</sup> For example, in Slovenia we have a law on disability organisations that states in Article 18 that representative disability organizations represent and advocate for people with disabilities and their interests in dialogue with authorities at national and international level; to gain the status of a representative organization, 33% of people with a specific type of disability have to be members, however, it says nothing about active involvement of members with disabilities in the organisation. (Similarly, the funds are distributed from the state to the disability organisations based on the number of members). E.g., the representative organisation for people with intellectual disabilities in Slovenia is parents-(or family members)-led and quite "traditional" in views and actions. How to make sure that a country does not take the status of representative as given, giving the "power" to lead the DI processes to a representative organization regardless of their views, leadership, etc.? A similar problem might arise with other "types" of disabilities. Shouldn't there be a clearer, more sensible guideline on this, so it is not taken too literally by a country and indirectly possibly exclude people with disabilities?

disabilities?

- In Slovenia, state bodies and other public institutions are officially also obliged to ensure that organisations of persons with disabilities which do not have representative status are given the opportunity to present the interests and views of persons with disabilities, however, that is usually done through umbrella representative organisations or is not regarded at all.
- **Missing** - What happens if a country does not respect the guidelines? What can an individual do? What can the EU (e. g.) do? How can it be made sure that there are some repercussions for these countries, so they start the processes? Should the monitoring bodies be also responsible to navigate this - initiate procedures for repercussions?