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**Committee on the Rights of Persons with Disabilities (CRPD)**

# Written submition of the MDRI-S self-advocates group

**Introduction:**

Beginning of 2020, Mental Disability Rights Initiative MDRI-S initiated an informal group of self-advocates. The group is made up of young people with intellectual and mental disabilities who wish their voices to be heard under the principle “Nothing About Us Without Us”. Most of them are living in residential institutions, or have history of institutionalization. Also, some of the members of this group are young people who live in the community. The objective of the activity is to empower them, with our support, to take actions which would contribute to the greater visibility of the position of our citizens with intellectual and mental disabilities. MDRI-S self-advocates meet on a regular basis to discuss important topics and thus prepare themselves to take part in public policies.

# General observations:

In order to get the inputs of self-advocates to the content of the Draft Guidelines for Deinstitutionalization, including in emergencies, MDRI-S organized meetings/ workshops. Participants of workshops are: about 10 people with mental disabilities living in residential institutions, 2 people with experience of institutionalization and 5 people living in a community with their families.

Comments on paragrafs:

The comments are reflected in red as an addition to the specific paragraphs.

1. Institutionalization includes all forms of placement and detention. Forms of institutionalization1 vary, but may include social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, special boarding schools, rehabilitation centres, half-way homes, group homes, respite care, family-type homes for children, sheltered or protected living homes, transit homes, albinism hostels, leprosy colonies and other congregated settings. Mental health settings where a person can be deprived of their liberty for purposes such as ‘observation, care or treatment’ and/or preventive detention are a form of institutionalization. Mainstream institutional settings, such as prisons, refugee camps, migrant shelters, shelters for homeless persons, or prayer camps, should also be included in deinstitutionalization efforts.
2. An institution is defined by certain elements, including obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice over whom to live with; exposure to violence, lack of preventive-protective measures (appeal mechanisms); 2 rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities in the same environment.

18. Processes of deinstitutionalization should not be led by management or those involved in the maintenance of institutions3, and should prevent

1 <https://www.youtube.com/watch?v=uBtt3sUr6No>

2 <https://www.mdri-s.org/public/documents/upload/publications-in-english/Publikacija-engleski.pdf>

3 The work of self-advocates living in institutions is very difficult. We have found a way to organize online workshops that are mostly via the Viber platform, and sometimes via Messenger. The workshops usually take place in the afternoon. The reason for that is that self-advocates then feel somewhat freer to speak, because

common errors that violate article 19, such as renovating settings, adding more beds, building up smaller facilities on the premises of the institution,

legislating standards such as “least restrictive alternative” into mental health legislation, which perpetuate human rights violations.

1. Living independently and being included in the community requires full legal capacity, access to housing, support and service options that enable persons to regain control of their lives. Having choice means that persons with disabilities, including women, older persons, and children, are respected in their decision-making. States Parties should provide access to multiple options to those leaving institutions and ensure they can access the support they may require to make their decisions a reality.4

there are fewer employees. Self- advocates are always afraid and unsafe because they know that always someone eavesdropping them. After one of the last workshops, one self-advocate told us:

"After the focus group, we had a problem with employees. They accused me of saying something to you (at the workshop), of gossiping about my boss, which did not happen. I had big problems. I cried and I was worried.”

MDRI-S self-advocate

"Every time we work with them, they usually have a problem with employees. It bothers them that they are telling the truth about how they are in the institution. They don't let them get empowered and to talk to us. Nobody talks to them. On the contrary, they convince them that they cannot live in the community "Coordinator of the group of self-advocates MDRI-S

4 One of the self-advocates spends most of her time with sister`s family. Sister has a child that our self- advocate takes care of when her sister is at work. Due to the lack of support in the community, she still stays in the residential institution for several months. Staff from the institution and her guardian, do not allow her to go out and live independently in the community, although all the time she is taking care of nephew, and lives like others.

Another self-advocate said: „I have a house where I was born. My brother also told me that I can go there whenever I want, but that is a lie. This is not true. The institution denies me because they say I can't travel alone. And my brother told me that I could come alone on the weekends. I would love to live in that house that my dad left me. I could live independently with medical support and financial support from the state.“

Our selfadvocate spent 14 years in supported living and than they return her to residential institution. She said: „I have lived 14 years in supported living. I cooked, did the dishes, did the laundry, maintained the apartment. But I was still not free. There were still rules, there were still others deciding what was good for me. It was better than in the institution. But supported living ends, and because I did not have a family, they sent me back to the same institution where I did not sleep and where I was afraid for my safety.

I would like to work, get a job, but a social worker tells me that if I work I have to leave institution. But, have nowhere to go. My biggest wish is to leave institution and be on my own. To have my own apartment and job, to receive a salary and maintain my apartment. To feel free. I want to go to the theater, the cinema. I know that I need support for some things, to consult with someone about important issues. But I don't think that's why I need to be in institution. No one should live in such conditions!“

1. States Parties should prioritise the development of a range of individualized supports and inclusive mainstream services in the community without delay. Support services must not be facility-related, it should be organized to support the person wherever he or she wants to be supported.5

40. States Parties should acknowledge that women and girls with disabilities are subject to multiple discrimination on the grounds of gender and disability and they are not a homogeneous group. Women with disabilities are at a heightened risk of violence, exploitation, and abuse compared to other women, and are at high risk of gender-based violence and harmful practices, such as forced contraception, abortions 6 and sterilization, during institutionalization. They are denied the right to legal capacity more often than men with disabilities, and more often than women without disabilities, leading to denial of access to justice, choice, and self- control. States Parties should consider these risks when designing and implementing deinstitutionalization plans to ensure the fulfilment and protection of the rights of women and girls with disabilities, ensuring gender equality is reflected transversally throughout all process and policies.

46. Article 23(4) of the Convention protects against the improper separation of children from their parents based on the disability of the child or the parent. States Parties should provide parents with disabilities necessary support and reasonable accommodations to keep their children and to prevent children from being placed in institutions. State Parties should absolutely prohibit the practice of admitting children to institutions, and to redirect all efforts to

5 Testimony from our self-advocate: “Recently I was at my center for social work to ask them about the apartment. They only offer me a social care institution as a home. I told them that I do not want to live in a social care institution because I want to work and live independently like a normal person. And they told me we have nothing else to offer you but a social care institution.”

Some of the MDRI-S self-advocates experienced leaving the institution in an unorganized, unsystemic manner. Namely, by sheer luck, they managed to move out of the social care institutions and now live in the community. They live without any kind of systemic support. They said:

“The two of us who came out were just lucky because we didn’t have support from the system, nor support for community services. Only by the good will of individuals.”

6 <https://www.youtube.com/watch?v=mS5k76GlsKM>

support children and their family members in order to prevent institutionalization.7

105. During emergency situations, such as pandemics, natural disasters, or conflicts, States Parties should continue and accelerate efforts to close institutions. During emergency situations, State Parties should provide prompt, accessible information and communication technologies to persons with disabilities, on equal basis with other.8 During emergencies, immediate efforts are necessary to identify people with disabilities in institutions, displaced persons with disabilities, and refugees with disabilities. Targeted efforts are needed to ensure inclusion in evacuation, humanitarian relief, and recovery. Emergency and recovery funding should not support continued institutionalization. Instead, plans for accelerated deinstitutionalization should be included in recovery efforts, and national deinstitutionalization strategies, and implemented immediately in emergencies.

7 Infants and children continue to be admitted and left in institutions. [https://www.minrzs.gov.rs/sr/aktuelnosti/vesti/ministarka-kisic-tepavcevic-zajedno-sa-predstavnicima-mdri-](https://www.minrzs.gov.rs/sr/aktuelnosti/vesti/ministarka-kisic-tepavcevic-zajedno-sa-predstavnicima-mdri-obisla-dom-za-decu-ometenu-u-razvoju-kolevka) [obisla-dom-za-decu-ometenu-u-razvoju-kolevka](https://www.minrzs.gov.rs/sr/aktuelnosti/vesti/ministarka-kisic-tepavcevic-zajedno-sa-predstavnicima-mdri-obisla-dom-za-decu-ometenu-u-razvoju-kolevka)

8 <https://www.mdri-s.org/public/documents/upload/publications-in-english/Isolated-in-isolation.pdf>