

HELSINKI COMMITTEE FOR HUMAN RIGHTS IN SERBIA Helsinki files №33

# Mental Healthcare Befitting Human Dignity



Helsinki Committee for Human Rights in Serbia

## MENTAL HEALTHCARE BEFITTING HUMAN DIGNITY

Belgrade, April 2014

MENTAL HEALTHCARE BEFITTING HUMAN DIGNITY Helsinki Files No. 33

Published by Helsinki Committee for Human Rights in Serbia www.helsinki.org.rs

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Layout and design: Ivan Hrašovec Printed and bound by "Diginet", Zrenjanin Circulation: 500

Belgrade, April 2014



This edition was published within the project "Civil Society Campaign for Efficient Protection of Persons with Mental Disorders" realized with the support of the Royal Norwegian Embassy in Belgrade. The Helsinki Committee implemented the project in partnership with the International Aid Network /IAN/ and in cooperation with the Ministry of Healthcare of the Republic of Serbia and the offices of the Citizens' Ombudsman and the Provincial Ombudsperson of Vojvodina.







Заштитник грађана Zaštitnik građana



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### Foreword

This collection of papers broaches some of the biggest stumbling blocs in the way of mental health reform and effective deinstitutionalization in the Republic of Serbia

Analyses, opinions and recommendations presented in it reflect the years-long advocacy by several non-governmental organizations and independent experts for mental health reform and transformation from institutional to community-based care. This is about a long-term campaign of committed individuals, organizations and associations for gradual shutdown of residential institutions catering for psychiatric patients, and children and adults with mental disabilities, and, moreover, for dignified lives of and equal opportunities for these most vulnerable groups of population.

Throughout the project "Civil Society Campaign for Efficient Protection of Persons with Mental Disorders" non-governmental organizations, public servants and other stakeholders making up a work group were discussing the issues crucial to the mental health reform and, particularly, to the respect of human rights of persons with mental disorders and disabilities.

The Helsinki Committee for Human Rights and its partner in the project, the International Aid Network (IAN), warmly thank all who helped in making this edition: Citizens' Ombudsman, Lawyers' Committee for Human Rights (YUCOM), Mental Disability Rights International (MDRI), Belgrade Center for Human Rights, Association of Beneficiaries of Psychiatric Services "Duša" (Soul), Dr. Paolo Serra, psychiatrist, Caritas mental health consultant and manager of mental health services of Florence and Arezzo, and Prof. Dejan Milenković of the Belgrade University.

We all hope this publication would provide additional insight into the present-day situation of institutionalized psychiatric patients and other vulnerable beneficiaries of social care homes, and, moreover, encourage further relevant authorities and decision-makers to speed up the process of deinstitutionalization in Serbia in accordance with contemporary standards in psychiatry and international documents.

## The Necessity to Speed up Deinstitutionalization of Persons with Mental Disabilities

#### Introductory remarks

Deinstitutionalization of persons with mental disabilities needs to be understood as a transformation of different and often bulky healthcare and social care systems – especially in transition countries – into community-based networks that respect and protect human rights of this vulnerable group of population. Deinstitutionalization implies a set of motions to ensure a radical reform of the present system based on institutionalized care into a system focused on everyday lives of affected persons in their natural environments: and this, in turn, implies the establishment of an efficient network of community-based services that would make it possible for adults and children with mental disabilities to live surrounded by their families, relatives and friends.

Basically, deinstitutionalization is a shift from residential to communitybased care providing active support in terms of: prompt and accessible medical services and treatments; independent living for adults with intellectual and mental disabilities in community homes or on their own; foster families for adults with no caring families or with no families at all; and other services available at all times to persons with mental disabilities and/or their families, meant to improve their lives in a non-discriminatory, therapeutically adequate and preventive manner.

On the other hand, a successful transformation necessitates wide public support. It also calls for citizens' raised awareness about mental disabilities not being "contagious diseases" and about crucial roles assigned not only to services but also to "communities" as wholes. The existing, wide-spread prejudiced attitudes toward persons with mental disabilities in Serbia (including different forms of stigmatization, defamation, exclusion, etc.) should be coped with by well-organized, anti-stigmatization campaigns with active participation of professionals, associations, schools and the media. Unfortunately, citizens are still insensible of this vulnerable social group and that is why Serbia badly needs a permanent, awareness-raising campaign for tolerance and non-discrimination.

#### **Developments**

Psychiatric hospitals were certainly among most deplorable institutions in Serbia in 1990s. Patients' living conditions were degrading and inhuman: their meals were meager, their dormitories overcrowded, beddings in shreds, medicines scarce...in brief, they were deprived of their dignity as human beings.

Activities to change this situation, undertaken mostly by citizens' associations and human rights defenders, marked the very beginning of Serbia's transition. These were the campaigns for hospitalization of most at risk patients only, the startup of deinstitutionalization and transformation of big psychiatric hospitals into community-based services.<sup>1</sup>

In January 2003 under the Stability Pact's Social Cohesion Initiative, the Ministry of Healthcare established the National Committee for Mental Health to initiate reforms in this domain. The Committee was solely composed of ten psychiatrists from all over the country, excluding other professionals.<sup>2</sup>

The Stability Pact's Mental Health Project produced a regional declaration eight countries of the Southeast Europe (Bulgaria, Romania, Moldova, Albania, Croatia, Bosnia-Herzegovina, Serbia, Montenegro and Macedonia) signed in 2003 in Helsinki and then amended in November of the same year in Ljubljana.<sup>3</sup>

The National Committee was responsible for the implementation of the project meant to: 1) assess the situation of mental healthcare system; 2) develop a strategy and an action plan; 3) draft a law on the protection of the rights of persons with mental disorders; 4) have the draft adopted by the government and enacted in the parliament; 5) and, establish a pilot community mental health service.

The Serbian government adopted the Committee's Strategy for Mental Health along with an action plan on January 19, 2007. A pilot community mental health service was established in the Mediana municipality, Niš<sup>4</sup>. Since no reports on the Strategy's implementation have been publicized for the past seven years, one cannot but question the extent to which it has met its goals.

The Serbia report the Mental Disability Rights International (MDRI) publicized in 2007 alarmed the general public of the situation of the country's specialized institutions and centers and drew their attention to the state's (non) recognition of the problem. MDRI report – supported by video-recordings and photos – laid bare the actual situation of institutionalized mental

More about the process in "Torture not Treatment: Segregation and Abuse of Children and Adults with Special Needs in Serbia," Mental Disability Rights International – MDRI, 2007.

<sup>2</sup> For more information see IAN website at *http://www.ian.org.rs/mentalnozdravlje/ reforme.htm.* 

<sup>3</sup> The Strategy for the Protection of Mental Health, the Government of the Republic of Serbia, 2007.

<sup>4</sup> http://www.ian.org.rs/mentalnozdravlje/reforme.htm.

health beneficiaries and called for urgent establishment of an efficient system of deinstitutionalization. The report, along with those published by other non-governmental organizations and stories run in the media, drew public attention to deplorable living conditions and inhuman treatment of institutionalized persons with mental disabilities.<sup>5</sup>

It was only in 2013 that the Serbian parliament passed the Law on the Protection of Persons with Mental Disabilities. This was the first legislation to regulate the issues that, directly or indirectly, affect this vulnerable group of population. The Law provides general principles of mental health organization and protection, treatment procedures and conditions, and prerequisites for hospitalization of persons with mental illness against their own free will.<sup>6</sup> The Law somewhat contributed to the improvement of the overall situation, especially in the context of long-term hospitalization of persons of the Section 2 of the Law on Extrajudicial Procedure (Hospitalization in a Neuropsychiatric Institution).<sup>7</sup> However, the very passing of the Law was marked by many controversies challenging the provisions that were not in keeping with contemporary standards.

The Serbian parliament – the People's Assembly – demonstrated interest in the problem even before the government adopted the Law. On February 28, 2013 the parliamentary Committee for Human and Minority Rights, and Gender Equality, and the Citizens' Ombudsman convened a session to discuss the problems and dilemmas plaguing the process of deinstitutionalization and community-based care. The European Expert Group's document titled "Common European Guidelines on the Transition from Institutional to Community-Based Care" – defining standards each country should comply

<sup>5</sup> See: "People on the Margins of Society: Human Rights in Psychiatric Hospitals," Helsinki Committee for Human Rights in Serbia, 2007, and "People on the Margins of Society: Report on the Situation of Social Care Institutions Catering for Children, Youth and Adults with Mental Disabilities, and Mental Illnesses," Helsinki Committee for Human Rights in Serbia, 2009 – http://www.helsinki.org.rs/serbian/doc/sveske25.pdf and http:// www.helsinki.org.rs/serbian/doc/Ljudi%20Na%20Margini%20-%204.pdf.

<sup>6</sup> Official Gazette of the Republic of Serbia, No. 45/2013.

<sup>7</sup> Official Gazette of the Republic of Serbia, No. 25//82, 48/88, 18/05 and 85/12.

with to properly respect the rights of persons with mental disabilities – was presented to the participants on the occasion.<sup>8</sup>

On the other hand, the parliament should have been more active while considering the draft law. It actually overlooked a number of critical remarks on its contents the Citizens' Ombudsman and civil society activists had articulated before the draft was submitted to its consideration. The majority of MPs voted in the draft taking that having any law was better than having none. Major criticisms of the draft were the following:

- 1. The draft fails to provide mandatory establishment of community-based mental health services, highlighted over the public debate; such services are optional under the draft;
- 2. The draft provides isolation, which contradicts CPT standards prohibiting isolation of persons with serious and acute mental disorders;
- 3. The draft provides unduly postponed new hearings in the cases of hospitalization in a psychiatric institution against a person's free will (within the period of seven days)<sup>9</sup>

As provided under the Law, the Ministry of Healthcare adopted two regulations in late 2013: the Rule on Types of Mental Health Services<sup>10</sup> and the Rule on Physical Restraint and Isolation of Persons with Mental Disorders Hospitalized in Psychiatric Institutions.<sup>11</sup> Both bylaws actually elaborate on and detail exactly the provisions fiercely disputed over the public debate.

The Rule on Types of Mental Health Services provides that communitybased mental health services shall be established as separate "departments for the protection of mental health of medical centers, which also treat persons with mental disorders hospitalized in psychiatric institutions."<sup>12</sup> This Rule just reflects the Law's shortcoming: protection of mental health cannot be treated as an "additional" activity but necessitates establishment of mental health services as special, autonomous, community-based centers (the Law fails to provide).

<sup>8</sup> See: Association for the Promotion of Inclusion in Serbia – *http://www.sapi.rs/2012/ index.php/sr/item/452.* 

<sup>9</sup> See: Deputy Citizens' Ombudsman Miloš Janković, Danas, March 26, www.danas.rs.

<sup>10</sup> The Official Gazette of the Republic of Serbia No. 106/2013.

<sup>11</sup> The Official Gazette of the Republic of Serbia No. 94/13.

<sup>12</sup> The Official Gazette of the Republic of Serbia No.106/2013.

The Rule on Physical Restraint and Isolation of Persons with Mental Disorders Hospitalized in Psychiatric Institutions, among other things, details the use of the highly disputable measure of isolation. A person with mental disorder, according to this regulation, can be placed in an isolated room with windows and doors locked from the outside if the measure of isolation is authorized by the person's psychiatrist and if "the measure of isolation is not used as punishment." Further on, a psychiatrist can prescribe isolation in order to (1) prevent a person from doing harm to himself/herself or to other persons, and (2) ensure the person's medical treatment. The psychiatrist is duty-bound to decide on the period of time during which the person shall be kept secluded.<sup>13</sup>

It could be said now, 14 years later, that the process of deinstitutionalization still starts from scratch. Moreover, it could be said that even the steps taken in that direction (some of which were utterly wrong) have not substantively triggered off the process itself.

In Serbia, about 8,500 mentally and psychosocially disabled adults are placed in different residential institutions. Under Article 19 of the UN Convention on the Rights of Persons with Disabilities they shall have the opportunity to choose their place of residence and where and with whom they live, and shall have access to a range of in-home, residential and other community support services.

## International standards on the rights of persons with mental disabilities

Two international documents are of key importance to the exercise of rights of persons with mental disabilities – the UN Convention on the Rights of Persons with Mental Disabilities and the Common European Guidelines on the Transition from Institutional to Community-Based Care.

Serbia ratified the UN Convention on the Rights of Persons with Mental Disabilities in 2009. The guiding principles of the Convention are medical care and rehabilitation provided to persons with disabilities. One of fundamental principles of the Convention is respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and

<sup>13</sup> The Official Gazette of the Republic of Serbia No. 94/13.

independence of persons. Signatories of the Convention – State Parties – shall take efficient and appropriate measures to ensure full independence, as well as physical, mental, social and professional capacities of persons with disabilities, and their social integration and participation in all aspects of public life. To this end, State Parties shall organize, strengthen and provide comprehensive rehabilitation services and programs, especially in the areas of healthcare, employment and education. Signatories of the Convention are also obliged to provide health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons. Last but not least, State Parties shall ensure that persons with disabilities are not deprived of their liberty unlawfully or arbitrarily, and that the existence of a disability shall in no case justify a deprivation of liberty.<sup>14</sup>

The Common European Guidelines on the Transition from Institutional to Community-Based Care are actually a toolkit for on implementing and supporting a sustained transition from institutional care to family-based and community-based alternatives for children, persons with disabilities, persons with mental health problems and older persons in Europe.<sup>15</sup> These Guidelines provide practical advice about how to make a sustained transition from institutional care to family-based and community-based alternatives for individuals currently living in institutions and those living in the community, often without adequate support. They are based on European and international best practice and have been developed in consultation with key European networks representing children, people with disabilities, mental health organizations, families, older people and public and non-profit service providers. After years-long analysis and collection of data on models of good practice, the work group developing the Guidelines concluded that all EU memberstates needed to adjust their mental health systems to the principles stated in the Guidelines, which also corresponded to the 10-year strategy Europe 2020. The strategy sets ambitious objectives for inclusive growth, which implies

<sup>14</sup> Official Gazzette of the Republic of Serbia No. 42/09.

<sup>15</sup> Common European Guidelines on the Transition from Institutional to Community-based Care European Expert Group on the Transition from Institutional to Community-based Care, Brussels, Belgium, November 2012. Translated into Serbian and published by UNDP, 2012.

measures that promote integration and adequate living standards of the poor and socially marginalized persons.

The Guidelines itemize the "steps" to be taken towards full deinstitutionalization: (1) making the case for developing community-based alternatives to institutions; (2) assessing the situation; (3) developing a strategy and an action plan; (4) establishing a legal framework for community-based services; (5) developing a range of services in the community; (6) allocating financial, material and human resources; (7) developing individual plans; (8) supporting individuals and communities during transition from institutional to community-based care; (9) defining, monitoring and evaluating the quality of services, and (10) developing the workforce.<sup>16</sup>

The Guidelines outline the support for the transition from institutional care to community-based services at the European and international level. It covers human rights and values, political commitments, and scientific and economic evidence of why deinstitutionalization is the right thing to do and how it can benefit not just the people concerned, but the whole of society.

#### The role of the Citizens' Ombudsman in the protection of persons with mental disabilities

Over the past few years the Citizens' Ombudsman has been considerably contributing to the respect of the rights of persons with mental disabilities in the Republic of Serbia. In this context, the Ombudsman's office, in its capacity as an independent regulatory agency, has been trying to speed up the process of deinstitutionalization through recommendations and advisory opinions on specific cases, but also by warning policy-makers of their responsibility for the implementation of international human rights documents and standards, particularly those related to this vulnerable group. The Ombudsman's office has also convened several conferences and round tables to discuss the problem. Representatives of psychiatric and other mental healthcare institutions have been participating in these and other forums organized by non-governmental organizations. The Ombudsman's office has submitted

<sup>16</sup> http://deinstitutionalisationguide.eu/wp-content/uploads/2013/09/ smernice\_korigovane\_priprema.pdf.

its critical remarks on the draft Law on the Protection of Mental Health and actively participated in the process of its adoption.

This chapter focuses on two reports in which Ombudsman draws public attention to the problems that either directly or indirectly affect the process of deinstitutionalization and the rights of persons with mental disorders. The first is his 2013 annual report and the second the NPM report for the year 2012.

In the section dealing with the administration's attitude towards citizens, and especially towards persons with mental disabilities, the 2013 annual report highlights that the Ministry of Healthcare should launch the mental health reform and develop relevant protective mechanism, notably through the promotion and establishment of community-based services, whereas the government should develop a plan for transformation of residential psychiatric institutions.<sup>17</sup>

In the context of the respect for rights of persons deprived of their liberty and NPM, the report – though commending the fact that the Law on the Protection of Persons with Mental Disabilities had been passed at long last, along with relevant bylaws – highlights the following major flaws that mark the process of deinstitutionalization:

- (1) The deadlines set in the Strategy for the Protection of Mental Health and in the accompanying Action Plan have not been met;
- (2) A large number of patients, no longer in need of hospitalization, are still accommodated in "big" psychiatric hospital because conditions for their community-based care have not been created;
- (3) The Law on the Protection of Persons with Mental Disabilities provides isolation of persons hospitalized in psychiatric institutions;
- (4) Residential social care institutions still accommodate a large number of beneficiaries just because conditions for their community-based care have not been created yet;
- (5) Residential social care institutions of asylum type are not only inadequate for the treatment of beneficiaries but also understaffed in terms of residential physicians, pedagogues and nurses;
- (6) No concrete measures have been taken to reduce the number of residential beneficiaries within the deadlines set under the law;

<sup>17 2013</sup> Annual Report, March 15, 2014, p. 72–73 – available at www.ombudsman.rs.

- (7) Some beneficiaries of residential social care insitutions are permanently kept in isolation, which equals torture;
- (8) Freedom of movement is restricted to a number of beneficiaries of residential social care institutions (they are locked up) and many of them are occasionally physically restrained without any legal justification;

The report duly elaborates and documents all these findings and observations.<sup>18</sup>

The National Protective Mechanism (NPM) has been established within the Citizens' Ombudsman office. Referring to the situation of residential institutions the 2012 NPM report<sup>19</sup> quotes:

"In 2012 NPM paid four fact-finding missions to psychiatric institutions, three of which were announced in advance, while the fourth was an unannounced visit late into the night. NPM addressed 25 recommendations to the authorities to have them adjust the present situation to the existing regulations and standards. The NPM team witnessed numerous consequences of long-term hospitalization of persons with mental disorders insular psychiatric hospitals. According to the interviewed physicians, patients are not released once they need medical treatment any longer because community-based services to provide them medical and social support in accordance to their needs have not been established. In one of Serbia's big psychiatric hospitals more than one half of total number of patients are hospitalized for over one year, and more than 100 of them for more than ten years. The main question is therefore: can treatment be something that takes more than ten years or a lifetime, or is it about an asylum of a sort? Patients living in psychiatric hospitals for years are completely excluded from a regular social environment, and many of them are even locked up. As time goes by they are losing their social and other skills and turning less and less capable of independent living. Taken as a system, long-term hospitalization in psychiatric institutions isolated from the outside community, combined with accommodation that is far from contemporary standards, can easily generate individual cases of torture but surely stands for inhuman and degrading treatment...The monitored hospitals are understaffed: they lack professional medical officers; nurses are not adequately trained; the criteria for subsidizing these hospitals are

<sup>18 2013</sup> NPM Annual Report, March 15, 2014, p. 86-88.

<sup>19 2012</sup> NPM Annual Report, April 2013, p. 27–30 – www.ombudsman.rs.

inadequate; patients are inadequately kept engaged and inadequately remunerated for the duties they perform; patients are not properly encouraged to partake in decision-making relevant to their hospitalization and treatment; security services are understaffed, according to the interviewed personnel... The team observed that the procedures for physical restraint of agitated or violent patients were inadequate."

What NPM team recommended was that patients should be physically restrained only if there was no other medically justified way to put their aggressive behavior under control. Physical restraint is a last resort to be taken only when all other less restrictive measures fail; it can be decided on solely by a medical doctor and implemented with the means that exclude any physical harm; a patient should be kept restrained for the shortest period possible and get unfastened as soon as calmed down by other means and methods; a medical officer should non-stop observe the restrained patient, and a patient should not be kept tied up in the presence of other patients. In addition, records on the measure of physical restraint, including the reasons why, should be kept meticulously...The team observed that the pharmacological therapies were predominant methods of treatment, while occupational therapies, group and individual psychotherapies, and recreational and educational activities were often inadequate for a great majority of patients or provided on unequal footing."

#### \* \* \* \* \*

The above-mentioned international documents, NPM findings and recommendations, along with those by non-governmental organizations, should prompt the administration to adopt several major instruments for deinstitutionalization in almost no time: (1) a feasibility study on the Strategy for Deinstitutionalization; (2) the Strategy for Deinstitutionalization; and (3) the Action Plan.

These documents should clearly state implementation deadlines, actors and measures to be taken. As such they should set out a genuine process of deinstitutionalization and help a considerable number of persons with mental disorders to freely resume their normal lives in the outside community.

## The Situation of Persons with Mental Disabilities and the Law on Their Protection

It has been almost a year since the adoption of the Law on the Protection of Persons with Mental Disorders. Although the Citizens' Ombudsman and civil society activists had alerted in time and to the point to the draft's many shortcomings, what prevailed was the stance – shared even by some international organizations – that no matter what having any law was better than having none. Intent not to comment on this any further, we believe the time has come to broach the Law's amendment.

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On December 18, 2012 the Citizens' Ombudsman – as provided under Article 18 of the Law on the Citizens' Ombudsman<sup>20</sup> – addressed his advisory opinion on the Draft Law on the Protection of Persons with Mental Disorders to the Ministry of Healthcare and general public, wishing to thus help to improve the situation of persons with mental disorders.

He commended the draft's provisions against discrimination on any ground<sup>21</sup> and for the protection of patients' dignity,<sup>22</sup> as well as the Draft's overall purpose, which was protection of persons with mental disorders, but also poipointed many flaws calling for amendment. He drew attention to the fact that the Draft Law was not exactly in accordance with the principles of

<sup>20~</sup> Official Gazzette of the Republic of Serbia No. 79/2005~and~54/2007.

<sup>21</sup> Article 4 of the Draft.

<sup>22</sup> Article 5 of the Draft.

the UN Convention on the Rights of Persons with Mental Disabilities,<sup>23</sup> the UN Convention on the Rights of the Child<sup>24</sup> and the governmental Strategy for the Development of Mental Health<sup>25</sup>.

Taken as a whole, the Draft, he said, actually steers persons with mental disabilities to the existing residential institutions (psychiatric hospitals) and medical centers, but practically overlooks the support to local communities they need to partake in deinstitutionalization and create conditions for transition from institutional to community-based care wherever possible, which implies gradual shutdown of "big" residential institutions.<sup>26</sup> Some provisions of the Draft, he quoted, could not but leave one under the impression that treatment of persons with mental disorders in the existing institutions is something that is being insisted on, which is contrary to the principles laid down in the Strategy, disadvantageous to social inclusion of persons with mental disabilities and, hence, "not exactly in the best interest of these groups of citizens."

In this context, the Citizens' Ombudsman underlined that the Strategy was about "mental health services providing contemporary and comprehensive treatment, implying bio-psychological approach to be taken in a community and as close as possible to the family of a sick person."<sup>27</sup> "This approach aims at mental health that protects, supports and maintains emotional and social well-being by the means that fortify and protect mental health itself, and pay respect to culture, equal opportunities, social justice, human dignity and fundamental human rights."<sup>28</sup> The Strategy – based on the principles of WHO Ottawa Charter for Health Promotion – clearly states the main objective, which is to help persons with mental disorders to "better control their own lives and improve their mental health by developing personal skills with

<sup>23</sup> Official Gazzette of the Republic of Serbia No 42/2009.

<sup>24</sup> Official Gazzette of the Republic of Serbia No 2/97.

<sup>25</sup> Official Gazzette of the Republic of Serbia No 8/2007.

<sup>26</sup> Mapping Exclusion, Institutional and community-based services in the mental health field in Europe, Mental Health Europe, Brussels, 2012; Common European Guidelines on the Transition from Institutional to Community-based Care, European Expert Group on the Transition from Institutional to Community-based Care, Novembar 2012. (*www. deinstitutionalisationguide.eu*).

<sup>27</sup> Article 3.2. of the Strategy

<sup>28</sup> Ibid.

the assistance of supportive communities and empowered people." According to the adopted Strategy, the mental health reform implied transition from conventional approaches based on medical treatment to "comprehensive, multi-dimensional approaches to mental health and mental disorders."<sup>29</sup>

On the one hand, the Draft Law did embrace the Strategy as it provided that "persons with mental disabilities shall be protected without discrimination on any ground" (Article 4); "a patient's dignity shall be protected" (Article 5); "the safeguard of mental health shall imply prevention of mental disorders, promotion of mental health, analysis and diagnosis of a person's mental condition, treatment and rehabilitation, and early detection of mental disorders (Article 3); "a mentally disabled person shall have the right to protection and improvement of his/her mental health through prevention, proper care, treatment and psychosocial rehabilitation in appropriate medical and other institutions, and the right to reintegrate into his/her family, social and working environment by his/her own choice whenever possible" (Article 6); and that "persons with mental disorders shall be treated in least restrictive environments and by the use of least restrictive medical methods respective of these persons' religious beliefs and cultural affiliations" (Article 8). On the other hand, however, the Draft Law provided no guarantees for all this. Moreover, by entrenching the pivotal role of medical institutions in treatment of persons with mental disorders it undermined the fundamental guidelines of the Strategy and threatened the exercise of human rights.

Over several fact-finding missions to psychiatric hospitals conducted in the past year – including four in 2012 in its capacity as NPM<sup>30</sup> – the Citizens' Ombudsman's team observed many adverse consequences of long-term hospitalization, including even the cases of lifelong hospitalization. For instance, out of 820 patients of the psychiatric hospital in Vršac, 420 have been hospitalized from more than a year and 111 of them for over ten years. All patients – especially those kept locked up – have been completely isolated from the outside community for long, thus turning less and less capable of social reintegration. In addition, the team observed deplorable conditions in which these patients were accommodated, and learned anew that patients were

<sup>29</sup> Article 3.1. of the Strategy

<sup>30</sup> The Law on Ratification of the CPT Optional Protocols – Official Gazette of the Republic of Serbia No. 16/2005, 2/2006 and 7/2011.

not released despite their improved state of mental health just because supportive, community-based services had not been available.

In his advisory opinion following these visits the Citizens' Ombudsman said mechanisms of social support to persons with mental disorders should be regulated by a law to provide community-based support and prevention, and methods of rehabilitation and social integration. Reliance on the existing mechanisms of support within the social care system is welcome but insufficient for full social integration and the respect of human rights of mentally disabled persons, he added.

The Citizens' Ombudsman also seriously questioned the policy of tasking "elementary healthcare, whenever possible" with the prevention of mental disorders – because, he argued, if the prevention of mental health stands for public good, as the Strategy posits, we should cope with the origins of mental disorders that are closely connected with families, schools, workplaces and entire communities. Preventive measures are highly important when it comes to mental health of children and young adults. Therefore, a law should provide prevention of children's and adolescents' mental health, especially prevention of suicide attempts among the young, prevention of drug addiction, as well as early detection of mental disorders and prompt intervention.

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Although all the participants in the public debate shared the opinion about the establishment of distinct, community-based mental health services, the enacted Law provides that mental health services shall be organized as supplementary departments within the existing psychiatric institutions and medical centers. Proper protection of mental health cannot be treated as an additional activity of the existing institutions. Community-based mental health services should be autonomous, while their competences and treatments provided by law. Halfway measures cannot solve the problem of mental health protection or ensure efficient treatment, care and support to persons with mental disorders within a community.

Obviously that responsibility for Serbia's snail-paced deinstitutionalization lies with relevant decision-makers, but also with the great majority of psychiatrists who obstruct the process out of fear reduction of psychiatric services in institutions would endanger their jobs. Today's psychiatric hospitals with too many patients under long-term treatment – and some hospitalized for lifetime – resemble asylums as they more often than not completely isolate patients from the outside world than treat them. What is being ignored nowadays is the fact that, as a rule, long-term "treatment" results not in recovery, on the contrary: patients hospitalized for years lose almost all the skills they used to have before entering the "treatment" process. In addition, many patients are hospitalized for years because there is simply no one in their community to take care of them or willing to do so. Be it as it may, as years go by these persons grow more and more dependent on hospitals, and more and more unable of independent life or even life within a supportive community.

What is also being ignored is that persons with mental disorders are equal before the law and that deprivation of any right whatsoever cannot be justified by treatment. What is further being ignored is the fact that longterm hospitalization, plus deplorable accommodation and conditions of life, generates torture, inhuman and degrading treatment.

The Law on the Protection of Persons with Mental Disorders provides the measure of isolation in psychiatric institutions. Isolation is not a medical method and cannot stand for treatment, let alone be therapeutically justified. Nevertheless the Law sees it as a preventive measure in high-risk situations caused by agitated patients. There certainly are other means and methods for calming down agitated patients, which are not harmful to their physical and mental integrities guaranteed under Article 25 of the Constitution. The provision on isolation of persons with mental disorders goes beyond the limits of constitutional restrictions in a democratic society and as such breaches the Article 23 of the Constitution of the Republic of Serbia – which guarantees inviolability of human dignity and everyone's duty to respect and protect it.

The UN Committee against Torture prohibits isolation of persons with acute mental disorders. For the UN Special Rapporteur on Torture, isolation of such persons – no matter how long – equals cruel, inhuman and degrading treatment. Consequently, the provisions on it in domestic legislation should be annulled, the more so since isolation is not an everyday practice of Serbia's psychiatric institutions.<sup>31</sup>

On occasion the use of physical force against a patient may be unavoidable in order to ensure the safety of staff and patients alike. Creating and

<sup>31</sup> CPT report on Serbia, February 2011.

maintaining good living conditions for patients, as well as a proper therapeutic climate – a primary task for hospital staff – presupposes an absence of aggression and violence amongst patients and against staff. For this reason, it is essential that staff be provided with the appropriate training and leadership to be capable of meeting in an ethically appropriate manner the challenge posed by an agitated and/or violent patient. The line separating proportional physical force to control a patient from acts of violence can be a fine one. When that line is crossed, it is often due to inadvertence or unpreparedness rather than a result of malevolent intention. In many cases the staff are simply not properly equipped to intervene when confronted with agitated and/or violent patients. And this is yet another reason why the Law has to be amended.<sup>32</sup>

Because of the Law's blurred, half-way provisions, a number of persons with mental disorders who have been voluntarily hospitalized are actually deprived of their liberty – they live behind closed doors and are not allowed to leave the institution. The Law should provide that a person entering the psychiatric institution by his/her own free will or with the consent of his/her guardian shall be deprived of liberty in no way (locked up or restrained in some other way). Only by a court decision could a person/patient be deprived of liberty.

There are cases – the Law failed to regulate – when persons are admitted to psychiatric hospitals upon signing consent on hospitalization despite the fact that they were highly agitated at the time (and often driven in by paramedics). This opens to doubt their free will, meaning their capacity of rational thinking at the time of agitation. The Law should clearly provide that in such cases a person shall be hospitalized solely by the decision on involuntary placement in a psychiatric hospital.

The Law has a most disputable provision on "involuntary detention." "Detention" presupposes deprivation of liberty and, therefore, one cannot give his/her consent to deprivation, let alone that such a consent can be given by his/her guardian. "Detention" implies a coercive action against a person rather than free will of a detained person. It is only logical that a person expressing his/her free will for treatment and admission to a psychiatric hospital is not being "detained." Such person can be detained/hospitalized

<sup>32</sup> CPT Standards (2002) 1-Rev.2010.

for a longer period only if decided so by a psychiatrist and a court of law – which is a legally justified measure of coercion.

Besides, the Law's provisions on the deadlines related to involuntary placement in a psychiatric institution need to be carefully scrutinized. Namely, unlike a person taken into policy custody, who must be brought before the judge within 48 hours from the time of arrest, a person with mental disorders hospitalized, for instance, by a psychiatrist on duty, may be brought before the judge in seven days since admission. The Law should provide the same period – 48 hours – for such persons. Why should a suspect of a crime or misconduct be more privileged than a sick person? Moreover, the court expert in the proceedings shall not be a medical doctor working for the psychiatric institution that has filed the request for involuntary hospitalization.

Last but not least, there are most disputable provisions on the role of police officers in psychiatric hospitals. The very presence of policemen in uniforms wearing guns and handcuffs can only aggravate the condition of not only agitated patients – against whom police officers are using force or other means of coercion – but also of all other patients. This is the more so absurd since security officers in prisons are unarmed and not equipped with handcuffs or clubs. These provisions should be erased from the Law. The task of keeping law and order should be left to institutional staff – not wearing uniforms or arms but trained in non-violent methods of treating agitated patients. Police presence in psychiatric institutions should be an exception rather than a rule. Under the Law on the Police and relevant bylaws, police officers can intervene at all times to resume law and order, or protect citizens' lives and property – and thus, as the last resort, they can also intervene in psychiatric institutions. The Law needs not to explicitly provide things that are only logical.

## Legal Capacity in Serbia: Failure to Meet the Standards for the Protection of the Right of Persons with Disabilities to Equality before the Law

#### **International Standards**

From the perspective of comparative law, the Council of Europe, domestic legal standards, as well as the court practice of the European Court of Human Rights, it is clear that the very approach to disability made significant progress from the time when it was viewed in terms of individual limitations and medical assistance, until the moment when special attention began to be devoted to the equality of human rights of persons with disabilities and the removal of barriers in society, which continue to hinder the realization of equal opportunities.<sup>33</sup> In 2006, pursuant to the Recommendation of the Committee of Ministers, the Council of Europe especially emphasized "the paradigm shift from patient to citizen", stating as follows: "We have moved from seeing the disabled person as a patient in need of care who does not contribute to society to seeing him/her as a person who needs the present barriers removed in order to take a rightful place as a fully participative member of

<sup>33</sup> Conclusions, Annual Report 2011, European Union Agency for Fundamental Rights; see also the publication "Model zakona o razlozima i postupku ograničenja i zaštite pojedinih prava i sloboda" (Model Law on the Reasons and Procedure for Limiting and Protecting Certain Rights and Freedoms), Centre for Advanced Legal Studies (CUPS), Belgrade, 2012, pp. 9–10, accessible at www.cups.rs.

society ... We therefore need to further facilitate the paradigm shift from the old medical model of society.<sup>34</sup> The concept of disability as a human rights issue was considerably improved after the adoption ot the UN Convention on the Rights of Persons with Disabilities, a comprehensive internationally binding document regulating the fundamental rights of persons with disabilities and establishing a special body to monitor the implementation of this international treaty.<sup>35</sup>

As for persons with intellectual and mental disabilities, who are especially sensitive and highly vulnerable, legal capacity affects their daily life in large measure. Legal capacity is a legal category that confirms persons' decisions and actions and make them visibile from the legal aspect.<sup>36</sup> In the member countries of the Council of Europe the limitation of a person's legal capacity has different legal effects. These legal effects may vary, from deprivation of legal capacity to that of the freedom to make decisions, involv-

<sup>34</sup> Ibid, p. 9.

<sup>35</sup> Law on the Confirmation of the Convention of the Rights of Persons with Disabilities, "Sl. Glasnik RS – Međunarodni ugovori", 42/2009.

<sup>36</sup> Ibid, p. 10.

ing where and with whom they can live, management of their property and finances, marriage and parenthood, voting and membership in political parties, trade unions and non-governmental organizations, as well as everyday decisions on dedicated contracts or contracts with cell phone providers.<sup>37</sup> Legal capacity implies a person's possibility to be recognized in the legal system or, more exactly, to acquire rights and obligations through his/her own activity, namely, the expression of his/her will. A person acquires legal capacity upon completion of 18 years and from that moment onwards he/ she can enter into contracts, give consent for medical treatment, make decisions on where to live, dispose of his/her property, file lawsuits and appeals, enter into marriage, make decisions on the recognition of motherhood or fatherhood, raise children, vote in elections or a referendum, raise a loan or, in other words, undertake all legal actions that an adult person may undertake in his/her everyday life. Without legal capacity an individual cannot manage his/her life autonomously, which implies decision-making on various everyday problems, so that the loss of legal capacity also implies the loss of control over one's life.38

Legal capacity, as the possibility (power) to make decisions on one's rights and obligations (or the power to be person recognized by law), is a segment of and condition for exercizing the *right to equal recognition before the law,* to have *legal personality* and, in a broader sense, have the *right to privacy and family life,* as some of the fundamental human rights. A modern approach to disability and human rights anticipates legal capacity as the possibility of every individual to make such decisions and as his/her fundamental right and, in that sense, regulates the procedure for providing support to those persons who have difficulties in the decision-making process (so-called *supported decision-making*). On the other hand, in some modern systems, the procedure for limiting the possibility of persons with some intellectual or mental dissabilities to make decisions – if such decisions might inflict a greater harm upon themselves, persons close to them or other legally interested persons – is regulated, but any such limitation of of a person's ability

<sup>37</sup> Ibid.

<sup>38 &</sup>quot;Poslovna sposobnost kao osnovno ljudsko pravo: Vodič kroz domaću praksu i moguće alternative starateljstvu" (Legal Capacity as the Fundamental Human Right: A Guide Through Domestic Practice and Possible Alternatives to Guardianship), Mental Disability Rights Initiative of Serbia (MDRI-S), Belgrade, 2012, accessible at www.mdri-s.org.

to make decisions must be justified. Insofar as human rights limitations are concerned, each case must be investigated by the court, while the reason for such limitations must proportionately prevail over the rights of a person to make decisions on his/her rights and obligations.<sup>39</sup> Consequently, any *general* limitation of legal capacity (which is anticipated upon coming of age) is not justified in a democratic society, while the approach that regulates this issue from the aspect of support and not prohibition, is much closer to the achieved international human rights standards. Supported decision-making, instead of so-called *substitute decision-making or guardianship*, is the system which, to the greatest extent, observes the fundamental rights of individuals that are acquired by birth.

In the UN Convention on the Rights of Persons with Disabilities, legal capacity is regulated by Article 12, within the *right to equality before the law*. The mentioned article represents the gist of this document in view of the fact that the exercise of legal capacity is a vital prerequisite for the exercise of all other rights guaranteed by the Convention. Article 12 stipulates that "states parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life". In its *Draft General Comment on Article 12 of the Convention*<sup>40</sup> the Committee on the Rights of Persons with Disabilities also emphasizes the following: *"The right to equality before the law has long been recognized as a civil and political right, with roots in the International Covenant on Civil and Political Rights (...) State parties must immediately begin to take steps towards the realization of the rights in Article 12 of the Convention, including the right to support in the realization of legal capacity". In explaining the exact meaning of the term "legal capacity", the Committee states that this term includes both the possession of rights (legal capacity.* 

<sup>39</sup> The comparative legal survey of the modern institute of supported decision-making and regulation of the limitation of legal capacity is contained in the publication *"Poslovna sposobnost kao ljudsko pravo – vodič kroz domaću praksu i moguće alternative starateljstvu"*, Mental Disability Rights Initiative of Serbia (MDRI-S), Belgrade, 2012, pp. 21–42.

<sup>40</sup> At its 10th session (2–13 September 2013), the Committee adopted the drafts of the General Comments stipulating the normative content of the rights guaranteed under Articles 9 and 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and referring to accessability and legal capacity. The Committee accepted the comments on the drafts adopted until 31 January 2014, while the final version should be adopted at the Committee's session to be held from 14 to 17 April 2014.

ity) and exercise of rights (legal capacity). In its General Comment, the UN Committee repeatedly states that the state parties concerned must "review the law allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the the person's autonomy, will and preferences".<sup>41</sup>

The guardianship reform in Serbia and harmonization of national legislation with the principles of the Convention on the Rights of Persons with Disabilities are crucial for laying the foundation for the full realization of the rights of persons with disabilities, especially those with intellectual and psychosocial disabilities. Therefore, it is necessary to embark on this process as soon as possible. The guardianship reform is a long-standing and comprehensive process, whose participants must be primarily decision-makers as well as practicioners, experts, civil society organizations and, in particular, persons with disabilities and their representatives.<sup>42</sup>

#### Legal Regulations in Serbia and Their Implementation

The Constitution of the Republic of Serbia stipulates within the *right to legal personality* (Article 37) that every person acquires the ability to independently decide on his/her rights and obligations upon coming of age. In practice, however, this guarantee does not apply to the majority of persons with disabilities, who are most often deprived from legal capacity, namely, the ability to make autonomous decisions on their rights and obligations. When their legal capacity is limited, the persons concerned are placed under guardianship of which there are two types. It can be partial, which refers to the scope of the guardian's decision-making (for example, decisions on the disposal of finances, but not on health care), or full, which means that the guardian has the right to decide on all matters (so-called *substitute decision-making*). Alternative solutions in international practice anticipate *supported decision-making* (where support is provided by a specified person or body), *prior opinion* (where a person with a disability presents his/her future ideas, but has no right to make autonomous decisions on them) or *power of attorney* 

<sup>41 &</sup>quot;PERSON" – Osnovna načela za reformu sistema poslovne sposobnosti (Basic Principles for the Reform of the Legal Capacity System), accessible at *www.mdri-s.org*.

<sup>42</sup> Factsheet Poslovna sposobnost, www.mdri-s.org.

(where a person with a disability appoints another person who will make decisions on his/her behalf, which he/she cannot).<sup>43</sup>

The conditions to be met for deprivation of legal capacity in Serbia are set forth in the Family Law,<sup>44</sup> while the relevant procedure is carried out through two linked yet separate processes: deprivation of legal capacity as a court procedure (in accordance with the Law on Extrajudicial Procedure)45 and placement of a person under guardianship by the guardianship body as an administrative procedure (in accordance with the Law on General Administrative Procedure).<sup>46</sup> In the extrajudicial procdure the court urgently decides whether deprivation of legal capacity should be partial or full, on the basis of the criterion whether an adult person is able to reason "normally"47 in order to care about his/her rights and interests by himself/herself.<sup>48</sup> In practice, the level of ability to reason "normally" is first determined by experts. In accordance with the law, the person being the subject of this procedure must be examined by at least two physicians working in the relevant specialty. The expert examination must be done in the presence of the judge, unless it takes place in a stationary medical institution. Despite these provisions, the practice in Serbia displays a different tendency: there is no recorded case that the judge was present during the medical examination, while in nearly 84% of all cases the judge did not see the person who had to be deprived of legal capacity. It is also emphasized that only in 53 cases, out of 997 processed firstinstance court decisions, it was the question of partial deprivation of legal capacity which, as opposed to full deprivation, opens up the possibility that the court – on the basis of medical expertise – decides on the jobs that an be autonomously performed by the person concerned, in addition to those to

<sup>43 &</sup>quot;Model zakona o razlozima i postupku ograničenja i zaštite pojedinih prava i sloboda", Centre for Advanced Legal Studies (CUPS), Belgrade 2012, p. 11, accessible at www. cups.rs.

<sup>44 &</sup>quot;Sl. glasnik RS", 18/2005, Articles 146, 147 and 64.

<sup>45 &</sup>quot;Sl. glasnik SRS", 25/82 and 48/88, and "Sl. glasnik RS", 46/95 – dr. zakon, 18/2005
– dr. zakon, 85/2012 and 45/2013 – dr. zakon, Articles 31–44.

<sup>46 &</sup>quot;Sl. Glasnik SRJ", 33/97 and 31/2001, and "Sl. glasnik RS", 30/2010.

<sup>47</sup> In this text some terms are put in quotation marks in order to point to stereotypical, archaic and perojative terminology which, in our opinion, does not acknowledge the personal dignity of persons with disabilities.

<sup>48</sup> Article 31 of the Law on Extrajudicial Proceedings of the Republic of Serbia.

which he/she is authorized by law.<sup>49</sup> Such data open doors for advocating the abolition of full deprivation of legal capacity and changing the current methods of expert examination and judging in this procedure. The legislator has anticipated that once the reasons for deprivation of legal capacity cease to exist the court must make the decision on restoring legal capacity or, if a person's "mental condition" improves and he/she is fully deprived of legal capacity, the court must change its earlier decision in favour of partial deprivation of legal capacity.<sup>50</sup>

The procedure involving deprivation of legal capacity in Serbia can be regarded as a summary procedure in which the basic safeguards of a fair procedure are not respected. The persons deprived of legal capacity belong to one of the most vulnerable groups in society due to social exclusion, inadequate legal solutions and widespread social prejudices. Discrimination is often present in the procedure involving deprivation of legal capacity in which persons with mental and intellectual disabilities are deprived of the majority of human rights, or their control over the exercise of those rights is taken away. The significant level of discrimination in the past can be the reason for stereotypical legislation that prevents individual assessment of the abilities and needs of the persons to be deprived of legal capacity.<sup>51</sup> Persons with intellectual disabilities are most often deprived of legal capacity (in 45.3% of cases); they are followed by persons with psychosocial disabilities, that is, mental health disabilities (in 31% of cases). In 99% of cases, the decision on deprivation of legal capacity clearly states the type of disability, based usually on medical documentation, which points to the fact that these persons

<sup>49</sup> The Belgrade Centre for Human Rights and Mental Disability Rights Initiative of Serbia (MDRI-S) analyzed more than 1,000 cases (997 basic court cases and 68 higher court cases) involving legal capacity deprivation or the extension of parental rights in the period from 2008 to 2010. The relevant data can be found in the publication *Univerzalnost prava u praksi: analiza primene Konvencije Ujedinjenih nacija o pravima osoba sa invaliditetom u odnosu na osobe sa intelektualnim teškoćama u Srbiji* (Practicing universality of rights: Analysis of the implementation of the UN Convention on the Rights of Persons with Disabilities in view of persons with intellectual disabilities in Serbia), Mental Disability Rights Initiative (MDRI-S), Belgrade 2012, accessible at *www.mdri-s. org.* 

<sup>50</sup> Article 42, paragraph 1, Law on Extrajudicial Procedure of the Republic of Serbia.

<sup>51</sup> See the judgement in the case of Alajos Kiss v. Hungary by the European court of Human Rights, ECtHR, App. No. 38832/06 (2010), p. 42.

are deprived of legal capacity only because of some disability.<sup>52</sup> These data point to the most restrictive approach to deprivation of legal capacity – the *medical model* or, more precisely, the approach based on requirement for the physician's diagnosis of mental impairment.<sup>53</sup> The *outcome-based approach* uses a psychiatric assessment in order to solve the dilemmas concerning the very ability of a person to make autonomous decisions, thus preventing the decisions (considered bad or irrational by others) that may have a harmful effect on that person or others. The *functional approach* is the least restrictive among these three approaches. It is based on putting the person concerned to a specified test (for example, testing his/her ability to perform a transaction in the bank) and the determination of his/her legal capacity as to whether he/she can perform that function. Such an approach differs from those mentioned above because it does not designate the person to be incapable.<sup>54</sup>

Consequently, in the Republic of Serbia legal capacity can be fully or partially deprived in an extrajudicial procedure before the court, whereby it is proceeded from the assumuption that the state and the family must undertake the protection of rights and interests of the person who is incapable of doing this by himself/herself, including persons suffering from dementia and addiction. However, in Serbia's judicial practice there is a tendency towards full depravation of legal capacity, while partial deprivation is rarely adjudicated, although it has the potential to adjust to a wide range of abilities of persons with disabilities and greater inclusion in society. In addition, in most cases the judge did not establish personal contact with the person being deprived of legal capacity, so that the ruling could not be appropriate in terms of a delicate determination of the limits of rights and freedoms of the person with a certain kind of disability, which shapes his/her life.<sup>55</sup> This

54 Ibid.

<sup>52</sup> Univerzalnost prava u praksi: analiza primene Konvencije Ujedinjenih nacija o pravima osoba sa invaliditetom u odnosu na osobe sa intelektualnim teškoćama u Srbiji, Mental Disability Rights Initiative (MDRI-S), Belgrade 2012, pp. 18–21, accessible at www.mdris.org.

<sup>53</sup> Model zakona o razlozima i postupku ograničenja i zaštite pojedinih prava i sloboda, Centre for Advanced Legal Studies (CUPS), Belgrade 2012, p. 11, accessible at www.cups.rs.

<sup>55 &</sup>quot;Zapošljavanje osoba sa invalidetom u Srbiji – Izveštaj za 2011" (Employment of Persons with Disabilities in the Republic of Serbia – 2011 Report), Centre for Society Orientation (COD) and Belgrade Centre for Human Rights, Belgrade 2012, pp. 34–44, accessible at www.cod.rs.

is contrary to the recommendation of the Council of Europe Committee<sup>56</sup>, Article 12 of the Convention on the Rights of Persons with Disabilities<sup>57</sup> and the stance taken by the European court of Human Rights, which insists on the compulsory court review of the reasons for deprivation of legal capacity. Apart from the impossibility to dispose of their property, persons deprived of legal capacity are also prevented from articulating and disseminating messages as the relevant actors in this procedure whose voice must be heard. This often leads to their institutionalization, so that they spend the rest of their lives under supervision and come under the social protection system.<sup>58</sup> More than a half (57%) of all persons deprived of legal capacity were once in their lives or during the process placed in such an institution of whom 4% were involuntarily hospitalized (institutionalized).<sup>59</sup> Namely, the person deprived of legal capacity may be placed in a social protection institution for life-long stay without his/her consent or the possibility to lodge a complaint.<sup>60</sup> Over time, it has become clear that this process does not contribute enough to the

- 57 In this respect, paragtraph 4 of Article 14 of the Convention is significant. It reads: "States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law (...) The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests".
- 58 Ibid, p. 35.
- 59 Univerzalnost prava u praksi: analiza primene Konvencije Ujedinjenih nacija o pravima osoba sa invaliditetom u odnosu na osobe sa intelektualnim teškoćama u Srbiji (Protecting universality of rights: Analysis of the UN Convention on the Rights of Persons with Disabilities in view of persons with intellectual disabilities in Serbia), Mental Disability Rights Initiative (MDRI-S), Belgrade 2012, accessible at www.mdri-s.org.
- 60 "Pravo da donesem odluku pitanje lišavanja poslovne sposobnosti osoba sa invaliditetom u Srbiji i preporuke za dalji rad na usklađivanju domaćeg zakonodavstva i prakse sa Konvencijom o pravima osoba sa invaliditetom (The right to make decision – the question of deprivation of legal capacity of persons with disabilities in Serbia and the recommendation for further action towards the harmonization of national legislation and practice with the Convention on the Rights of Persons with Disabilities), VelikiMali, Pančevo, 2010, p 4.

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<sup>56</sup> The Recommendation No. R(99)48 of the Council of Europe Committee of Ministers concerning the principles governing legal protection of adult persons with impaired abilities provides clear guidelines on the principles of their legal protection in such a procedure. Source: Ljudska prava u Srbiji 2011: pravo, praksa i međunarodni standardi ljudskih prava (Human Rights in Serbia 2011: Legal Provisions and Practice Compared to International Human Rights Standards), Belgrade Centre for Human Rights, 2012, accessible at www.bgcentar.org.rs.

equal participation of persons with disabilities in society and that the system of community-based services must be developed parallel to the closing down of residential care facilities. In Serbia, jowever, the process of deinstitutionalization has not progressed as expected and there is still a large number of persons placed in such institutions.

At the time of writing this contribution, the practice of legal capacity deprivation was not changed much (which is confirmed by the practice of legal representation of persons with intellectual and mental disabilities) relative to the situation depicted in the research conducted by the Belgrade Centre for Human Rights and Mental Disability Rights Initiative (MDRI) in late 2011. Namely it showed that in most cases persons deprived of legal capacity were not given a fair and equitable trial.<sup>61</sup> The European court of Human Rights emphasizes the need for the court to hear the person concerned in the procedure involving deprivation of legal fcapacitz and that it is of utmost importance that it makes at least a short eye contact with him/her.<sup>62</sup> A large number of cases in which the guardian or representative of the person concerned did not object to the deprivation proposal also points to the ineffectiveness of legal representation, which can also be due to the fact that in 28% of cases the guardianship body (the centre for social work in this case) had a dual role – as the proposer and as the guardian of a person with disabilities. The European court of Human Rights set the standard relating to the exercise of the rights safeguarded by the Convention that the Convention would safeguard practical and effective rights and not formal and illusory ones. In this context, it is also necessary to consider the fact that most persons deprived of legal capacity had temporary guardians and that they objected to the deprivation proposal only in an extremely small number of cases. The unequal status of the proposer and his/her opponent also shows that there is no equality of arms between the parties to the procedure. In the context of civil procedure, the European court of Human Rights has concluded that the principle of equality of arms implies that each party must be afforded a reasonable opportunity to present his/her case, including supporting evidence, under the

<sup>61</sup> Complete research can be found in the publication Univerzalnost prava u praksi: analiza primene Konvencije Ujedinjenih nacija o pravima osoba sa invaliditetom u odnosu na osobe sa intelektualnim teškoćama u Srbiji, Mental Disability Rights Initiative of Serbia (MDRI-S), Belgrade 2012, accessible at www.mdri-s.org.

<sup>62</sup> See the case of Shtrukaturov v. Russia, ECHR, App. No. 44009/05 (2008), p. 73.

conditions that do not place him/her at a substantial disadvantage vis-à-vis his opponent.<sup>63</sup> The justifications of decisions are also not precise. In some cases, it is not clear which facts have provided the basis for the court to derive the conclusion on a person's inability to care about his/her or other person's rights and interests, except on the basis of diagnosis. Court experts' reports often provide information on persons' personal characteristics which in no way can provide ground for deprivation of legal capacity. On the other hand, they rarely provide specific examples that support the causal link between a person's behaviour and his/her jeopardization of his/her and/or other person's rights and interests. In this respect, the role of experts in this process is rather problamatic because it seems that in most cases they exceed the scope of their competence. Thus, apart from their findings and opinions "about a person's mental health and ability to make judgements", they also make conclusions on a person's legal capacity.<sup>64</sup> These findings raise numerous questions about the problem of inclusion, education and deinstitutionalization. It is evident that in most cases those who participate in the preparation of these solutions are not sufficiently sensibilized, have no sufficient will to perceive the complexity of the situation of persons with disabilities or, in other words, to assess all effects of legal capacity deprivation. There is even less understanding for these persons' personal development, either by judges or by experts - psychologists and psychiatrists.65

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<sup>63</sup> The case of *Dombo Beheer B. V. v. The Netherlands*, ECtHR, App. No. 14448/88 (1993), p. 33.

<sup>64</sup> An insight into the justification of court decisions reveals that, instead of his/her personality, the characteristic description of a person is based on listing the elements helping with argumentation for the classification of a case into a certain category. Source: "Zapošljavanje osoba sa invaliditetom u Srbiji – Izveštaj za 2011", Centre for Society Orientation (COD) and Belgrade Centre for Human Rights, Belgrade 2012, accessible at *www.cod.rs*.

<sup>65</sup> Ibid.

#### The Strategic Framework and Fulfilment of International Obligations

The Strategy for Prevention and Protection against Discrimination in Serbia for the period 2013–2018<sup>66</sup> singles out persons with intellectual disabilities from among persons with disabilities as a special group. The document states that they also face specific problems such as, for example, deprivation of legal capacity (and the consequences of such decision-making) and placement in specified institutions, which often means for life-long stay. Research shows that even 55% of persons with intellectual disabilities spend more than ten years in such institutions. One measure (measure 7) for achieving the general objective of the Strategy, which refers to the prevention and reduction of the discrimination of persons with disabilities reads: "When depriving persons with intellectual disabilities of legal capacity, it will be necessary to act in accordance with the positions expressed in the verdicts of the European Court of Human Rights (to provide the right to a hearing, right of access to a court, right to a fair trial, etc.) and improve the operation of centres for social work with respect to their role in the implementation of the institute of deprivation of legal capacity."67

In the context of work and employment or, more precisely, the repercussions of deprivation of legal capacity of persons with mental and intellectual disabilities for this field, the Strategy states that it is necessary to provide conditions for preventing the discrimination of persons with disabilities in the field of work of employment in both the public and private sector, including specifically the prevention of unequal treatment compared to other employed persons due to their personal characteristics. The Strategy also stipulates that it is necessary to ensure the consistent and full implementation of the Law on Professional Rehabilitation and Employment of Persons with Disabilities and, by modifying the Law, to enable persons with disabilities to find employment on the "open" market. As for their personal status, the Strategy states that it is necessary to carry out legislative reform concerning the deprivation of persons with disabilities of legal capacity and create conditions that the family environment becomes the primary and best solution for a person with disabilities, in addition to the provision of strong support to their

<sup>66 &</sup>quot;Sl. glasnik RS", 60/2013.

<sup>67</sup> Ibid, p. 52.

deinstitutionalization and continuing development, and improvement and enrichment of support to families with children with disabilities and developmental disorders.<sup>68</sup>

It is symptomatic that the Strategy for Improving the Position of Persons with Disabilities in the Republic of Serbia for the period 2007–2015 refers to legal capacity only in one item within the special objective (16) of the Strate-gy.<sup>69</sup> Namely, measure 16.7 specifies "the establishment of a legal frame for the management of inheritance, endowments and bequests left by families to persons with disabilities who are deprived od legal capacity in order to prevent the institutionalization of such persons after the death of their parents or guardians".<sup>70</sup>

The data on the total number of persons deprived of legal capacity in Serbia are not available. The available data show that in 2011 the number of persons under guardianship increased even by one third relative to the previous year's data (11,212 adult and 4,083 elderly persons, compared to 8,672 adult and 3,049 elderly persons in 2010). The Report on the Activities of the Centre for Social Work in Serbia<sup>71</sup> points out that 3,778 persons were fully deprived of legal capacity during 2011, although the data were collected only for a smaller number of adult persons placed under guardianship, namely, one-fourth of the mentioned figure. It is logical to assume that the number of persons deprived of legal capacity is much greater. Despite being permitted by law, there were no cases of partial deprivation of legal capacity.

In accordance with Article 35, paragtraph 1, of the Convention on the Rights of Persons with Disabilities, the Republic of Serbia obliged itself to submit to the Committee on the Rights of Persons with Disabilities the reports on the measures taken with a view to fulfilling the obligations under the Convention, thus providing a survey of the measures taken by the government in order to harmonize the national legislation and policy with the provisions of the Convention, as well as the results and problems and deficiencies in its

<sup>68</sup> Ibid, p. 53-54.

<sup>69</sup> Special objective 16 reads: "Provide social securty and the full and unhindered exercise of this right to all persons with disabilities." This is evidently the obsolete approach to the rights of persons with disabilities from the aspect of social protection and not from the aspect of human rights.

<sup>70 &</sup>quot;Sl. glasnik RS", 1/2007.

<sup>71</sup> Report on the Activities of the Centre for Social Work in Serbia in 2011, Republic Institute for Social Protection, July 2012.

approach to the fulfillment of the assumed obligations. In the Initial Report on the Implementation of the Convention on the Rights of Persons with Disabilities in the Republic of Serbia, submitted by the Government in 2012, the provisions of the national legislation regulating the deprivation of legal capacity and undertaking of guardianship measures were especially criticized.<sup>72</sup> Namely, it is stated that the system has become obsolete and that it should be harmonized with the provisions and obligations assumed under the Convention. It is also stated that guardianship over persons deprived of legal capacity in the Republic of Serbia is regulated by the laws that have not been significantly changed for years, while the majority of these regulations was adopted at the time when persons with disabilities were excluded from society.<sup>73</sup>

# Current Changes to the Regulations in Serbia

There were no interventions in this respect in the Amendments to the Law on Extrajudicial Procedure adopted on 31 August 2012 and the Proposal of the Law on Extrajudicial Procedure submitted by the Protector of Citizens, which has been in parliamentary procedure since 19 April 2013.<sup>74</sup> However, on the website of the Ministry of Justice and Public Administration<sup>75</sup> one can find the Draft Law on Amendments, which changes the provisions of the cur-

<sup>72 &</sup>quot;Ljudska prava u Srbiji 2012" – izveštaj o stanju ljudskih prava (Human Rights in Serbia 2012 – Human Rights Report), Belgrade Centre for Human Rights, Belgrade, pp. 81–87, accessible at *www.bgcentar.rs*.

<sup>73</sup> At one time, the need to amend the laws governing the deprivation of legal capacity, in accordance with the Convention on the Rights of Persons with Disabilities, was also emphasized by Thomas Hammarberg, the then Commissioner for Human Rights of the Council of Europe. In the same context, in its verdict in the case of *Salontaiji-Drobnjak v. Serbia*, the European Court of Human Rights had previously pointed to a number of omissions by the relevant government bodies and lack of the domestic legislation regulating the procedure involving deprivation of legal capacity – *http://www.helsinki.org.rs/hrlawyers/doc/Presuda%20ECHR.pdf*.

<sup>74</sup> Only with respect to the procedure involving the establishment of the facts – place and date of birth; accessible on the National Assembly's website at: *www.parlament.gov.rs.* 

<sup>75</sup> www.mpravde.gov.rs – Zakonodavstvo, Radne verzije propisa, Radna verzija Zakona o izmenama i dopunama zakona o vanparničnom postupku (Legislation, Working Versions of the Regulations, Working Versions of the Law Amending the Law on Extrajudicial

rent Law on Extrajudicial Procedure concerning deprivation of legal capacity. This is the working version of 27 June 2013 (Draft Law of 2013), which is more restrictive than another draft that was presented by the working group within the Ministry of Justice and Public Administration and can be found on a separate address in this website's files (Draft Law of 2012).<sup>76</sup> Consequently that Draft Law on Amending the Law on Extrajudicial Procedure of late 2012 underwent certain changes (restrictions) but, unfortunately, despite significantly better solutions in its current working version vis-à-vis the current and absolutely obsolete Law on Extrajudicial Procedure, this draft, in essence, does not fulfil the obligations under Article 12 of the Convention on the Rights of Persons with Disabilities. Namely, this draft law does not abolish the institute of full deprivation of legal capacity, which is a direct recommendation set forth in the Convention and achieved standards. In addition, this draft does not prevent a conflict of interest in the procedure, nor does it limit the duration of the measure, shortening it as much as possible,<sup>77</sup> which are the obligations assumed under the Convention.78 Thus, despite Serbia's obligation to recognize that persons with disabilities must enjoy legal capacity on an equal basis with others in all aspects of life, it has retained the approach based on the limitation of rights, without introducing the mechanisms providing support to persons with disabilities in decision-making on the issues having an effect on their life.

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The current Draft Law anticipates the mandatory period for reviewing the decision on deprivation of legal capacity (review period), which can last and be extended, every time after checking, up to three years. However, it "takes a few steps backwards" by introducing a new standard to the detriment

- 77 Article 12, paragraph 4, of the Convention; it seems that the 2012 Draft Law limits its duration by the inept provision stipulating: "The duration of the measure such as the limitation of legtal capacity cannot be unlimited".
- 78 The 2012 version of the text contained the provision referring to the prevention of a conflict of interest (Article 33a, paragraph 3): "The guardianship body that has initiated the procedure for limitation of legal legal capacity cannot represent the person being the subject of that procedure."

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Procedure).edings (Zakonodavstvo, Radne verzije propisa, Radna verzija Zakona o izmenama i dopunama zakona o vanparničnom postupku).

<sup>76</sup> Zakonodavna aktivnost, *Radna verzija Zakona o izmenama i dopunama zakona o vanparničnom postupku* (Legislative Activity, Working Versions of the Law Amending the Law on Extrajudicial Procedure); *www.arhiva.mpravde.gov.rs*.

of persons with disabilities because, after the review period, partial deprivation of legal capacity may be altered into full one. As for terminology, it can be observed that the term "mental state" was replaced by the term "mental health", in accordance with the *Strategy for the Development of Mental Health Protection*<sup>79</sup> and special *Law on the Protection of Persons with Mental Health Disabilities*.<sup>80</sup> Also, the term "limitation" instead of "deprivation" of legal capacity was avoided because, at the very least, that would imply certain changes to the family law defining this institute.

In its justification of the 2013 Draft Law,<sup>81</sup> the Ministry states that "such a proposal has modified the rules of this procedure, so that the person to be partially or fully deprived of legal capacity can plead to such a matter and express his/her own opinion during the procedure in accordance with his/ her mental capacity, that the draft respects the dignity, privacy and rights of the person concerned, that it takes into account the existence of "different levels of incapacity", that "the level of incapacity" may change over time, so that it also anticipates the procedure for reviewing a person's legal capacity and procedure for restoring a person's legal capacity prior to the expiry of the review period, if it is established that the reasons for depriving a person of legal capacity cease to exist". Although there is no doubt that the proposal may bring some progress, it does not depart, in essence, from the general deprivation of the possibility to make legal decisions as a rule and the obsolete medical approach to disability and placing emphasis on an individual's incapacity and not on his/her capacity and the appropriate level of support.

The court decision on deprivation of legal capacity must also specify the duration of the imposed measure. The court may also specify the period when the guardianship authority will have to check whether the reasons for limiting legal capacity still exist. After the review period, the court ex officio determines whether there are reasons for "restraining" legal capacity, changes in the level of deprivation or abolition. In its decision by which it has determined that there are no conditions for the restoration of legal capacity, the court sets the time-limit within which it will be checked whether there are still reasons for the retention of the imposed measure and, as already mentioned,

<sup>79 &</sup>quot;Sl. glasnik RS", 8/2007.

<sup>80 &</sup>quot;Sl. glasnik RS", 45/2013.

<sup>81</sup> www.mpravde.gov.rs (Zakonodavstvo - Radne verzije propisa).

the extension period cannot be longer than three years.<sup>82</sup> The time-limit for a person's temporary placement in the appropriate medical institution has been shortened from three months to 30 days. The Draft also sets the eight-day time-limit for an appeal and prescribes the obligation of the second-instance court to handle an appeal within eight days upon receipt. The 2013 Draft also prescribes the obligation that a person placed in a medical institution must be heard by such a institution in which case the hearing will be formally and factually held on its premises.

Despite showing some progress, the current draft law does not introduce stronger procedural safeguards to persons who are the subject of the procedure (it does not prescribe that the person concerned must be heard by the judge, or at least the compulsory effort to hear the person whose legal capacity is being decided upon<sup>83</sup> or, in other words, the exception to the rule that the person concerned is heard, that free legal assistance is compulsory, etc.). The proposal that the court decides on the kinds of jobs the person concerned cannot perform autonomously in a concrete case, which was proposed in the 2012 Draft, was replaced by the earlier, restrictive solution that the court should determine the range of legal jobs that *may* be autonomously performed in addition to the jobs to which he/she is "authorized by law", but it is now imperative for the court to do so.<sup>84</sup> In addition, the 2012 Draft, which is considerably more liberal<sup>85</sup>, prescribes the limitation of legal capacity for a specified period, which is in compliance with the Council of Europe recommendations and the Convention, while the current, working version of the law seemingly "resolves" this issue by anticipating the review period.

<sup>82</sup> Article 17 of the Draft Law.

<sup>83</sup> In the Draft Law, which was available on the website in late 2012, the word "obligation" (to hold a hearing) was not used, but there is a stronger safeguard – failure to hold a hearing is considered as an exception to the rule (Article 36, paragraph 1).

<sup>84</sup> Under Article 42, paragraph 2, of the current law, the court *may* prescribe the kinds of jobs, which created significant legal uncertainty and arbitrariness.

<sup>85</sup> This draft (Article 31, paragraph 3) also stipulates the obligation to respect the dignity of the person whose status is being decided upon, which is in conformity with modern legislation.

## **Conclusion and Recommendations**

During 2013, there were no more significant changes with respect to the problems of the factual deprivation of liberty of some persons (primarily those with mental disabilities who are accommodated in social protection institutions) or keeping them in psychiatric hospitals.

The Law on the Protection of Persons with Mental Disorders stipulates that a person being kept in a psychiatric facility may lodge an appeal regardless of his/her mental health. The same applies to the submission of a request for release from a psychiatric hospital before the expiry of the anticipated time-limit. In this respect, the provisions of the Law are in compliance with the stance of the European court of Human Rights, which insists on the fact that everyone must have the right to initiate the procedure for the protection of fundamental rights, such as the right to freedom and security of the person regardless of his/her health condition.

The more general recommendations of the Belgrade Centre for Human Rights and MDRI, which have been joined by the Lawyers' Committee for Human Rights – YUCOM, include the termination of institutionalization, i.e. the deprivation of liberty of persons deprived of legal capacity without their consent, but on the basis of the consent of their legal guardians, as well as the right of access of these persons to a court, which would decide on the justifiability of their placement in an institution in accordance with the provisions on involuntary hospitalization. It is also necessary to enable persons with psychosocial and intellectual disabilities to live in a community or less restrictive environment, as well as to prevent the factual deprivation of liberty of persons placed in social protection institutions, since there is no legal ground to do that.

It is also necessary to abolish the institute of full deprivation of legal capacity and, if there is no census on this issue in the state and community, to introduce one of more liberal models, such as *supported decision-making*; it is necessary to adjust the system to the system of substitute (guardianship) decision-making in order to protect the rights of persons with disabilities to a significantly greater extent. In this case, it would be more appropriate to use the term *limitation* (instead of "deprivation") of the capacity (right) to dispose of rights and obligations, which is in much greater compliance with the essence of this institute and inherent human rights that are mostly absolute and, in especially justified and rare cases, can be limited. It is also necessary to enable the equality of arms between the person being deprived of legal capacity and the proposer, which could be realized by providing adequate legal assistance to all persons being the subject of such a procedure (primarily through the institute of compulsory free legal assistance during this procedure)<sup>86</sup> and through the imperative of hearing (with restrictive exceptions) the person whose legal capacity is being decided upon (or at least try to hold a hearing with the assistance of someone being trusted). In this connection, it is necessary to enable the proposer's opponent, i.e. the representative of the person concerned, to dispute the expert's findings, in addition to enabling the person whose status is being decided upon to take an active part in the procedure.<sup>87</sup> It is also necessary to explicitly prevent a conflict of interest, i.e. the situation where the proposer (centre for social work) is also the temporary guardian of the person whose legal capacity is being decided upon.<sup>88</sup> Should the system including the limitation of a person's possibility (right) to dispose of rights and obligations, the duration of such limitation must be as short as possible in practice and must be prescribed by law. As for expertise, it is necessary to provide a stronger guarantee for an expert's professionalism and impartiality, in addition to more precisely defining the subject of expertise by law. Also, the explanation of restrictions in the court decision must be clear and refer to the clear actions being restricted as well as the nature of these restrictions. It is also necessary to stipulate the compulsory periodic court review of the decision on deprivation of legal capacity<sup>89</sup> as well as the obligation to inform the court about changes on which

<sup>86</sup> Bearing in mind that all hitherto studies have pointed to a very poor economic/material status of persons with intellectual and mental disabilities.

<sup>87</sup> In this respect, Article 10 of the 2013 Draft Law stipulates as follows: "*The court shall respect the opinion and attitudes of the person being the subject of the procedure, to the extent that is possible bearing in mind his/her mental health*". The 2012 Draft introduces a significantly more explicit and thus stronger procedural guarantee in the provisions of Article 33a.

<sup>88</sup> Such a provision exists in the 2012 Draft. Under Article 33a, paragraph 3: "The guardianship body that has initiated the procedure for the limitation of legal capacity cannot represent the person being the subject of this procedure".

<sup>89</sup> As stated, the working version of the Law Amending the Law on Extrajudicial Procedure does not abolish the institute of full deprivation of legal capacity, although it stipulates the obligation of a periodic review of the court decision on deprivation.

the status of the person concerned might depend.<sup>90</sup> It is also recommended that the procedure for restoration of legal capacity is really initiated ex officio and that the proposal for restoration of legal capacity, which is submitted by the person deprived of legal capacity and/or his/her guardian, must always be acted upon.

All mentioned normative changes must be effected within the shortest possible time. At the same time, it will be necessary to provide for the permanent training and senzibilisation of judges with respect to handling these cases, whereby a major role could be played by the Judicial Academy. The underlying reason lies in the fact that, all things considered, the state and society still stick to the system under which the ability to dispose of rights and obligations is limited by the court, as opposed to the provision of support to decision-making as an organized service, which exists in some more developed systems.

<sup>90~</sup> For example, in the manner proposed in the 2012 Draft (Articles 41a and 41 b).

# Psychiatric Hospitals in Serbia: A Brief

## **Overview**

There are five special psychiatric hospitals in Serbia, with approximately 3000 beds: Special Psychiatric Hospital (SPH) Gornja Toponica, Niš (app. 800 beds), SPH Dr S. Bakalović, Vršac (app. 800), SPH Sveti Vrači, N. Kneževac (app. 350), SPH Kovin (900), and Dr L. Lazarević Institute for Psychiatry, with the Department in Padinska Skela (350) which is organized as an asylum. There are also ten clinics and institutions and 30 psychiatric departments in general hospitals. Although all these institutions are in the focus of our attention, our main focus during the past few years was the prevention of torture and inhuman treatment in special hospitals.

There are many reports about the situation in these hospitals, issued by international agencies (like the Helsinki Committee, or CPT), National Preventive Mechanism, or published in local or international newspapers. We can state that over the last ten years the situation in these hospitals has been improved – the number of beds has been reduced and the same applies to the average number of days per hospitalization. Many buildings and facilities have been renovated and some psychosocial rehabilitation activities have been initiated.

However, all these five hospitals are still functioning like asylums: they are isolated from urban areas, located in huge, pavilion-like buildings, with a large number of beds per room, enclosed by fencing with security regulations that sometimes seem to be unnecessary, with patients spending most of their time just doing nothing, while their treatment is based on medicines, without a developed system of rehabilitation, resocialization, etc. In some of these hospitals there are still patients who have been interned there for many years. In a greater number of patients there is no clear medical indication for staying in a hospital: during our monitoring visits (2011–2014) we observed (the data collected by interviewing patients and staff, and examining medical and legal documentation) that there were as many as 30–40% of patients having no medical indications for hospitalization, and they could be discharged if only they could have a safe place to live and financial support. Large secluded hospitals are places at risk of involvement in human rights abuse and/or torture; although incidents of abuse are relatively rare, we were the witnesses of some inhuman, degrading and humiliating practices<sup>91</sup>. This fact needs to be understood from the perspective of the nature of mental disorders and the nature of the system of psychiatric institutions.

The majority of severe mental disorders are chronic conditions which significantly affect patients as well as their families and community: they begin in early adulthood (15–25 years) and usually have an intermittent course with exacerbations and remissions, which are more frequent during the first years. That means that in our psychiatric system, during the early phase of his/her disorder, a person will be hospitalized a few times in the course of several years – most often in psychiatric departments of general hospitals or

<sup>91</sup> Some dehumanizing practices in hospitals are part of the daily routine. For example, patients are obliged to wear pajamas during the day; they are not allowed to go out of the building during the night; there is little respect for their intimate space (e.g. group showering); physical restraint was sometimes used as a punishment, etc.

in clinics and institutions (i.e. still within the community). Since the course of the disorder is highly influenced by social factors, those individuals with poor social support (no family or no non-supportive family, lack of income, lack of any property – or loss of property) are more likely to find themselves in special psychiatric hospitals for long-term hospitalization (more than ten years), or be transferred to social institutions, which are viewed as their permanent place of residence, where they will probably stay for the rest of their lives. As a result, we now have a couple thousand individuals with severe mental disorders who reside in social institutions (which should always be taken into account while speaking about mental health reforms). Thus, we see the link between "madness" and poverty, as Basaglia explained years ago (ref.) in a series of powerful articles that provided a theoretical basis for the development of community-based mental health services in Trieste and elsewhere in Italy, and also influenced the worldwide professional public.

After decades of scientific research, we still do not know the causes of severe mental disorders. The highly influential "biological paradigm", which views schizophrenia and other mental disorders as diseases of the brain, resulted in the development of pharmacological therapies that seemingly changed the ways of treatment, but failed to explain the mechanisms of the "disease". On the other hand, it is now apparent that medicines alone cannot solve all problems and that there is a huge need to combat the long-term consequences of disorders, which result in the destruction of professional, social and family life, disability, stigma and discrimination.

Instead of repeated hospitalizations and a complete lack of any mental health care in communities, there is a wide range of services which could change the course of mental disorders for the majority of those affected. There is a complete lack of care for patients once they leave the hospital: there are no community centres where they can come to seek advice or treatment, there are no organized home visits. It happens very often that after leaving hospitals patients simply stop taking medicines and gradually become more anxious and develop more symptoms, which will again result in hospitalization. There is also the need to work with families who rarely manage to cope with their members suffering from severe psychotic disorders; there is a need for legal support in respect of their rights in the areas of work, parenthood and ownership, as well as the need for social networking, cultural activities, etc. There is a growing body of literature showing that an active psychosocial response from and within the community can slow down the process of deterioration and significantly improve the quality of life of those affected. However, all this is incompatible with asylum-based treatment that mostly relies on drugs and simple "containment" of patients in institutions (which is explained as being for safety or social reasons). Moreover, we still do not have any alternative way of treatment in open, community-based institutions, even for patients from wealthy and active families that are willing to commit themselves to the betterment of their relatives.

Instead, we still have large, asylum-like psychiatric hospitals that are placed at the very "bottom" of the psychiatric system. However, it is impossible to understand these hospitals and change them without understanding (and changing) the overall system. In fact, in all these hospitals we met highly qualified and dedicated professionals who tried to humanize hospital treatment on many occasions, but lacked proper systematic support.

#### Why Is the Reform Process So Slow?

The first proclaimed attempts to reform the psychiatric system were made in 2003, when the first National Mental Health Committee was established and Serbia joined the Mental Health Project of the Stability Pact. During the realization of this project, we prepared the National Mental Health Policy and Action Plan (adopted in January 2007); the first mental health law was drafted, but was not adopted. The law on the protection of the rights of persons with mental disabilities was adopted in December 2012, but without the provisions securing the transformation of services and development of community-based mental health services.

Under the same project and in accordance with the Action Plan, the first, pilot community mental health centre (CMHC) was established in the Mediana Municipality in Niš in 2005. This centre was dismantled in 2008, after a hunger strike in the hospital and due to the lack of any support by the Ministry of Health. Even during this short 3-year period we were able to provide clear data about the benefits: for about 100 patients who were the clients of the centre the number of hospitalizations and number of hospital days were halved. This unfortunate incident was probably one of the factors that contributed to the fact that the Ministry of Health never actually supported the Action Plan adopted in January 2007; there was no legal framework for the establishment of CMHCs, there was no support for those leaders and managers in the psychiatric system who had initiated changes at the local level.

Here we propose several issues that need to be considered in the future efforts towards the transformation of psychiatric services into communitybased mental health care.

1. National MH Strategy and Action Plan. Since this problem is not only the problem of psychiatric hospitals, it should be addressed through a systematic nationwide approach. An attempt was made in 2007 with National MH Policy, but it was not supported. At this moment, it is even more important to have a national document with the operationalized Action Plan that will provide a basis for future programmes, especially those coming from the EU (like IPA). This Action Plan should serve as a framework for any future projects as well as an evaluation tool that can be used by both the ministries and EU officials.

2. Legal framework. As already mentioned, the new law on the protection of the rights of persons with mental disabilities does not support the transformation of the psychiatric system into community-based mental health care. The Sub-law on the Establishment of CMHCs is a supportive document, the first to regulate this area, but it needs to be improved. The most important change that needs to be regulated is the hospital financing system, which is still partly based on the number of beds (thus discouraging managers to reduce large departments) and not on the number of services, which could be gradually transferred to the community.

3. Institutions and/or bodies at the national and local levels. There is no clear responsibility for the reform process. Although psychiatric hospitals come under the competence of the Ministry of Health, we must also consider the roles of the Ministry of Social Welfare, Ministry of Education, Ministry of Interior and the like, as well as the role of local governments. There is the need to establish a body (committee) that will coordinate these institutions and be responsible for reforms. The National Committee for Mental Health should also include other stakeholders (not only psychiatrists and directors of institutions), while at the same time taking into account the opinions of users, families, CSO, professional associations, etc. 4. Intersectorial collaboration. The Ministry of Health (MoH) and Ministry of Social Welfare (MSW) are at different levels with respect to the development of community-based services. While significant progress was made in the deinstitutionalization process on the part of MSW, MoH is not implementing the mental health strategy and action plan. We believe that there is a substantial difference in their positions that reflects differences in politics: the social system is struggling with overload and the lack of finance, and is interested in reducing the number of its users. Psychiatric hospitals are struggling with the diminished need for long-term treatment and in some of them one can observe a shift towards the hospitalization of elderly persons, which is explained as the development of "psychogeriatric departments". This collaboration needs to be established, since the development of communitybased mental health care is impossible without it.

# Examples of the Good Practice of the Organizational Model of Mental Health – The Tuscan Model

When 35 years ago Italy adopted the law shifting psychiatric care to the community, this move sparked a heated debate on the organization of mental health services in the community which has not calmed down to this day. Under the Constitution of the Republic of Italia, the regional authorities are delegated to regulate their health care, so that each region has a different organization of health services and thus psychiatric ones. However, the basic principles of change are common across all regions:

- (1) avoid chronicity as the consequence of long-term institutionalization;
- (2) provide prompt answers to health needs, which are:
  - effective,
  - quick,
  - respectful of human dignity and, in particular, the will of the individual,
  - reliable;
- (3) struggle against the stigmatization and marginalization of persons with psychiatric disorders by supporting their social inclusion;
- (4) intervene preventively, even when the disorder is stable (e.g. the prevention of a psychiatric crisis).

Each region has found its own way how to implement these principles organizationally. In the region of Tuscany (3,700,000 inhabitants), the organization is characterized by small structures, sufficiently flexible to adjust to the needs of each user. In continuation, we will present the Tuscan experience that should not be regarded as the model proposed for Serbia, bearing in mind that the mental health service must be organized on the basis of the culture of the country that is establishing it.

The principle inspiring the Tuscan model of the organization of mental health services characterizes its articulation in the dimension of community, with the aim of promoting health by activating the resources and competences of the community concerned, in the service of changing the actual treatment needs wihout the answers that are strictly determined in advance. The services are oriented to each psychiatric illness and each patient age, with direct access from the primary level of health care. Their main task is to provide care and rehabilitation services, including prevention.

The basic technical instrument to do work is the therapeutic relationship that requires permanent staff training in order to prevent its becoming spontaneous. The Tuscan organizational model provides the appropriate conditions that will ensure that the relationship is based on cognitive flexibility, multidimensionality, and the wealth and versatility of knowledge that must be used in a special context and according to treatment needs. In organizational terms, mental health services are defined as a complete and differentiated network of psychiatric structures that keep their specific functions, but respond to treatment needs as a unified and balanced system. Namely, the integrated network is held together by the <u>single</u> multiprofessional working group, which assumes the responsibility for prevention, care and rehabilitation in the territory that is identified by its anthropological-culturological and geographical-territorial continuity. Consequently, mental health services are oriented to small, homogenous local communities. In this way it is possible to structure the services rooted in the population's social and health problems, while at the same time activating the available resources in the community itself.

The network of mental health services is comprised of the following structures that have specific functions:

**Mental health centre**: the organizational and programme centre of the mental health service where health care is provided. It coordinates the whole network of services and their specific functions. Health care services include therapeutic activities in infirmaries, home visits, territorial rehabilitation activities and prevention. The mental health centre links the entire service, local community and local and other institutions.

**Psychiatric Department**: it is located in the General Hospital and has no more than 15 beds. Its function is to treat an acute crisis in the hospital environment, when there are indications for a strong therapeutic treatment and when it is necessary to have the emergency department and other specialized hospital departments in the immediate vicinity.

**Residential structures**: they vary from service to service, depending on structural resources and complete therapeutic strategy:

- Therapeutic community: accommodation intended for high-intensity psychotherapy and rehabilitation, with a maximum of 12 beds and staff present 24 hours a day. It is mostly intended for young patients, possibly in the early stage of the illness, who have more serious forms of the illness and complex psychosocial problems, and need an intensive and short therapeutic intervention;
- Therpaeutic-rehabilitation residential structure: rehabilitation accommodation with therapeutic interventions, with a maximum of 12 beds and staff present 24 hours a day. It is intended for young/adult patients, with a severe form of the illness and psychosocial problems, those who need a medium-term therapeutic-rehabilitation intervention;
- Social-rehabilitation residential structure: accommodation with mostly rehabilitation interventions, with a maximum of 12 beds and staff present 24 hours a day. Patients are mostly young/adults with more severe forms of chronic and psychosocial disorders, who need longer rehabilitation;

- Sheltered housing: rehabilitation accommodation facilities with 8 beds and staff present 12 hours a day. It is used for patients with minor psychosocial disorders, who are mostly autonomous, in the stage of social inclusion with extensive rehabilitation and of variable duration;
- Flats: a flat in the city with no more than 4–5 beds, which meet the housing ineeds, either socially owned or belonging to patients. Educational assistance is provided a few hours a week. Residents are autonomous and some of them are in the stage of social inclusion;

**Day care centre**: Semiresidential structure for strong-intensity rehabilitation, with a maximum of 15 patients, which is open 6–8 hours a day. It is intended for semiautonomous patients who live alone or with the family. The duration of its programmes varies.

As is evident, the existence of the services being mostly health-related and services being mostly socially-related, or even exclusively socially related, enables continuity between the service and local community, thus promoting inclusion in the original environment through a therapeutic-rehabilitation process which offers the highest possible degree of autonomy. To this end, the service network offers the scale of health care intensity ranging from mostly health-related intervention (Psychiatric Department) to social intervention (community). The activation of different stages can be sequential, synchronic and partial, depending on care needs. The activities oriented to the community itself, with its formal and informal social entities, attempt to make normal social circles accessible to the patient. This is opposite of an enclosed space that separates the patient from the normal environment.

The working group is multiprofessional and comprised of the following individuals:

- psychiatrist
- psychologist
- technician
- social-sanitation worker
- educator
- social worker
- informal social network (activated in the case of intervention)
- formal social network (activated in the case of intervention)

The composition of the working group can be viewed as the group that is structured according to the care intensity scale, ranging from professional figures, who are competent for largely health-related interventions, to formal and informal social entities included under the therapeutic-rehabilitation project. Such a composition enables the decoding of patients' complex needs and preparation of individual bio-psycho-social plans, favouring the patient's social inclusion.

Equalization based on the degree of care intensity in the service networks and multiprofessional team geared towards bio-psycho-social intervention enables the presence of the propulsive force in the system, which drives it towards patients' inclusion in the normal environment of the community concerned.

In developing the above concepts, we can single out the optimal organization of services, taking into account the given structural parameters that anticipate the regional rules for the territories ranging from 60,000 to 80,000 inhabitants, up to 100,000 in the urban environment:

- 0.6 beds in the hospital department per 10,000 inhabitants with 1.75 nurses per bed;
- one psychiatrist per 10,000 inhabitants;
- one team for the hospital and the territory;
- the presence of the entire network of intermediary structures in the territory falling under the competence of the service, in addition to mental health centres and day care centres;
- 1.2 beds in accommodation structures per 10,000 inhabitants.

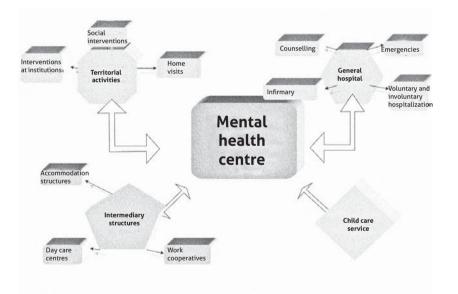
Should each service be dimensioned in this way, it could have all structures necessary for its work, respecting both efficiency and effectiveness criteria, and could function as the real working group due to the number of employed.

In contributing to the ongoing debate in Serbia, it must be pointed to two threats looming on the horizon:

- The law does not stipulate the compulsory formation of services in the community, so that local governments are less sensitive to this problem and may decide not to change the current situation;
- (2) Territorial services, which are hypothetically envisaged by the Law, are not an "alternative"; they represent a "supplement" to hospitalization. Unless being supported by the "deinstitutionalizing culture of the service", all this may paradoxically lead to an increase in the

number of hospitalized persons, since a greater number of citizens (than before) may refer to this service and the employed – either to avoid any responsibility or because they are new in this field in the community (in terms of the ability to use the potentials of their community) – send new patients into the hospital.

These threats are quite realistic and the only way out can be found in the "culturological change" (from institutionalization to deinstitutionalization) of the employed, as well as local authorities and ordinary citizens. Serbia must find the strength and courage to implement this change.



## Organizational chart of the mental health service

# Trentino – The Inspiration for Hard Times in Life

From 3 to 8 February 2014, the organizations Trentino for the Balkans and Caritas Serbia organized a study tour to the city of Trento in Italy (the Province of Trentino, Region Trentino-Alto Adige), entitled "Serbia and Trentino Together on the Path to Psychiatric Reform". The group consisted of the users of psychiatric services delegated by the users' associations from Serbia, psychiatrists and social workers. Below are the impressions of Trento taken by members of the Duša Association of Psychiatric Service Users from Belgrade.

According to the latest data, the city of Trento and the Province of Trentino have the highest quality of life in Italy, which can be seen at every step, while their model and approach to persons with mental health problems are among the most humane and highest quality ones in the world.

After the long process of continuous progress and humanization in this field, Italy does not have large psychiatric hospitals any more. In accordance with the Law, there must be no more than one bed per 10,000 inhabitants. Patients with the most severe mental health problems are placed in the General Hospital Psychiatric Department. However, they are not surrounded by bars; instead, the Department has sliding sash windows and offers high-quality comfort; all walls are decorated with paintings and murals, so that one has the impression of being in the children's department.

Hospitalized patients cannot go out for 48 hours; thereafter, they can file the appeal to be discharged from the hospital. After receiving approval – the hospital door will be opened. The use of physical restraints is not allowed. There is the prescribed procedure how to notice the signs and first symptoms of agitation in a hospitalized patient. Thanks to the humane and relaxed atmosphere in this department, dramatic situations are very rare. Psychiatrist Claudio, Director of the Mental Health Day Centre in Cles and one of our hosts, never instructed his staff to restrain any patient during his 30-year long career. As he says: "Every psychiatrist gets a slap, but every surgeon also sometimes cuts himself with a scalpel".

Patients have said that aggression is the daughter of fear. Thus, if there is less fear there is less aggression. It has been observed that the incidents of aggression are less frequent if there are more women in the psychiatric department.

Apart from fine medical staff, the UFE group (Utenti e Familiari Esperti) also keeps hospitalized patients company. The group is comprised of patients or members of patients' families who, due to their experience of suffering, or experience gained by living in the vicinity of such a person, know very well how to approach and understand the patient and how to make his/her hospital stay easier for him/her. They make hospitalized patients company, go for a walk with them, buy them what they need and the like. All this contributes to a much better atmosphere in the hospital and has also contributed to a decrease in the number of hospitalizations, especially repeated ones. The average length of psychiatric hospitalization is 12 days.

In order to join the UFE, the person must be in good health, stable, goodhumoured, and relaxed; he/she must successfully pass the probation period with an experienced UFE member; he/she must be well received by the staff and must not be addicted to alcohol or psychoactive drugs. The UFE group also has its representatives on the Board of Directors.

In addition to the psychiatric department, a UFE member may do various jobs at the Mental Health Centre (Servizio di Salute Mentale). A large number of patients and members of their families have found a sense of purpose in this humane occupation. Moreover, they can earn some money and supplement their regular incomes, which are small due to the nature of their illness. UFE members are held in high esteem by professional staff and attend their meetings; their opinion is respected and they are entitled to it. A UFE member cannot become a psychiatrist because he/she is not qualified for this profession, so that he/she cannot be an alternative to the psychiatrist, but the great advantages of this group have been recognized. Their experience of suffering and success, as well as their strength to cope and overcome their illness mean a lot to those getting through difficult time as an inspiration.

Every morning, the Mental Health Centre and General Hospital Psychiatrist Department establish contact via video conference. The Mental Health Centre seeks information about the condition of each hospitalized patient.

The Mental Health Centre is located in the very centre of the city, a few hundred metres far from the central square. The Centre houses both the Day Care Hospital and Day Care Service. The service responsible for caring for persons with mental health problems is territorially organized; apart from the psychiatric department, all of them are accommodated in their homes or are provided with so-called sheltered housing where they can stay up to three years – in the case of severe mental disorders and difficult social standing.

We visited one such house. Its name is "La Casa del Sole" (House of the Sun). This is a very comfortable house with a nice garden, located on the outskirts of the city. Many people would envy such accommodation. Patients provided with sheltered housing have medical staff at their disposal; they also do some jobs in order to earn pocket money, while their stay is publicly and privately funded. They also engage in some kind of catering and prepare delicious meals, which is also a form of therapeutic work. Within the house complex there a children's playground, which is the best evidence of what has been done in the area of integration and destigmatization.

Psychotherapy in the Mental Health Centre is free and accessible to all who need it. The Day Care Service is open from 8 am to 7 pm on workdays and from 8 am to 2 pm on Saturdays and Sundays. It is envisaged for persons who feel good, but wish to spend time in an organized way. In addition, if someone is in a crisis, he/she will come to the Mental Health Centre where his/her condition will be examined. The employed in the Centre say that they engage in help, not in control. Within the Centre there are also organized selfhelp groups. There are groups for depression (with the greatest number of members), for bipolar disorders and for those who hear voices. The UFE, patients and Mental Health Centre also publish the journal "Libera la Mente" (Liberate Your Mind). They also organize various activities for patients' entertainment and resocialization. They attend numerous cultural events, visit cultural institutions, participate in sports events... The destigmatization of patients and creation of the positive image of the UFE as people who have succeeded in overcoming their problems and now help professional and technical staff with the view of improving patients' mental state picture, are achieved through various media, thus breaking down prejudice and removing distrust and fear vis-à-vis patients.

During our stay in Trento, we also realized that patients were more ready to open up to other patients about their problems. Every UFE is satisfied because he/she has managed to overcome his/her problems; he/she is respected, useful and regarded by physicians as an associate. Should he/she be in a crisis, he/she will stop being a UFO, but after overcoming the crisis, he/she can join the group again.

At the time of reception to the Mental Health Centre there is almost always one UFE member present. He/she will offer a warm welcome to all those who come to the Centre. The UFE members also fill fulfilled because they help the staff that helped them at one time. The UFE members also make rounds together with physicians and other staff. They never wear white coats, which makes them even closer to patients. Everything is done in the spirit of unity, under the motto "Fiducia e Speranza" (Confidence and Hope).

One objective is also to have as few involuntary hospitalizations as possible. Over the past years, there have been only about 10 involuntary hospitalizations per year in Trento! Eight serious crises, out of 10, are resolved territorially and not by hospitalization. The success of mental health reform is also evidenced by the reduced number of suicides, because many persons now seek help early from the psychiatrist.

The Mental Health Centre and UFE also organize so-called extraordinary events, so in 2011 they travelled in three cars from the East to the West Coast of the United States, while in 2010 they launched the initiative to raise funds for building a school in Africa. They raised 30,000 euros and the government and private donors contributed 70,000 euros. They crossed the Atlantic by sailboat in 2006 and travelled to China by train in 2007. About 30% of the costs of these extraordinary events are paid by the UFE and the remainder

of 70% is covered by private sponsors. UFE, patients and professionals travel together.

According to local physicians and other experts (economists, lawyers, etc.), this system is more profitable than the classical one in every respect, but at the start it need large investments. The fear of the employed that they will lose their jobs is unfounded. On the contrary, the system of the Mental Health Centre will imply the need to increase professional staff.

The Centre for Cooperatives is also interesting. Social cooperatives, which can also include patients, constitute a large part of the system.

There is no need to emphasize the warm welcome extended to us by all people from the organizations Trentino for the Balkans, Caritas and all physicians, medical technicians and nurses, UFE, psychologists, patients and volunteers. We returned from Italy bringing only positive impressions about very good relations between professional and technical staff and patients, excellent organization, important role played not only by nurses but also by educators (therapists), great experience of this people, organization of sheltered housing, UFE model, distinctly human attitude towards patients put in the centre of events, attention and commitment of the employed, as well as the fact that Trentino has succeeded in achieving a remarkable level of resocialization of patients.

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In conclusion, we wish to mention another strong impression brought from Italy. Namely, despite the ongoing economic crisis affecting even those who are richer, the social and political elite in the Province of Trentino decided not to enjoy self-sufficiency and their high standard of living. Namely, its members are prepared to finance and help improving the life quality of mental health patients in Serbia. Dr De Stefani, Director of the Mental Health Centre, explains this initiative by quoting great Mahatma Ghandi:

"Be the change you wish to see in the world"

# Some Observations Concerning the Deinstitutionalization of Persons with Mental Disabilities

# **Social Protection Institutions**

Many persons with disabilities in Serbia have been deprived of legal capacity, thus being denied the possibility of self-representation and decisionmaking concerning their future. In 2012, MDRI carried out the monitoring of seven social protection institutions and established that out of 5,364 adult persons put in these institutions for life-long stay, 3,493 (66.4%) are placed under guardianship, i.e. they are deprived of legal capacity.

On the basis of contacts with persons with disabilities and their parents, who have appealed to MDRI-Serbia for support in the realization of their rights, as well as on the basis of our own experience, we have realized that in many instances the Centres for Social Work misinform parents – potential guardians by claiming that the deprivation of legal capacity is necessary. Therefore, many parents hold that the deprivation of legal capacity is their legal obligation and in the best interest of their adult children and that the realization of other benefits is conditioned by it.

In the process of deinstitutionalization of persons with intellectual disabilities and autism, the Ministry od Labour, Employment and Social Policy promotes the following services:

- Day care service for daily accommodation of persons with intellectual disabilities and autism;
- support housing;
- "respite" or weekend programme for their care on weekends, or temporary care if the parent/guardian gets sick, or is prevented from taking care of his/her child for some other reason.

In their public appearances, the competent government representatives emphasize that these services are designed to prevent institutionalization while the programmes implemented within the scope of these services are often termed "inclusive".

Naturally, it is very important for parents/guardians to have someone who will take care of their children, so that they can work and be relieved of pressure, which forms part of life with persons with intellectual disabilities and autism. However, although these types of support have positive sides, the question that imposes itself is whether these services really lead to the deinstitutionalization and social inclusion of persons with intellectual disabilities and autism. A person can become the user of these services on the basis of his/her diagnosis, which represents segregation and, by that very fact, it is the question of institutionalization. W do not know whether the opinion of the person to be placed in an institution was asked while making the decisions on the use of these services.

#### **Day Care Service**

In Serbia, the number of day care services is on the increase. In the media, the opening of these services by politicians is always accompanied by emphasis on their significance and parents' statements of satisfaction. One of the positive sides of opening day care services is the fact that they can reduce the number of applications for placement in inpatient institutions and contribute to the return of persons from inpatient institutions to their families. However, the day care programme does not envisage the training of users for independent living in the community. The programme contents are prepared by experts in the "best interest" of users, but the question that imposes itself is for whom these programmes are appropriate. Even the arrangement of users in groups falls within the competence of experts. In addition, day care services are expensive institutions, while day care services for children are in violation of their right to education.

### **Supported Housing**

Our social protection system also includes the supported housing service, but at present there is only a smaller number of housing units whoe funding is project-based. Since the opening of new institutions is not consistent with the deinstitutionalization policy proclaimed by the government, while parents keep pressing for the opening of new life-long stay institutions, the requests for opening inpatient facilities are renamed to requests for supported housing. These days, the parents belonging to the Belgrade Society of Autism repeated their request for the building of a new institution, which they called supported housing for 36 persons.

Supported housing can be considered as an inclusive form of support only if the will and preference principle is respected. In the opposite, this will only be a new type of institution, regardless of the number of users.

# "Respite" Service or Weekend Programme

It is quite clear that this service is designed to meet parents' needs. As the only solution for supporting persons with intellectual disabilities and autism when parents are unable to take care of them, it offers institutional stay (day care service or inpatient facility).

#### Employment

The Law on Professional Rehabilitation and Employment of Persons with Disabilities, which was adopted in 2009, discriminates to a significant extent against persons with intellectual disabilities and autism, because its employment criteria are such that these persons cannot fulfil them. To expect from persons who are socially excluded and have intellectual or communication disabilities to be "active job seekers", as stipulated by Article 7 of this Law, is senseless and cynical to say the least.

The Law anticipates that the work capability assessment is made by the Commission, mostly on the basis of medical documentation. The Commission may declare a person unfit for work, thus denying him/her employment opportunities, which is contrary to the right to work and employment, which is guaranteed by the Constitution.

The unambigous double-standard indicator in the Law is that persons who have the right of self-representation can be employed on the basis of active policy measures. As for persons with disabilities being deprived of legal capacity, it anticipates work centres as the only option for their work engagement. These centres are based on the segregation principle; their users work within the scope of their therapy, which is a medical model<sup>92</sup>; at the same time, they have no opportunity to make money from working.

# **Family Support**

One of the main reasons why many parents are forced to place their children in institutions is insufficient support to the biological family. The procedure for receiving regular carer's allowance should be simplifed, while the level of allowance must be the same as that anticipated for foster families.

It is also very important to stop experts' practice of saying to parents that they should not have high expectations for their children with developmental disorders. So far, sgnificant progress in raising parents' awareness about the possibilities of their children has been made thanks to systemic support to inclusive education.

Apart from financial assistance, it is necessary to develop other forms of support to families, such as home assistance, care for persons with disabilities in crisis situations, psychological support, etc.

Foster care is largely supported by the government, but the control system is not adequate, so that it is not known whether the needs of persons placed with foster families are satisfied. There are indications of foster care abuses. It is paradoxical that the government does not providee sufficient support to the biological family due to which parents are often forced to place their child in an institution, while in the process of deinstitutionalization the government earmarks larger funds for placing the same persons with foster families.

<sup>92</sup> Article 43 of the Law: The work centre is a special type of institution that provides work engagement as a therapeutic activity to persons with disabilities, who cannot be employed or keep their jobs under general nor special conditions or, more precisely, whose work performance is less than one-third of the performance of the employed at his/her usual workplace.

#### **Community-Based Services**

To our knowledge, there are persons without any intellectual or other disabilities but have been circumstantially placed in institutions. Naturally, long stay in institutions has its consequences, so that these persons also need support to adjust to living in an open society.

Apart from housing, the person leaving an institution must also be supported in increasing their level of independence, organization of life in the household, finding a job and keeping it, in limproving their skills in communications with other people and the like.

In the current circumstances, the provision of support to persons with intellectual disabilities and autism in the deinstitutionalization process falls largely within the competence of the Centres for Social Work. In practice, however, these centres cannot meet all requirements set for them. On the basis of concrete cases we have established the fact that the employed in the Centres are not interested in providing support to the person who should leave an institution.

The funding of the services provided by non-governmental organizations is most often only project-based, so that, as a rule, their sustainability is uncertain. It is well known that many successful projects intended for the provision of community-based services did not get further financial support, or are carried out with great difficulty. Hence it is necessary to creat conditions that the funds earmarked for deinstitutionalization is available to all potential providers of services under equal terms.

In devising the policy for community-based services one must bear in mind that the building of an inclusive society and the social model of disability are based on the universal design principles. Thus, services must not have the sign showing for whom they are intended. For example, if someone needs home assistance, it should be accessible regardless of whether it is the question of an elderly person, person with disability, single mother, sick person... The process of designing new services must be based on the recognition of the needs of potential beneficiaries. The current system is expensive, inflexible and satisfies the interests of the representatives of persons with intellectual disabilities and autism rather than the interests of these persons.

## Instead of the Conclusion

The social model in the approach to disability, social inclusion and deinstitutionalization of persons with disabilities are possible only if the principle of self-representation is respected. With appropriate support, every person can express his/her will and wishes, make decisions and exercise his/her human rights. Government representatives and parents' societies often neglect this fact.

The government must exercise control over community-based services with greater responsibility and more precisely developed mechanisms. It is especially important to establish whether services satisfy individual needs and enable the realization of human rights of persons for whom they are intended. To this end, it is necessary to respect the results produced by independent monitoring organizations.

A great problem is also posed by the fact that government decision makers are not qualified enough for the field falling within their competence, or have formal qualifications but do not understand or do not know the essence of the problems relating to persons with disabilities and developmental disorders. The problem also lies in the fact that the persons authorized to conduct the deinstitutionalization process have been mostly educated in the spirit of medical model and do not understand the human rights concept.

There is an increasing number of different associations and nongovernmental organizations working for and with persons with disabilities. However, the question of their representativeness, purpose, interests and initiators of their establishment, remains open. Some of these organizations protect the interests of parents and experts and not the rights of persons with disabilities. Thus, the question that imposes itself is whether government-financed organizations can really be independent, or serve as a cover that the nongovernmental sector exists. Therefore, one cannot count on these organizations as the authentic collaborators in the deinstitutionalization process as well as in the monitoring system.

Finally, we wish to turn attention to the situation in one of the smallest social protection institutions in which significant funds have been invested, as a bad example of care for persons with intellectual disabilities and autism.

According to its capacity (49 beneficiaries), the Home for Children and Youth with Autism is the smallest institution in Serbia, but has the greatest number of employed – 59.

The excerpt from the 2012 MDRI-S Report "The Hidden and Forgotten – Segregation and Neglect of Children and Adults with Intellectual Disabilities in Serbia":

"The recently renovated facility of the Home for Children and Youth with Autism (Stacionar za decu i omladinu sa autizmom) ahows to what extent investing in the outward appearance fails to positively reflect on the quality of life of residents. Furthermore, the impression is stronger due to existing contrast between the condition of the facility itself and the state in which the residents were found. There are eight dormitories in this institution with three to seven veds per room. An absolute lack of personal items, clothes, footwear, personal hygiene items, is notable (if there were any personal items, they were locked in the storage facility). Residents have no right to privacy, because as staff claims "everything is potentially dangerous" for them. Surveillance cameras are set up in the institution (with the exception of the toilet cubicles). Despite good hygiene, the toilets have no doors or toilet seats and the showers have no doors, which the staff justified by saying that it is because of the "residents' condition" and "bad experience" that they had a few years back. Men and women share dormitories. When asked to comment, the psychologist said that they had no awareness of their sexuality, and that they were placed in rooms on the basis of their level of disability

In Stacionar, it is particularly noticeable that the employees see the residents as persons who cannot do anything, who are "gone-for-good". They consider that everybody among the residents has problematic behaviour, that they are prone to running away, aggression, breaking things, eating inedible objects, that they are persons to whom nothing can be explained and that nobody would be able to "deal" with their unwanted behaviour. Problematic behaviour is perceived as an integral part of the residents' condition, or of their "disorder" and not as a consequence of their unsatisfied needs, lack of activity and the length of institutionalization. The condition of persons with autism, according to the staff, is correlated with "psychiatric problems" such as psychosis. The staff fails to see the relation between these types of behaviour, the treatment, and the consequence of being institutionalized.

# Recommendations to the Serbian government and relevant ministries for efficient deinstitutionalization process

Bearing in mind the international covenants the Serbian government has signed and its declared commitment to deinstitutionalization and reform of healthcare and social care systems, as well as the fact that this delicate processes have been too slow and accompanied by unresolved questions and huge resistance, the work group established within the project "Civil Society Campaign for Efficient Protection of Persons with Mental Disorders" recommends the following:

- To start with, the Ministry of Healthcare and the Ministry of Labor and Social Policy should take necessary steps against the widespread practice of long-term institutionalization of persons with mental disorders and their institutionalized treatment; at this point psychiatric patients and person with developmental disabilities should be institutionalized only when truly necessary when no other opportunities for their community-based care are available;
- In parallel with thwarting further institutionalization, the two ministries should initiate reforms of the healthcare system, especially in the domain of psychiatry, and start developing a network of communitybased services under the jurisdiction of other governmental offices;
- Medical officers, personnel of social care institutions catering for beneficiaries, responsible public servants in local self-government, police officers and other relevant players should be obliged to attend systemic in-service course of training that would capacitate them for efficient participation in the process of deinstitutionalization;

- Capacity-building programs for institutionalized persons to prepare them for the life in the outside community should be developed; institutional personnel should be trained in implementing these programs, including the support to "alternative institutions;"
- The state of Serbia should provide more support to the families of institutionalized persons – both financial by the principle "funds accompany beneficiaries/patients" and community-based;
- The state should permanently campaign against stigmatization of persons with mental disorders/developmental disabilities;
- Contacts between families and their institutionalized members should be encouraged and intensified; families with institutionalized members should be instructed in mental health treatments;
- The situation and needs of psychiatric patients in the entire territory of Serbia should be thoroughly analyzed and consequently plan how many and where to establish counseling offices or mental health centers;
- The healthcare system should be decentralized in accordance with local specificities and needs;
- A strategy for the development of mental health centers should be developed for the entire territory of Serbia;
- Several counseling offices should be established in different areas as pilot projects for future mental health centers;

- Regulations on counseling offices and relevant guidelines for their functioning should be adopted;
- Procedures for the cooperation between general practitioners, specialists, clinics and general hospitals, special psychiatric hospitals and counseling services or mental health centers should be established to ensure proper support to community-based treatment;
- The number of institutionalized beneficiaries should be permanently reduced, along with the period of their hospitalization; hospitals should engage more occupational therapists;
- The premises accommodating persons with mental disorders should be humanized;
- Expert supervision and visits to beneficiaries released from hospitals should be regulated by the law;
- Electroshock therapies should be prohibited by the law;
- Procedures for physical restraint or isolation of agitated patients should be constantly scrutinized, including punishment for those who abuse them; institutional personnel should be trained in contemporary nonconfrontation approaches to agitated patients;
- All laws and bylaws dealing with the situation and rights of persons with mental disorders should be harmonized;
- Additional protective mechanisms in the cases of involuntary hospitalisation should be developed and adopted;
- Provisions on the grounds of which a person is deprived of his/her earning capacity should be adjusted to modern standards of human rights; judges should be trained in managing the cases in which a person with mental disorder is one of the two parties;
- The criteria for disability pensions for persons with mental disorders should be revised;

- Support teams for community-based care of persons with mental disorders should be established, and the assistance they provided diversified (based on the experience of support teams for inclusive education);
- The educational system should be adjusted to the process of deinstitutionalisation so as to adequately qualify persons with mental disorders, as well as professionals treating them;
- Benefits for companies and employers in the position to hire persons with mental disorders should be established;
- Community work centers and social enterprises should be provided under the law;
- A strategy for the development of community-based housing should be developed;
- A special authority a commission, secretariat or ministry to deal exclusively with mental health, including deinstitutionalization, should be established.