

Comments on the Draft Law on the Protection of Persons with Mental Disabilities

Following analysis and comments are prepared by International Aid Network IAN and refer to the Draft Law on the Protection of Persons with Mental Disabilities, presented by the Ministry of Health of the Republic of Serbia in October, 2012.

With this comments, we want to draw attention to the basic problems/settings in the draft that are in our great concern with respect to the promotion and protection of the rights of persons with mental disabilities in general, and especially for certain subgroups within this heterogeneously defined core target group.

Our analysis and comments consist of three parts:

First of all, we see our contribution in the comments that we presented in section A, related to issues of human rights with long institutionalization of people who suffer from mental disabilities.

In section B, comments are related to matters of users, families and human rights defenders involvement in the draft preparation, and the possible contribution of their involvement in the protection of the rights of persons with mental disabilities

In the third part, or section C we are dealing with the issue of different groups that this law relates to (people with intellectual disabilities, people with mental health problems, including those suffering from substance abuse).

Most of the analyzes and reviews come from our long term experience working on issues of development of mental health services and the involvement of users and families in the process of treatment and recovery, as well as from decades of dealing with the issues of the rights and support of the most marginalized communities in our society.

A. Group of comments related to the protection of the rights of **users of psychiatric services who need long-term treatment and comprehensive rehabilitation (this group is often referred to as people with severe mental health problems)**

Is it possible to protect the rights without reform of mental health care system?!

When it comes to improving the legal status and equality of rights of mentally ill patients from other patients, we think that this is a legal solution that has **no potential**, as Minister of Health, Professor Dejanovic announced, **to take these patients out of the second order position**. (Quoted from the website news of the Ministry of Health "*If there are the second order patients in our country, apart from those with rare diseases, certainly those patients are, unfortunately, people with mental disabilities*", noted Minister).

Currently, in Serbia, large part of long-term recovery and psychosocial rehabilitation of mentally ill persons is carried in large psychiatric hospitals, social institutions of asylum type as well as in families that for years and decades, also nurture their mentally ill members.

During the visit of the National Mechanism for the Prevention of Torture, to one of the five large psychiatric hospitals¹ we got the data that 460 patients are in the hospital for more than a year, and

111 of them are there for over than 10 years. Similar situation is also described by other independent bodies such as the European Committee for the Prevention of Torture, the local non-governmental organizations (Helsinki Committee for Human Rights, Mental Disability Rights Initiative-MDRI and other). Doctors and administration of these institutions regularly and publicly speak about the problem of discharge of patients in stable remission.

Apart from these **patients** who are placed **in institution**, in the absence of hunger family resources and/or lack of care of the family and the wider community, there is a large number of patients whose entire **burden of rehabilitation and care are up to family members** with no or very little support from official institutions. For most of the families, this situation is a burden that can not pass without major effects on rehabilitation process of persons suffering from mental disorders and also on quality of life of other household members.

We believe that a legal solution should offer the improvement of the legal position of **all persons** with mental disabilities. In this sense, any solution that does not define or regulate the issue of reform of mental health services is **not comprehensive enough and leaves this large group of people and their families, in our opinion, in a position which itself is a serious violation of their rights** (freedom from torture, cruel and inhuman treatment, the right to life in the community, the right to affordable health care, the right to liberty and security, the right to privacy and other rights).

Problems that are associated with patients who are detained or placed permanently in a large institution on one side, and with patients who are deprived of the opportunity to receive professional psychosocial rehabilitation in the community on the other, we see in **the outdated method of organization of psychiatric services**.

The National Strategy for Mental Health², which is in line with recommendations from the World Health Organization, recognizes these problems and offers a range of solutions which basically consist of the reform of psychiatric treatment and mental health development through the establishment of centers and services in the community. In addition to this strategic document, in Serbia, there are experiences related to the establishment and development of the center and mental health services in the community as an alternative to the dominant model of the existing organization of psychiatric services, with attempts of deinstitutionalization of patients from large hospitals and offering comprehensive community care for all residents of a given area.

We consider that either positive or negative experiences that were collected during the last 10 years in an attempt to establish community services and make them function, were not taken into account when defining the draft, also that the draft is not in line with the National Strategy for the Development of Mental Health, so remains the big question what policy document is behind the draft proposal.

In the current draft, in Article 2 which defines basic terms, misses the definition of the community mental health services, and the center for mental health in the community, involving protected housing and rehabilitation work. Community mental health services that offer solutions to problems that we have mentioned, and which are clearly defined in the National Strategy for the Development of Mental Health of the Republic of Serbia, are referred to in Article 12 of the draft, which defines the types of institutions for the treatment of people with mental disorders just as

organizational units of psychiatric institutions that these **can (and therefore have no obligation)** to set up.

We believe that **the biggest drawback** of the current draft law is the fact that it **does not offer solutions that would contribute to better organization, ie. transformation of existing psychiatric services in the modern mental health services in the community**, and which are necessary for any further health promotion and **protection of rights of all persons with mental disorders**. This view is supported by the WHO, and is listed as a basic principle in the Strategy³, as well as in numerous professional documents.

We also believe that the role of centers for mental health care needs to be more clearly defined in a way that would indicate that the centers for mental health care in the community should develop all necessary forms of psychosocial rehabilitation with outpatient services, day care, services for the treatment at home, psychosocial rehabilitation services, vocational training and protected housing, which will support the process of deinstitutionalization, ie. facilitate the inclusion of people with mental disabilities in the society.

B. Group of comments regarding the lack of user, families and human rights defenders' involvement

Nothing about us without us - the slogan of the international disability movement

Our next comment concerns the way of making the current draft of the law. With full respect for the expertise, experience and the good intentions of the National Commission expert team standing behind the draft, we believe that the Ministry of Health should include in the **consultation process** of the draft definition **other stakeholders** as well, especially **people with mental disabilities and their families**. In Serbia, there are several associations of persons with mental disability active for many years, while some parents' associations of people with intellectual disability have been actively working for several decades. Apart from persons whose rights are supposed to be protected by this law, it was important to include **human rights defenders and other individuals and civil society organizations** that are also able to make a significant contribution in finding practical solutions to the problems that the draft aims to solve.

We believe that the draft law should include mechanisms to actively involve persons with mental disabilities, as well as a detailed description of the position and role of their rights protector

The draft does not mention any **organized form of communication between health facilities and service users, like Patients' Council or the patient mediator**, to improve the position of people who are placed in an institution for a longer period of time. We also have experience with the institution of the Patients' Council in our country, which can be the basis for the regulation of this area. Support to the institutionalization of the dialogue between users and providers of psychiatric services, comes from a number of local and foreign experts and independent institutions (the European Committee for the Prevention of Torture supports the practice of creating Patients' Council in psychiatric hospitals)⁴.

When it comes to the institution of the Protector of patient' rights, we welcome legal solution offered in the other draft law prepared by the Ministry of Health - Draft Law on the Protection of

Patients' Rights, according to which the protector of patients' rights is independent from health institutions. What is lacking here is a detailed definition of protector of patients with mental disabilities rights' role, because this is a very specific area from the point of view of human rights protection. The current solution predicts that the protector of the patients' rights is responsible for all patients in a given territory, including people with mental disabilities. We believe that it is necessary to engage the **protector of human rights of patients with mental disability**, because their needs for protection are specific and relatively more often than in other areas of health care.

We would like to remind that one of the principles of the United Nations for the protection of persons with mental disability says that "the law should ensure automatic periodic review of the mechanism that affect the integrity or liberty of persons with mental disabilities in all instances " (UN, 1991)⁵, and that there should be legislation on automatic **monitoring mechanisms in all cases of involuntary hospitalization, also in cases of voluntary admission and treatment that lasts for a longer period of time**. It would be preferable if these monitoring mechanisms are conducted by an **independent regulatory body with legal status**⁶.

Through a mandate of protector of people with mental disability rights', the status and rights of people can significantly be improved, especially during involuntary hospitalization, as well as regarding the use of means of restraint. Specialized independent protectors of the rights of patients with mental disabilities can be a **guarantee of impartiality**, and ensure **effective** way of improving patients' rights through building trust and partnership between patients and staff, and may also increase the efficiency of the procedure and reduce the burden of administration which is dealt by health workers during these procedures.

We believe that the present draft law should define **specialized protectors** of psychiatric services users' rights, and set **one of the existing independent institutions** (such as the Ombudsman or the Commissioner for Equality) **as the superior parent body**. We are concerned that, as predicted, the protectors of patients' rights who are not specialized, and without extensive knowledge on mental health and the nature and course of mental illness, could have find it difficult to cope with the complex needs of human rights protection during involuntary hospitalization, and during restraint. Their parent body – Health Councils in municipalities, in our view, could hardly ensure compliance with one of the most important principles of the UN when it comes to the protection of persons with mental disabilities, and that is monitoring in all cases of involuntary retention and medical treatment without consent, as well as in cases of voluntary admission and treatment that lasts longer than a determined period of time. According to this, we believe that the **Ombudsman** or the **Commissioner for Equality**, are institutions that can guarantee a higher level of compliance with these principle.

C. Comments on the needs and possibilities of protecting the rights of all three sub-groups – people with intellectual disabilities, people with mental health problems and people suffering from substance abuse

Since International Aid Network IAN hasn't in the same manner and with the same commitment been dealing with all three groups (people with intellectual disabilities, people with mental health

problems and those who suffer from addiction), our comments on this important issue will be given only generally and particularly from the perspective of the organization that advocates for opening alternatives in the community and for deinstitutionalization.

We believe that **opening efficient and accessible services in the community is crucial for all three** groups of persons whose rights law applies. These are services in which people suffering from mental disabilities including addiction, can be effectively treated and rehabilitated, and people with intellectual disabilities are given adequate support. In two of the three groups it is about treatment and rehabilitation, and in people with intellectual disabilities it is not the case, so it remains unclear whether the draft law relates to the general population of people with intellectual disabilities, or persons with intellectual disabilities, who at the same time have a mental health problem. This issue is also considered extremely important, as well as the issue of aging and mental disabilities, one of the most urgent issues, when promotion of human rights is concerned. Our experience related primarily to material conditions and the quality of care in hospitals, has shown that **people with intellectual disabilities and seniors are in a more difficult position than other users/patients placed in large hospitals.**

We believe, that although the draft law comprises all groups mentioned, it offers the largest number of solutions for one sub-group within a group of people with mental health problems - (in this analysis, we used the terms users of psychiatric services who need long-term treatment and comprehensive rehabilitation and support). We believe, that on one hand the draft focused on addressing important issues such as voluntary housing and voluntary treatment, use of measures for physical restraint and isolation, aid provided by officials, **but lacks in other elements of human rights protection** that would solve the most pressing problems related to the human rights violation of these people due to long-term accommodation in an institution, as well poor support to living in the community.

Therefore, we believe that **if there is a need to protect human rights of all the three groups by unique legal solution, this legal solution is supposed to include components related to the creation of alternatives for the treatment and support within the community in a much larger scale**, and with reference to reality and the needs of the people with intellectual disabilities and people suffering from substance abuse, and their families.

Our desire and intention is to be constructive, and to make our experience and knowledge, as well as good relations with users, with domestic and foreign experts, available to the proponent of the Law and to the Parliament. Therefore, we ask you to organize more detailed and longer public debate around this draft, debate that would include all stakeholders and offer solutions that would put this large group of patients in front of, or the same line with other users of health and social services, with other citizens of the Republic of Serbia.

Sincerely,
IAN Team

¹ The visit was carried out in the framework of the National Mechanism for the Prevention of Torture to Special hospital for psychiatric disorders "Dr Slavoljub Bakalović", Vrsac 29th and 30th November 2012

² <http://www.zdravlje.gov.rs/tmpmzadmin/downloads/zakoni1/Strategija%20Razvoja%20Zastite%20Mentalnog%20Zdravlja.pdf>

³ Thus, for example, in the Strategy there can be found following paragraphs:

Old-fashioned psychiatric institutions must be reduced or closed. (In the Introduction, page 2, from "Regional statements on mental health vision", paragraph 3.5.)

The reform of the mental health needs to promote community-based services that are not discriminatory, are easily accessible and whose work (preventive and therapeutic) is based on evidence and values. (In The Vision, values, principles and goals, page 7.)

The mental health care services [...] should be organized at the community level, in which people with mental disabilities live. (The values and principles, page 9).

Similar views can be found in international documents, some of which have received political support of representatives of the Republic of Serbia (eg The Helsinki Declaration of January 2005., Or "Green Paper" The European Commission).

⁴ <http://www.cpt.coe.int/documents/srb/2012-17-inf-srb.pdf>

⁵ United Nations (1991) Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (Resolution 46/119). New York: United Nations General Assembly.

⁶ Independent bodies which protect the rights of people with mental disabilities should be competent to:

- a) follow the procedures under the Law and propose to psychiatric institution and the relevant state authorities measures for elimination of irregularities;
- b) monitor the respect of human rights and freedom and the dignity of people with mental disabilities;
- c) at its own option, or on the motion of the third person, examine instances of involuntary placement or detention in a psychiatric institution, ie, placement of children, minors, persons deprived of their legal capacity, as well as adults who are not competent to give consent;
- d) receive complaints and grievances of persons with mental disabilities, their legal representatives, family members, attorneys, lawyers, third parties, centers for social work, and to take the necessary measures for validation and monitoring;