 

# 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 person diagnosed with an “autism spectrum disorder”

With the support of

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30 June 2022

I am a person diagnosed with an autism spectrum disorder.

It’s good that we have these guidelines to help countries keep people in communities and in families. The Guidelines are quite understandable. The pictures (of the ETR version) are good; they represent the content well.

The law should be definitely changed. A lot of money goes to institutions. And then we ask where money have gone. On the salaries of those who work in institutions. More money should go to the Alpine association and inclusive hikes, which now have to raise money for themselves.

A law is needed to support those in the institutions to go to the community, such as the “New Paradox” in Senožeče.

It is better to give money to such organisations as Aspi than to these institutions. Or to the associations like »Bodi zdrav« (Be Healthy). Or to go to a swimming pool. There is already enough money for institutions.

If you don’t feel okay in the institutions, you should move to the community. If you are fine in the institutions, then you can live in them. But you can also try to live in the community for 1-2 months and then decide whether it is better.

It has to be an individual approach, counselling, and conversation groups like in the Aspi (organisation that supports youth with autism). Aspi is a support service.

It is definitely important that people with disabilities are there to make decisions.

And it’s good to be able to choose who will support you. It could be that someone from the family, and that one should be paid for it.

Women and children

I haven't noticed that there would be a worse treatment for women, but if it says, then probably it is. There were times when women did not have voting rights. They have them now. But women are still more discriminated against.

Some older persons, who do not like their children with special needs, put them in foster families. If they are small, they get used to it. But this becomes painful for 10-years-old kids.

It is good that the children get a new family, at least in another family they will live happily. I know one girl, but she grows up at home with her family. Although it is difficult for them, they love her.

Rights

People with disabilities have the right to education. Not everyone has the right to be respected. Teachers have respect, but students and children have no respect.

Everyone should have voting rights.

About community life

There is one house in Senožete, "New Paradox". There, 3 persons with disabilities live in the community. I know some of them because they took a dog for a walk. They have a shared kitchen.

Institutions and the situation of persons living in institutions

I know Ana, who lives in the institution; I text her. She can visit her family only for the weekend. She lives in an institution; they have a shared kitchen.

They are really locked up there. She said it is often boring. She can go out only until 9 pm. If she comes later, they can call the police. Wherever she goes, she has to say, except when she goes to work. She cannot really go out. And if she does, they are angry with her.

Ana works at a factory, she doesn't like the work, but she got used to it. She dreams of living with her mother.

Sometimes, she goes home for the weekend, but I don’t know why she can’t always live with her mom.

She is separated from her family.

There is also an institution for such people on K street. Some are always living there. Some, however, as students, go home for a weekend. I don't know how they live there.

I also heard about the “madhouse” in Ljubljana - Ljubljana-Polje. Mom and grandma say they keep them in nets and cages. They get very small amount of food. That it's even worse than in prison. When I misbehaved, Grandpa scared me that my mom would take me to a “madhouse.” Do you think they are still being treated with electric shocks there?

There are really no rights in the institution. That needs to be changed; they need to allow everything. Wrong if you don't choose a roommate. If they give you a roommate, you can have many conflicts with them.

**NOTE: The views presented in this submission are of the person interviewed and do not necessarily reflect the opinions of Validity that made it possible for the person concerned to participate in the consultation process.**