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Models of deinstitutionalization and methods of protecting mental health in community

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MODELS OF DEINSTITUTIONALIZATION AND METHODS OF PROTECTING MENTAL HEALTH IN COMMUNITY

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This report was prepared within the project "Beyond exclusion - Effective rights for mental health patients" implemented by Human Rights Action (HRA), Center for women's and peace education (ANIMA) and Mental Disability Advocacy Centre (MDAC) from Budapest, with the support of the European Union and Kotor municipality.

Contents:

The purpose and description of the document

This document is developed within the project "Beyond exclusion – effective rights for mental health patients" implemented by the Human Rights Action (HRA), Center for Women and Peace Education – ANIMA and Mental Disability Advocacy Center – MDAC, with the support of the European Union and Kotor municipality. The project responds to a strong need to improve human rights situation of mental health patients with the overall objective to increase capacity of CSOs to support the respect for mental health patients' human rights.

Although mental health reform in Montenegro promotes deinstitutionalization of patients who do not require further hospital treatment as the future direction and result of mental health reform[1], the competent institutions still search for the best approach to respond to local conditions and needs. The analysis before you contains the presentation of various models of deinstitutionalization and good practice examples, as well as a list of recommendations which take into account the local context. It should serve as basis for debate among the key stakeholders in order to identify most adequate solutions and reach an agreement on the future direction of the reform.

Bearing in mind that the document is intended for a wide audience, state officers and experts of different profile, at the beginning of the document there are definitions of the basic terms in order to provide for the correct interpretation of their meaning.

The second part of the document presents a context where the shift of focus occurred from the institutional treatment to community-based treatment and support. The importance of the process of deinstitutionalization has been underlined by looking at the detrimental effects of the practice of institutionalization on the lives and health of individuals, while also describing international standards for the protection of the human rights of persons with mental disabilities. The next section presents deinstitutionalization models and examples of good practice. We will present examples of states considered as pioneers of deinstitutionalization, but also those who later initiated their reforms. When it comes to newer reforms, we usually observe good legal frameworks and a general vision towards a process of deinstitutionalization. However, in most cases the reform is run by one authority only (often ministry of health and/or social protection) with little or no inclusion of other relevant authorities/bodies. Therefore when we talk about good practice reforms we primarily refer to pilot projects that are not accompanied by all-encompassing systemic reforms that can ensure their sustainability.

Finally, the document also includes an overview of the current situation in Montenegro and recommendations on how to apply elements of the presented models in the local context and on how to implement the deinstitutionalization process.

1 Strategy for the Integration of Persons with Disabilities in Montenegro (2008 – 2016), available at:http://www.mrs.gov.me/ResourceManager/FileDownload.aspx?rId=93285&rType=2 (accessed on 13 January 2017).

BASIC TERMS

Persons with mental disabilities

The expression „persons with mental disabilities“ is usually used as a joint expression for persons with intellectual, cognitive, psycho-social and any other disabilities related to the mental functioning of a person. It may refer to persons who have a psychiatric diagnosis and have been medically treated in accordance to that. The Convention on the Rights of Persons with Disabilities[2] includes this group of people, although many of them do not identify themselves as persons with disabilities due to the traditional understanding of the term disability, which is usually identified with physical disabilities.

Institutional care

Institutional care includes long-term placement of persons with mental disabilities in segregated specialized institutions, where the number of users varies from small to very large, sometimes reaching hundreds of people. Many persons with mental disabilities are to be found in psychiatric hospitals and psychiatric wards; others are in social care institutions, particularly those designated for persons with disabilities and in homes for the elderly. Institutional care is above all, characterized by segregation, exclusion from the community, lack of privacy and personal autonomy, loss of control over people's own lives, where the needs of the institution have priority over the individual needs and wishes of persons living there. Although in many cases persons with mental disabilities are initially placed in institutions for treatment, they often end up staying there for years, even decades. That is not due to a continuing need for treatment, but often to the lack of community-based social services that could provide support for these people so they can leave the institution.[3]

Deinstitutionalization

The process of deinstitutionalization represents the transition from institutional care to community-based care and support, i.e. the practice of providing individualized care, adjusted to the person, in a community-based environment. Deinstitutionalization is sometimes incorrectly interpreted as constituting only of a relocation of people from large residential institu-

2 „Official Gazette of Montenegro-International agreements“, no. 2/2009.

3 In the Special Psychiatric Hospital in Kotor almost a third of the patients are still staying, although there is no longer need for their hospital treatment, details below on page 37.

tions to residential institutions of smaller capacity. In fact, deinstitutionalization is a complex process that involves a change in approach, the main objective being that each and every single individual gets to live independently and be included in the community. This involves providing support to persons with mental disabilities and other forms of disabilities through development of community services, including prevention programs aimed at reducing the need for institutional care.

Prevention

Prevention is an integral part of the process of transition from institutional care to community-based services. It includes a wide range of support services for individuals and their families, ensuring timely and adequate response to the specific needs of a person in order to prevent the need for institutionalization or frequent hospitalization.

Prevention is especially important for persons with mental disabilities. Preventive services, such as mental health centers and shelters, must be developed so that they can be easily accessed in the moment of crisis. Also, they must have a proactive character, so that a person can get service at home, even when it is not actively seeking it. In this regard, the role of these services consists in mapping both existing and potential customers who have a need for such support.

Community-based mental health care

The concept of community-based mental health care is extremely important within the disability rights movement and is vital for any deinstitutionalization process. Community-based mental health care involves the development of mental health services which provide treatment and protection to patients in the environment where they live, that is easily accessible to them and their families. The comprehensiveness of these services is reflected in the provision of a wide range of services needed to meet the wide-range of mental health needs of the population as a whole, as well as of specific groups. Community-based mental health care saves people from the social exclusion connected to long-term hospitalization of patients with severe mental disabilities. It also offers an alternative to hospitalization in psychiatric hospitals or placement of patients with serious chronic illnesses in institutions.[4]
Community-based mental health care is based on different principles than institutional care. Such services focus on the characteristic of each individual person with mental disabilities and the variety of specific circumstances which may be relevant for the creation of a long-term treatment and care plan for that person.

4 Stanojković, M. Professional-methodological instruction for the formation of mental health services in community: the concept of mental health care in community, Collection of papers and recommendations - business capacity and community life: protection of the rights of persons with disabilities, MDRI-S, 2014.

Community services

Community services include all those services provided to individuals in order to enable them to receive all the support they need in the community where they live. This expression first includes general services: housing, health care, education, employment, culture and recreations, i.e. all those services that should be available to everyone, regardless of disability or need for support. This expression also refers to specialized services such as personal assistance, supported housing, temporary care and other services that meet the specific needs of people in relation to the type or degree of impairment, but also the specific life circumstances of that person. Community services include, among other things, vocational rehabilitation, supported employment, family care, psychiatric beds outside specialized hospitals (for example, in general hospitals), daily activities, services for living in community, mobile clinics, outreach services, telephone line for crisis situations, self-help groups and consumer associations.

Community-based mental health services

Community based mental health services (centers) should be the pillar of a mental health care system, which involves case managers, field teams to provide support and care, home care and treatment, rehabilitation, crisis response, hostels as alternative to hospital accommodation and other services. Out-of-hospital clinics can have a triage function, carrying out the situation assessment, guiding the patient to where he/she needs to go and monitoring the patient's condition.

Hospital treatment in form of urgent psychiatric intervention service or short-term hospitalization serves to prevent long-term hospitalization and even institutionalization. Such intervention includes treatment and monitoring during the acute episodes, allowing further treatment and support in less restrictive environments between such episodes.

Independent living

The expressions „independent living" „supported living" or „protected living" are usually used to indicate services that can provide the support that might be needed to ensure people live independently in communities. This does not imply necessarily that the person lives completely alone. What it does always imply is that persons can choose and decide on where and with whom to live, how to organize their daily life and what kind of support they need to maintain or improve their quality of life.

Such services can be provided to a person in an individual home or in a home-like shared-space. In all cases it must be ensured that the environment does not have the characteristics of organized life in an institution and is not a segregated setting.

What is deinstitutionalization and how it must be done

Introduction

Due to the lack of community-based services and alternatives, huge numbers of people with disabilities live in institutional settings. This is not something specific to Montenegro. It is estimated that in in 25 European countries approximately 1.2 million children and adults with disabilities are living in institutions.[5]

Institutional care has been considered for a long period of time as an appropriate form of care for persons with mental disabilities. In recent decades however, community-based mental health care has been gaining recognition more and more often as the human rights compliant choice. The development of social psychiatry and the emergence of a new generation of drugs is changing the perception on treatment options for persons with severe mental disabilities and not only. Mental health care is more and more widely perceived as in need to include respect for human rights, respect for the autonomy and the integrity of the person and respect for the decisions that a person makes about his/her own life.

What the disability rights movement and the relevant international human rights instruments and bodies are currently promoting is a model no longer based on large psychiatric hospitals, but one based on modern comprehensive models of care and treatment, which include acute hospital departments in general hospitals.

The World Health Organization (WHO) Report in 2001 - Mental Health: New Understanding, New Hope - states:

Recommendation 3: ***Give care in the community***

Community care has a better effect than institutional treatment on the outcome and quality of life of individuals with chronic mental disabilities. Shifting patients from mental hospitals to care in the community is also cost-effective and respects human rights. Mental health services should therefore be provided in the community, with the use of all available resources. Community-based services can lead to early intervention and limit the stigma of taking treatment. Large custodial mental hospitals should be replaced by community care facilities, backed by general hospital psychiatric beds and home care support, which meet all the needs of the ill that were the responsibility of those hospitals. This shift towards The Way Forward 111 community care requires health workers and rehabilitation services to be available at community level, along with the provision of crisis support, protected housing, and sheltered employment.

By recognizing the significance of deinstitutionalization for the general health of individuals[6],

5 Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University ofKent.

6 http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/priority-areas/services-and-deinstitutionalization (accessed on 31/12/2016).

the WHO sets, in its Action plan (2013)[7], among others, the following priorities:

(a) Everyone has an equal opportunity to realize mental well-being throughout their lifespan, particularly those who are most vulnerable or at risk;;
(b) People with mental health problems are citizens whose human rights are fully valued, protected and promoted;
(c) Mental health services are accessible and affordable, available in the community according to need; and
(d) People are entitled to respectful, safe and effective treatment.

The three cross-cutting objectives are:

(a) Health systems provide good physical and mental health care for all;
(b) Mental health systems work in well-coordinated partnerships with other sectors; and
(c) Mental health governance and delivery are driven by good information and knowledge.

Within the fourth objective (right to a safe and effective treatment based on respect), the WHO recommends the following:

Service reorganization and expanded coverage:

Systematically shift the locus of care away from long-stay mental hospitals towards non-specialized health settings with increasing coverage of evidence-based interventions (including the use of stepped care principles, as appropriate] for priority conditions and using a network of linked community-based mental health services, including short-stay inpatient care, and outpatient care in general hospitals, primary care, comprehensive mental health centers, day care centers, support of persons with mental disabilities living with their families, and supported housing.

Integrated and responsive care: Integrate and coordinate holistic prevention, promotion, rehabilitation, care and support that aims at meeting both mental and physical health care needs and facilitates the recovery of persons of all ages with mental disabilities within and across general health and social services (including the promotion of the right to employment, housing, and education] through service user-driven treatment and recovery plans and, where appropriate, with the inputs of families and care givers.

Detrimental effect of institutionalization

Institutionalization can have a series of detrimental effect on the life and health of a person. The institutional environments have been shown to themselves generate impairments that can affect a person for the rest of their life. The lack of a personal life, lack of autonomy and a lack of respect for one's personal integrity can hamper the individual's emotional and social development. Terms such as 'social deprivation' and 'taught helplessness' were coined to describe the psychological effects of living in an institution.[8]

7 The European Mental Health Action Plan, Sixty-third session of the WHO Regional Committee for Europe, Çeşme Izmir, Turkey, 16–19 September 2013, EUR/RC63/11, http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/publications/2013/the-european-mental-health-action-plan (accessed on 31/12/2016).

8 Grunewald, 2003, Source: Common European Guidelines on the Transition from Institutional to Community-based

The turning point in relation to the institutional care of persons with mental disabilities was made by documenting and exposing the devastating conditions and treatment that persons in institutions were exposed to (for example, a series of scandals in England in the sixties, and the work of human rights organizations such as the *Disability Rights International*[9], *Mental Disability Advocacy Center (MDAC)*[10], *Amnesty International*[11], *Human Rights Watch*[12] and others). This included various forms of abuse and neglect, outdated methods of treatment, drugs abuse, fixation and isolation, incompetent or inadequate staffing, overpopulation, lack of personnel, bad and inhumane conditions, failures in the review of complaints and victimization of persons who file complaints, including users and staff members.

While there were voice stating such violations were isolated cases, the numerous reports from many countries have fast confirmed that this is a "pattern" of generally present omissions that are typical for institutional care in general, regardless of the physical conditions of stay. One should not forget that the institution is not only determined by the location and size but, above all, the organization of life that ignores individuality and privacy so that the needs of the institution have priority over the personal needs of people who live in them. Therefore, special attention should be paid to preventing the transmission of institutional culture to new services, which would only lead to the creation of several smaller institutions that would operate on the same principle.

Deinstitutionalization and human rights

The widespread violations of human rights of people in institutions are one of the main arguments for abandoning this model of care for persons with mental disabilities. Even though before the Convention on the Rights of Persons with Disabilities (CRPD) the right to living independently and being included in the community was not explicitly provided for in international law, many other international and regional instrument were indicating the need for deinstitutionalization. That includes instruments such as the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights which provided for the right to the highest attainable standard of physical and mental health, the right to liberty and security, the right to freedom from inhuman and degrading treatment, the right to personal and family life, the right to health, the right to equality before the law and prohibition of discrimination.

Care, European Expert Group on the Transition from Institutional to Community-based Care, Brussels, 2012.

9 http://www.driadvocacy.org/media-gallery/our-reports-publications/.

10 http://mdac.org/en/resources.

11 https://www.amnesty.org/en/latest/research/.

12 https://www.hrw.org/publications.

Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons withdisabilities to live in the community, with choices equal to others, and shalltake effective and appropriate measures to facilitate full enjoyment bypersons with disabilities of this right and their full inclusion and participation inthe community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place ofresidence and where and with whom they live on an equal basis with othersand are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residentialand other community support services, including personal assistancenecessary to support living and inclusion in the community, and to preventisolation or segregation from the community;

(c) Community services and facilities for the general population are availableon an equal basis to persons with disabilities and are responsive to theirneeds.

The Convention on the Rights of Persons with Disabilities, Article 19.

At the regional level arguments for deinstitutionalization could be found in the **European Convention on Human Rights**[13] in Article 3, which states that "no one shall be subjected to torture or to inhuman or degrading treatment or punishment", without exception . Deinstitutionalization is also associated with Article 8 of the Convention which guarantees the right to respect for private and family life, and that any interference with that right must be necessary and proportionate.

The Convention on the Rights of Persons with Disabilities[14] **(CRPD)** is the first binding international treaty where the right to living independently and being included in the community is explicitly provided for. Its Article 19 establishes the right of persons with disabilities to "live in the community, with choices equal to others" and requires States Parties to develop "range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." This right has three key elements: choice; individualized support that promotes inclusion and prevents isolation; and customization of services for the general population to be accessible to persons with disabilities.

Right to live in the community and legal capacity

The right to live in the community, the legal basis for the States' obligation to initiate deinstitutionalization, is closely related to the equal recognition of persons before the law, a right guaranteed by Article 12 of the Convention on the Rights of Persons with Disabilities. That is because guardianship is often interlinked with institutionalization, as many people who are placed in institutions for many years are under guardianship, their guardians being relatives,

13 Law on ratification of European Convention for the Protection of Human Rights and Fundamental Freedoms, "Official Gazette of Montenegro – International agreements ", br. 9/2003 i 5/2005.

14 „Official Gazette of Montenegro – International agreements" 2/2009.

centers for social work, other public authorities or the institutions themselves. The fact that persons under guardianship are not able to make any important decisions in life, including where, how and with whom they want to live, indicates that this system violates their right to live in the community. The European Court of Human Rights pointed out the problematic practice of lodging people in the institution with the consent of a guardian and explained that such systems need to value more the decisions of the people in question.[15]

Thomas Hammarberg, a former Commissioner for Human rights of the Council of Europe, called on member states, when he was still holding that mandate, to end involuntary placements[16] of persons in closed wards and social care homes, as well as what some member states call 'voluntary' placements; such "voluntary" placements refer to situations where placement is done against the person's will, but with the consent of guardians or legal representatives. Placement in closed settings without the free and informed consent of the individual concerned should always be considered a deprivation of liberty and subjected to the safeguards established under Article 5 of the European Convention on Human Rights.

The recognition of legal capacity is of great importance to the process of deinstitutionalization given that life in the community involves making decisions of importance for the life of a person in different areas. Developing services which offer support in decision-making should therefore be an integral part of any deinstitutionalization process. An example of how important such services can be is the experience gathered within the Active support services provided in communities by the Global Initiative in Psychiatry - Sofia from Bulgaria. The support in decision-making within these services contributed to reducing the number of cases where deterioration in the mental health condition was observed and also of cases where there was a need for involuntary hospitalization. Users of the service acquired the skills and information relevant for decision making.[17]

The following types of decisions were made by using the model of supported decision-making: decisions about where a person shall live (type of accommodation, location, whether to live alone or with others), relationships with people and lifestyle (with whom they spend time, in what activities they will take part), choice of employment, education and recreational activities, treatment related decisions (estimation of advices from experts, the choice of treatment), financial decisions (how to manage money, spending and saving) and contractual relationships (support a person in understanding the essence of certain contractual relations).[18]

Bulgaria is committed to a holistic concept of legislative reform in accordance with the Convention, particularly relevant for the provisions of Article 12 relating to legal capacity.[19] For example, it has developed a law proposal which proposes the abolition of the system which allows for deprivation of legal capacity and substitute decision-making (the guardianship system). That system is to be replaced by a system that will recognize the autonomy of persons with intellectual and psycho-social disabilities; the principle of „best interest" is to be replaced as well by the principle of „respect for the will and preferences" of persons with disabilities. It

15 Stanev v. Bulgaria 36760/06 (2012) ECHR 46, (2012).

16 Council of Europe, Commissioner for Human Rights, Who Gets To Decide?Right to legal capacity for persons with intellectualand psychosocial disabilities, CommDH/Isse Paper (2012)2, p.5.

17 DimitrovaMarieta and Hristakieva Valentina, Effective rights for mental health patients-Bulgaria, 2016 (a document owned by Human Rights Action).

18 AJUPID Guide of promising practices on legal capacity and access to justice, available at: http://www.ajupid.eu/images/documents/promising_pratices/BAG_AJUPID_UK_2015_BV.pdf.

19 In Bulgaria there is partial and complete deprivation of legal capacity. According to data from 2012, 7,500 persons were deprived of legal capacity, half of which are located in specialized institutions. To over 80% of the persons in institutions that are deprived of legal capacity, frequently director of the institution is appointed as their guardian.

is believed that the implementation of this framework will contribute significantly to deinstitutionalization and the inclusion of persons with disabilities in communities. The main challenges related to inclusion are the deeply imbedded practices of placing people under guardianship and institutionalization and isolation. To address these challenges the law proposal referred to above does not only abolish the guardianship system, but also introduces measures of support in decision-making, based on a relationship of trust, that include: an agreement on receiving support in decision-making, shared decision-making, setting limitations on disposal of certain assets at the request of the person concerned and recognition of advanced directives (decisions for the future).

Using available resources

Resolution 1642 (2009) of the Parliamentary Assembly of the Council of Europe on access to rights for people with disabilities and their full and active participation in society calls on Member States to „commit themselves to the process of deinstitutionalisation by reorganising services and reallocating resources from specialised institutions to community-based services; ".

General principles

Deinstitutionalization requires the adequate relocation of resources, financial, as well as material and human resources. Proper planning and relocation are crucial for the success of any deinstitutionalization process. Resources should be directed to where the person is located, proportionately with the level of support the person needs. Good planning of resources must also enable people to use the most adequate services for their needs.

How funding is allocated can greatly disrupt the planning of adequate care and treatment. In Montenegro, as in the most countries where the process of deinstitutionalization is at the beginning, the funds are still directed primarily towards institutions. One of the key principles of adequate support to persons with disabilities is that the **money follows the person.** This is how the state can ensure the needed support reaches the person which lives outside an institution. This approach also ensures that the person concerned can choose the service that better fits her needs. In the meantime, it is, of course, necessary to continue funding the institutions, but only as a temporary measure which gives people the time they need to move into places where they benefit of alternative forms of support.

A very often asked question is how to use material resources. There are a wide variety of answers to that: resources can be shifted towards general health care services, rental facilities, and residential areas for the general population or tourist facilities. Community-based services for people with disabilities can be offered in places where other general services are provided, or such places can change their functioning to focusing on services for people with disabilities.

Good human resource management in the process of deinstitutionalization is important for

several reasons. Within such process one needs to take into consideration the likely resistance to changes that is so often manifested both among employees of large institutions and employees of municipal services, who are used to „forwarding" persons with mental disabilities to specialized services and institutions. In the same time however, staff who knows users very well and who has significant experience in caring for persons with the most severe disabilities are an important resource for providing adequate support; that is, of course, if they are willing to accept, learn and apply new methods of care.

Finally, the process of deinstitutionalization is not possible without enthusiastic leaders, who will push this process forward. Such people are needed among professional staff and managers, politicians and all other people who are willing to engage in the fight for a better life for persons with mental disabilities.

Using European Union funds

EU member states, states in process of accession and candidate states for accession to the EU can use EU funds – Structural and IPA Funds – to cover the costs related to the transition from institutional care to community-based care. The funds allocated for this area can be identified by looking at Partnership Agreements and Operational Programmes for the forthcoming funding period, where deinstitutionalization of different target groups is one of the priority activities. These funds can cover different areas of reform, including:

- *infrastructure investments – i.e. housing, as well as renovation of apartments* (never of institutions!);
- trainings for employees to prepare them for working in new services;
- creation of employment opportunities in the community); and
- technical assistance, including needs assessment and coordination or management of the entire process of change.

Thus, for example, the European Regional Development Fund (ERDF) can be used to improve the physical infrastructure of mental health services, while activities such as promoting social inclusion of people with mental disabilities and training of professionals in the field of mental health can be financed from the European Social Fund (ESF).

* ***Taken from the Common European Guidelines on the Transition from Institutional to Community-based Care, European Expert Group on the Transition from Institutional to Community-based Care, 2012***

The lack of funding is often used as a justification for non-initiation or slow implementation of deinstitutionalization policies. In this section we will now look at the relevant strategies of the European Union and the funds that it makes available for deinstitutionalization. Such funds are available both for EU Member States and for countries that are in the **process of joining the European Union**. It is important to mention that the European Union ratified the Convention on Rights of Persons with Disabilities on 5 January 2011. That is the first, and for now the only international human rights treaty ratified by the European Union.

The UN Convention on the Rights of Persons with Disabilities (UN CPRD), the UN Convention on the Rights of the Child and the European Convention on Human Rights require the

European Union and its Member States to urgently initiate the transition from institutional to community-based services. Among the key articles of the UN CPRD relevant for deinstitutionalization, Article 19 lays down the right to living independently and being included in the community.[20]

The European Disability Strategy 2010-2020[21] provides the framework for empowering persons with disability to fully participate in society and ensure they can enjoy their fundamental rights. The strategy reiterates the EU commitment to promote the participation of persons with disabilities in leisure activities, employment, education, health, social services and to achieve the transition from institutional to community-based care.

The European Structural and Investment Funds (ESIF) can support a wide range of measures in line with the requirement of the poverty reduction policy framework (thematic objective 9) prevent institutionalization and support the reforms for the transition. **Building or renovating long-stay residential institutions is excluded from the ESIF support, regardless of the size of the institution.** Measures proposed are part of a strategic vision on how the transition from institutional to community based care will be implemented, in line with the criteria under the proposed *ex-ante* conditionality for active inclusion.

The Cohesion Policy[22] 2014 – 2020 mentions deinstitutionalization as an explicit priority for the European Structural Investment Funds, especially the European Social Fund and European Regional Development Fund.

Guidance in the area of binding elements in fund planning from 2014 in the field of mental health states the following activities: [23]

- To promote treatments and care models provided in the community and encourage social inclusion (deinstitutionalization) and improve the approach to support for persons with mental disabilities.
- To promote health programs and early intervention programs for members of groups with high tendency to mental illness and provide support mechanisms in social/ health system in cases of mental illness/deterioration and especially after suicide attempt.
- To confront discrimination on the basis of mental illness and stigma and to promote social and work integration of persons with mental disabilities.

20 Source: http://ec.europa.eu/regional_policy/en/policy/themes/social-inclusion/desinstit/ (accessed on 30/ 12/2016).

21 European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, European Commission, Brussels, 15.11.2010.

22 It contains measures for reduce of disparities and equalize the powers of various of EU member states (in terms of income, wealth and opportunities).

23 Internal Guidance on Ex Ante Conditionality for the European Structural and Investment Funds, 2014, http://ec.europa.eu/regional_policy/index.cfm/en/information/legislation/guidance/ (accessed on 13/01/2017).

Comparative analysis of deinstitutionalization processes: good practice examples

Across Europe (and the rest of the world), numerous efforts have been made over the past decades to overcome the challenges related to providing quality long-term care for persons with mental disabilities, including severe mental illness. Examples of such initiatives include the psychiatry sector in France, the social psychiatry and mental health in primary health care in the United Kingdom and the reform of psychiatry and the deinstitutionalization process in Italy.

These early initiatives were followed by a multitude of different processes throughout Europe, which promoted improved mental health care systems. Such processes include improvements in the physical conditions within psychiatric hospitals, development of community services, the integration of mental health care into primary health care, the development of psychosocial support (housing, vocational training), the protection of human rights of persons with mental disabilities and the increased participation of users and their families in processes of improvement of policies and services. Numerous studies that followed these processes have expanded the evidence base that should be taken into consideration when investing in creating adequate mental health care systems.

In the chapter that follows we will try to present some examples of mental health reforms focused on deinstitutionalization. A detailed analysis of the process of deinstitutionalization at the international level, with all the successes and challenges, goes beyond the scope of this document. Our current goal is to show that deinstitutionalization is indeed based on binding principles and standards of human rights, but it does not constitute an utopic idea, having a strong grounding in the experiences of other countries.

Italy

Italy is one of the first countries that initiated the deinstitutionalization of people with mental disabilities, developing a system of community-based mental health care. It decided to relocate psychiatric treatment and support from psychiatric hospitals to community-based **centers for mental health, which** ensure the integration and connection with other services and resources in the community. Such change has led to changes in the role of family doctors regarding the care of psychiatric patients.

Key provisions of "Law 180" which introduced fundamental changes:

- **The prohibition of admission of new patients in the existing psychiatric hospitals**
- **The prohibition of construction of new psychiatric hospitals**
- **Opening departments for psychiatry in general hospitals with a maximum capacity of 15 beds**
- **Creation of community-based centers for mental health which provide ambulatory psychiatric treatment in all geographical divisions of the country**
- **Forced treatment may be applied only in exceptional circumstances when it is not possible to access appropriate services in the community, and when the patient does not accept treatment outside hospital conditions**

Significant changes have begun with adopting "Law 180" in 1978. The law provided for the establishment of a comprehensive and integrated system of mental health care, which was to be adapted and implemented at regional levels, covering a certain percentage of the population.

The reform in Trieste, as a characteristic of the Italian reform, has led to the closure of psychiatric hospitals and development of a network of community services organized in different health sectors so as to meet all the health and social needs of persons with serious mental illness. This network includes centers for mental health, with a small number of beds, psychiatric department in the general hospital, housing services and a wide range of rehabilitation programs (vocational training and social cooperatives, among others).

The reform of mental health care in other regions has followed the same goals and strategies with certain variations according to the specific characteristics of each region. Therefore, the reform of psychiatric services in other regions varied in terms of dynamics and concrete steps in the implementation of this process.

The development of psychiatric services in the community in the region of Emilia-Romagna is a good example of a phased approach. In the early 80-ies they established community-based mental health centers and began the relocation of patients from psychiatric hospitals into out-of-hospital residential units; the establishment of a network of psychiatric departments in general hospitals was also initiated. Resources for the realization of these tasks were provided by gradually releasing resources made available by closing large psychiatric hospitals. Although not all of them, many professionals have accepted the transition from the old to the new type of services, which was followed by intense training at the new workplaces. The **Regional Center for Psychiatry** was established in order to coordinate and supervise the entire process. This center runs under the responsibility of local administration, and it is always guided by an expert in the field of mental health. Last psychiatric hospital in the region was closed in 1997, 19 years after the beginning of the reform.

While Italy continues to develop innovative services that provide comprehensive multi-disciplinary psychiatric care and treatment, there are still significant geographical differences in terms of the quality of the services provided.

United Kingdom

England and Wales are usually taken as an example of good practice in the reform carried out in the UK. Although the first initiatives aimed at closing large psychiatric hospitals date back to the sixties, an official strategy was only adopted in 1971. It proclaimed a complete abandonment of the model of psychiatric hospitals and the necessity to transition to community-based mental health care, where all services are provided by general hospitals in close collaboration with primary care and social services. Such services must include support for independent living, day-care services and multidisciplinary teams for mental health in the community. The strategy was followed by **redirecting funds from the health system (which had the authority over institutions) to the local government**.

Key changes have occurred during the eighties and nineties, and by 2000 the British government has closed 90 of the 120 psychiatric hospitals, shifting the majority of patients who were exposed to long-term institutionalization in group housing units and centers for care in the community.

The National service framework for mental health[24], adopted in 1999, has provided details for the creation of *specialized teams for mental health in the community*. Over 200 teams for support and treatment in the community (ACT - *assertive community treatment teams*) were formed throughout England, along with 50 services for early intervention and 300 teams for crisis situations and home treatment. All of them have been working alongside the teams of mental health centers in the community and local hospital departments for temporary hospitalization.

Recent strategic documents have been directed to the encouragement of cooperation between primary and specialist psychiatric care units, so they can together work in providing treatment for common mental illnesses. The new documents also support a better approach to psychological counseling and psychotherapy, paying attention to the physical health of persons with severe mental illness and a greater representation of approach based on recovery.

Despite all the challenges, the British experience is an excellent example of a carefully planned and consistent strategy guided by the understanding among decision-makers that the institutional care of persons with mental disabilities is unacceptable.

Spain

Radical changes in the public mental health system were launched in the eighties in Andalusia, one of 17 provinces of Spain. Until then, psychiatric treatment was allocated from the general system of health care, with limited resources aimed exclusively at eight psychiatric hospitals and a small number of clinics for out-patient treatment. Psychiatric hospitals had a total capacity of about 3,000 beds, with 2,700 chronic patients on long-term hospitalization.

The strategy for the creation of a social services network to provide community-based support for people with mental disabilities is one of the most original and most creative aspects of the reform. *Namely, the essence of the strategy is the formation of a public (state) Foundation funded equally by the four most relevant state departments for the provision of support for mentally ill people (health, social care, employment and technological development and economy and finance). The education sector subsequently joined.*

The great success of this strategy was reflected in the fact that it provided: national inter-sector funding; coordinated planning and management of social support services in close cooperation with health services; flexible and efficient management of the allocation of resources; the participation of local organizations as well as associations of users and families and staff in developing and monitoring the implementation of these programs.

24 National service framework for mental health, 1999, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198051/National_Service_Framework_for_Mental_Health.pdf (accessed on 13/01/2017).

The outcome of the reform is reflected in the following:

- **The closure of all psychiatric hospitals,** through individual plans for deinstitutionalization and repurposing of existing objects (mostly used for general health care);
- **The creation of new network of specialized services for mental health** that are provided in the community and integrated in general health system. Such network is organized by sectors, so called „areas of mental health" and includes: teams for mental health in community which work in tight connection with primary health care; hospital departments in general hospitals, centres for out-of-hospital treatment of children with mental health problems, day care centres, rehabilitation centres and therapy (centres for the treatment of patients who need a longer period of structured therapeutic environment).
- The creation of new state organization - Andalusian **Public Foundation for Social Integration of the People with Mental Disabilities** (FAISEM), which manages the network of social services. This network includes residential, **occupational and work centres and programmes.**
- **The formulation of intersectoral strategy** that promotes cooperation of health sectors with services provided by others departments (social welfare, justice, education), as well as cooperation with associations of users and their families.

At this time, the Foundation provides support in housing for more than 2,000 users, occupational activities for more than 2,500 users, vocational training for 200 users each year, employment in social enterprises for about 300 persons with mental disabilities and the development of many other activities (support in employment, social clubs, support for users and family associations and researches, among others). Access to the services that the Foundation offers is always ensured in coordination with the mental health services through coordinating bodies for each territory, including also the general social services on the territory (Caldas de Almeida & Torres, 2005).

France

Accessibility, continuity of support and intersectoral cooperation are the main characteristics of this system.

The example of deinstitutionalization at local level comes from Lille in France and points out the importance of involving the entire local community to ensure the success of the deinstitutionalization process.

The reform is focused on deinstitutionalization and the development of community support services, and is based on the principles of sectorial psychiatry, where each "sector" covers a population of about 54,000 people. The process of deinstitutionalization began in Lille during the seventies, being initiated by psychiatric hospitals and non-profit medical psycho-social associations, with the inclusion of members of local government, professionals in the field of mental health, social workers, users and representatives of support services staff.

At the very beginning, they created a Medical-psychological center and a Center for housing

and deinstitutionalization, which were specialized in the rehabilitation of chronic, long-term institutionalized patients. Thereafter, the cooperation with local governments and contacts with managers of social housing was initiated in order to establish joint and "therapeutic" apartments, and to access support and housing units distributed throughout the community. The programs were initiated in the field of representation, combating stigma, research to develop strategies and development of services and program of psycho-social rehabilitation.

The reform was conducted in two key steps. The first step (1975-1995) was the relocation from psychiatric hospitals into the community, through the development of sectorization, with the support of the state (central) budget. The second step (1995-2006) consisted of decentralization and the opening of psychiatric services by involving professionals in the health, social and cultural services at the local level. This integration has encouraged the participation of other interest groups (users, families, professionals and elected representatives) in making decisions concerning psychiatric health care.

Within this system a person is reviewed by a qualified worker after being referred to him/her by a general practitioner. The qualified worker makes an assessment of the situation in less than 24 hours. If necessary, the person can be sent to a psychiatrist on the same day. Teams are assigned on various locations in the community while providing outpatient treatment.

As an alternative to hospitalization, they developed, in 2000, the possibility of receiving accommodation in "therapeutic" families. There are currently 12 such families, the average length of staying with them being of 21 days. Patients in the acute stage are referred directly to families, or referral is done after short-term hospitalization. The caregiver and the social and medical team are responsible for mental health care during home visits. Support is similar to that offered within hospitalization in hospital conditions.

As the second alternative to hospitalization, an intensive care unit was developed, with a maximum capacity of 10 users. This service is provided at the patient's home after an urgent intervention, in order to guarantee support and treatment.

Services and programs that promote social inclusion are integrated in other community services. Apartments that are assigned around the community make one of the basic components of this inclusive approach. In order to provide adequate housing solutions, a "Committee for the apartments" has been formed, which decides on the allocation of available apartments. Currently, the "Committee" provides support for 57 apartments with 95 people living there, who have accepted the agreement on social inclusion and support.
Professional rehabilitation and employment are promoted through a broad specter of activities, including therapy workshops, professional training, and support schemes in employment and rehabilitation programs in the community.

Finland: Treatment through open dialogue[25]

As an alternative to the traditional mental health care system for people diagnosed with psychosis a program called Open dialogue has been developed in Finland. This approach represents a method of support through a network consisting of family members and friends, respecting the decisions of the person with disabilities.

25 http://www.mindfreedom.org/kb/mental-health-alternatives/finland-open-dialogue/open-dialogue-finland-outcomes.pdf/at_download/file.

This service is provided in the home and it is most efficient when applied in an early stage. Within 24 hours, a team of experts brings together as many people as possible who are close to the person. They meet every day or every other day for two to three weeks. In most cases, the intervention does not involve the use of medications, focusing on the inclusion of the service user and his/her important persons in all key decisions. It ensures immediate, flexible and individualized help with the evaluation of different opinions.

"Open dialogue" rests on seven principles: immediate help, maintaining social networks, flexibility, responsibility, psychological continuity, tolerance of uncertainty and dialogue.

Members of the mobile teams are mobilized among existing staff from five centers for outpatient treatment and one hospital department for acute treatment (capacity of 30 beds), which have undergone proper training. In this way the continuity of treatment is achieved for patients who were hospitalized and those who are treated in outpatient conditions.

Greece: Prevention of a crisis situation[26]

The Institute of Mental Health for Children and Adults in Greece has established a unit of psychiatric treatment in the home of patients, which is largely based on the same principles as mobile psychiatric units.
Persons who satisfy conditions for service use are:

- Persons with psycho-social disabilities passing through acute psychiatric crisis.
- Persons with psycho-social disabilities returning home after a long or a short stay in hospital.
- Ambulatory patients who have never been hospitalized.
- Stabilized individuals with psycho-social disabilities and problems with mobility.

The criteria include the need for a sufficiently stable environment with the aim of shared responsibility for safe accommodation in a house of a person with psycho-social disabilities, in cooperation with a team of therapists and services user.

This unit operates according to the following model:

- During the first days of psychiatric crisis, a team is in the service user's home almost all day, trying to establish a strong relationship with the person, based on trust. This may include the provision of medication.
- From the very beginning, the team is trying to make the service user accept responsibility and does not allow him/her adopt the role of patient.
- As soon as possible, the team supports the user in returning to work and in social life.
- Gradually, and in accordance with the needs of the individual, the team leaves the home, continuing to provide constant support.
- The Institute also offers families stable support and training in mental health.
- The team provides support to users at the workplace and in social environment in general, which strengthens support networks.
- The Institute applies programs of community sensitization (training in mental health) and organizes training for people in key public positions to ensure community support for the rehabilitation and social inclusion of service users.

26 Source: Common European Guidelines on the Transition from Institutional to Community-based Care.

Examples of recent deinstitutionalization processes

In so-called new democracies, mainly countries that acceded recently to the European Union, the process of reform of the mental health care for persons with disabilities began developing in the last twenty years. This reform process largely follows the examples of what happened in Western Europe 50-60 years ago.

It is difficult to determine the exact number of persons who are in psychiatric hospitals and other residential institutions for persons with mental disabilities in these countries, most often due to uneven method of data collection. However, in most of these countries there is a trend of reducing the total number of beds in large psychiatric hospitals.

Unfortunately, the reduction of beds is not always followed by the development of services in the community. Most often, the problem is the method of financing because the funds are routed directly to psychiatric hospitals, according to the capacity that is filled i.e. the number of beds. This method of funding is not flexible, and makes it difficult to fund new services in the community, especially when they are developed at the local level.

Despite these obstacles, there has been a development of different services, such as community-based mental health centers. They generally vary in size and type of services they provide, but they have multidisciplinary teams working on the territorial principle and have an individualized approach. These services are in most cases initiated by NGOs, which often involve the users themselves and their families. The downside is that they largely depend on the enthusiasm of individuals and on personal initiative and are not the result of a coordinated process with a clear strategy developed by the government. Therefore, the representation of these services is unequal with little or no mutual coordination, which is why the continuity of support to persons with mental disabilities is not being established during the transition from hospital back into the community environment.

Some countries have had more structured process of deinstitutionalization, which are mainly related to the field of social care and housing, and are largely financed by funds from the European Union. What characterizes these processes is, most often, poor coordination i.e. the division of responsibilities of various departments which hinders the implementation of strategic documents, especially when their implementation falls under the responsibility of a ministry, usually the Ministry of Social Care.

Bulgaria[27]

The Bulgarian Government has recognized the great importance of deinstitutionalization back in 2001, by adopting the National Strategy for Equalization of Opportunities for Persons with Disabilities for the period 2001-2005, which was aimed at: ensuring the transition from institutional care to community-based services through the priority development of alternative services and deinstitutionalization.

Later, in 2008, the National Strategy for Equal Opportunities for Disabled People 2008-2015 was adopted, with a focus on "restructuring specialized institutions and their transformation

27 Source of information: Valentina Hristakeva (Director ofGlobal Initiative on Psychiatry-Sofia) and MarietaDimitrova (Consultant in the field of law, the Bulgarian Center for Not-for-Profit Law).

into different types of social services in the community." This process is supported by the adoption of the Law on Social Assistance 2008. This law grants municipalities' full authority over the provision of social services. As a result, funding was provided for a large number of new services, which started functioning alongside the existing ones. Municipalities can manage the services either directly, or delegate management of services to another organization, which is a registered provider.

In January 2014, the Bulgarian government adopted a National Strategy for Long-term Care[28] concerning adults. Like the strategic document they already had for children, this strategy anticipates that the Council of Ministers is responsible for the implementation process. The Strategy was adopted in response to the key issues contained in the Convention on the Rights of Persons with Disabilities and the Optional Protocol to the European Convention on Human Rights, the European Social Charter and other international documents. The strategy defines deinstitutionalization as a bilateral process involving the closure or transformation of existing specialist institutions and the development of alternative services for care in the community for adults. Deinstitutionalization should focus on developing a network of services provided in the community or family (home) for adults with disabilities, including those with mental health problems, with the aim to support their independent living and inclusion in society.

The specific aims of the Strategy are:

- Development of a network of improved community-based social services which take into account the needs of the elderly and people with disabilities. Such services are to be provided not only stationary, but also at home, through mobile services. Such services find the customer (in his/her residential district, home, at hospital); they inform, support and encourage the inclusion of people belonging to vulnerable groups of society in activities appropriate for them;
- Regulation of a broad range of stationary, mobile and integrated cross-sectional services in the community for people belonging to the target groups and their families, leveraging on the best practices and applying innovative approaches.
- Ensuring sustainable financing of the long-term care services;
- Improving the coordination between the systems for social and health care both in terms of the policies and of the participating structures;
- Gradual closing and/or reforming of all functionally outdated and not complying with the current needs of the target groups specialized institutions for elderly people and people with disabilities.
- Gradual restructuring of the systems for stationary medical treatment of patients and deinstitutionalization of the cares through development of suitable forms for care and medical treatment of people with mental disabilities and those who need palliative care.

The strategy is based on the principles and approach of the *Voluntary European Quality Framework for Social Services*[29].

Although deinstitutionalization is an integral part of this strategy, it seems that it is not the primary focus of the document, which states that deinstitutionalization is to be achieved: ...*in*

28 National Strategy for Long-term Care: https://www.mlsp.government.bg/ckfinder/userfiles/files/politiki/socialni%20uslugi/deinstitucionalizaciq%20na%20grijata%20za%20vuzrastni%20hora%20i%20hora%20s%20uvrejdaniq/EN_Long_Term_Care_Strategy_final.doc (accessed on 13/01/2017).

29 http://ec.europa.eu/social/BlobServlet?docId=6140&langId=en, (accessed on 13/01/2017).

the next 20 years. Spreading the services network will lead to closure of all special institutions for adults and disabled persons as they are functionally outdated and not in accordance with real need of target groups.[30]

Despite the existing development of community-based services for persons with mental disabilities, mainly in small local areas, , care for people with mental disabilities is still primarily provided by residential institutions, where an individualized approach is lacking, and where cases of violations of human rights are still being recorded.

Currently, in Bulgaria there are 11 day-care centers for persons with psycho-social disabilities. These centers should focus both on rehabilitation and prevention of long-term hospitalizations. However, many centers operate as „hang-outs", without any real activities aimed at preventing hospitalization.

The expertise for the development of alternative services came from non-governmental organizations, which carry out most of the activities related to capacity building for community services. Thus, the Global Initiative on Psychiatry - Sofia (GIP-Sofia) has developed a successful service, the Active community treatment, that is recognized by the relevant government institutions and which received a certificate from the Agency for Social Assistance. At the same time, 'expert by experience in social inclusion' has been recognized as a profession and was officially included in the national register of professions. However, the Active community treatment does not receive state funding, being partly financed from different projects, and partly through the Day-Care center for Rehabilitation, which incorporates the mechanism of supported decision-making as a programme of the center.

The Active community treatment is implemented in Sofia. It is intended for persons who are at the greatest risk of neglect due to mental illness. In most cases, persons who use this service have a diagnosis of schizophrenia; they do not have regular income, personal documentation and/or are homeless without close relatives and/or friends who could take care of them; they all have a mental or somatic illnesses. Due to the specificity of their mental condition or life circumstances, these persons cannot reach the system of social and health care and receive adequate and quality care and support. Potential programme users are identified in different ways, most of them being directed to the service by local and health services in Sofia.

The guiding principle of the programme is „nothing for the client without the client". The way to ensure the participation of the target group is by including experts by experience, who themselves have experienced mental health problems. The Active community treatment involves three social employee and five experts by experience. All team members have passed specialized training where they adopted the stances and gained skills and knowledge to fight against social exclusion in all areas.

Social workers and experts by experience work as a team and do field work, create support plans and monitor their implementation. The programme insists on the active participation of the client in decision-making processes regarding implementation of their support plans, in order to ensure that their rights are respected according to the Convention on Rights of Persons with Disabilities.

Although the GIP-Sofia is the direct service provider, the programme mobilizes all existing resources in the community, including social and health care services, local services, state

30 DimitrovaMarieta and Hristakieva Valentina, Effective rights for mental health patients-Bulgaria, 2016 (a document owned by Human Rights Action).

institutions, and also all those from the immediate environment of the person, including practitioners, psychiatrists, families, friends etc.

This service has succeeded, through active field work, to fill the gap between the social and health care systems, especially for people who are released from hospitals. The achievements of the programme involve the decrease of exposure to poverty and neglect, better health condition, as well as a better coordination among relevant services and authorities. Objective indicators have recorded a better quality of life for the user due to support in decision-making, an approach based on the person's strengths and coordinated support and planning. The number of cases where the mental health condition of people deteriorates and forced hospitalization occurs has been reduced. The views of users, but also of others involved, have changed after the experience.

This model and related education can be applied in other areas, in relation to persons who are affected by serious and long-term conditions that result in disability and where complex support is needed. This model of support in decision-making is implemented in other municipalities (Plovdiv, Stara Zagora).

Moldova[31]

The "Community for All - Moldova" is a program with different components. One main activity aims at relocating boys and men with severe mental disabilities from the Residential home for persons with mental disabilities back into their families or alternative community services. Their activity also aims at contributing to the development of a legal framework for new services in the community and to a better social inclusion of persons with mental disabilities.

Other components of the project include drafting policy and legal documents, such as the Social Inclusion Strategy for Persons with Disabilities, the draft Law on Social Inclusion of Persons with Disabilities and the draft Standards and regulations for the joint housing and supported housing services. At the local level, the project focuses on enabling exit of persons with disabilities from institutions and the prevention of institutionalization. This is achieved through cooperation with local partner organizations, based in the communities where people with disabilities live (or, in the case of persons who are in institutions, in the communities where people used to live or could live).

During the period 2008 - 2012 more than 70 people have left one institution for people with disabilities (from Orhei), and the placement in an institution was prevented for 40 people. Services developed by Keystone in Moldova include family support services, supported housing, group housing, foster care, shared housing, mobile teams, teaching assistants and personal assistance.

It is important to mention that Moldova is one of the poorest countries in Europe and it was affected more heavily by the financial crisis than any other country in the world. [32] Despite that,

31 The Community for All - Moldova Program was created through the established partnership between Keystone Human Services International in the United States, the Ministry of Labour, Social Protection and Family, Open Society Foundations/Mental Health Initiatives, Soros Foundation – Moldova, and Keystone Moldova. The goal of this partnership was to support the reforms of the Government of the Republic of Moldova in the field of social protection of persons with disabilities. Source: http://www.keystonemoldova.md/en/projects/community-for-all.php, (accessed on 29/12/2016).

32 World Bank (2010), Source: Common European Guidelines on the Transition from Institutional to Community-based Care.

Moldova has managed to get people out of institutions, and to redirect some funds towards community services, showing that the implementation of a deinstitutionalization process is possible even when limited funding is available.

EXAMPLE OF PROTECTION AND REDIRECTION OF RESOURCES FROM INSTITUTIONAL CARE TO CARE AND SUPPORT WITHIN THE COMMUNITY IN THE REPUBLIC OF MOLDOVA*

In one county, local authorities developed a plan for the comprehensive deinstitutionalization of children's services, including the closure of three institutions. All three institutions were funded centrally by the Ministry of Education. The community services required (including social services and inclusive education) would be funded by the county council. The NGO worked with the Ministry of Education, Ministry of Finance and county councils to develop a three-stage process for redirecting finances. Firstly, the budgets for the institutions were protected and it was agreed they would not be subject to reduction as the numbers of children in the institutions reduced. Secondly, the budgets were decentralised to the responsibility of the County Council, while the institutions were still open. This decentralization was based on the condition that the local authority would not reduce the budget or direct the finances to anything other than children's services. Thirdly, as the institutions gradually closed, the budgets and personnel posts were transferred to the new community-based services, making it possible for the County Council to sustain the new services in the future.

taken from the Common European Guidelines on the Transition from Institutional to Community-based Care

Hungary

In 2011 the Hungarian Government adopted a Strategy of Deinstitutionalization. Disadvantages of the Strategy are that it aims at closing all its institutions in an extremely long period of time, 30 years, allowing during the transition process the construction of new institutions with smaller capacities. During 2013, six large institutions were selected (with a total of 700 users) to be closed. There is a justified concern that a small number of their residents will actually manage to live in the community, while the majority will be transferred to other residential institutions of smaller capacity.

The closure of these six institutions and other projects related to deinstitutionalization are managed by an organization established by the Government - The Equal Opportunities of Persons with Disabilities Non-profit Ltd. (FSZK). The work of FSZK is supervised and funded by the Ministry of Human Resources, whose activities are related to education, health and social issues. In addition, there is the National Committee for deinstitutionalization chaired by FSZK, consisting of representatives of all relevant stakeholders (including ministries and regional authorities, other government bodies, organizations of persons with disabilities, other NGOs and universities).

The National Committee has an advisory role and can submit a veto to proposals that are not in accordance with the aims of the Strategy. However, certain decisions that are made are not fully aligned with key principles which should lead a deinstitutionalization process. In any

case, such structure represents an example of good process management, which could function with the right leaders.

Serbia[33]

Recognizing the need for the humanization of the care provided to people with mental disabilities, including severe mental disabilities, and for creating conditions for their re-socialization Serbia engaged, in 2003,, together with eight other countries in the region, in the project the Stability Pact for South-Eastern Europe entitled "Enhancing social cohesion through strengthening community mental health services".

This project constituted the beginning of the implementation of the concept of community-based mental health care in Serbia. The project is managed by the World Health Organization and is coordinated, in Serbia, by the National Commission for Mental Health of the Ministry of Health. The project has created a document which is considered the national policy on mental health, which in January 2007 was adopted by the Government of the Republic of Serbia. This document is entitled "Strategy of Development of Mental Health Care." This document is in line with WHO recommendations from 2001, which are related to mental health, and the Mental Health Declaration for Europe, adopted at the European Ministerial Conference in January 2005 in Helsinki. Under this project Serbia saw the establishment of its first community-based center for mental health. The structure and organization of services in the Pilot Center are designed in such a way that it can provide a model for the opening of other similar centers across Serbia.

The first Serbian Center for the Protection of Mental Health in the Community was established in Medijana municipality, a part of the City of Niš. The Pilot Center was established as a separate organizational unit of the Special hospital for psychiatric illness "Gornja Toponica", with the involvement of professional staff from the hospital. It was however relocated from the hospital grounds, and moved in the very center of the municipality. This relocation allowed the Pilot Center to become an alternative to hospitalization, being more easily available to those in need and oriented towards non-institutional treatment. The Center aimed at providing comprehensive psychiatric treatment for all citizens of the municipality Medijana, regardless of the type or level of the mental health disorder, or whether patients are in psychotic or non-psychotic phases. In the realization of this idea, the multidisciplinary team of the Pilot Center was managed through:

- The territorial principle,
- the principle of therapeutic continuity,
- the individualization of treatment,
- the introduction of case management,
- 24-hour availability for users, and
- intersectional cooperation.

The provision of a comprehensive and, most importantly, continuous psychiatric treatment for patients with psychosis who live in the municipality of Medijana, quickly lead to almost

33 For more information see: Stanojković, M. Professional-methodological instructions for the formation of mental health care services in the community: the concept of mental health care in the community, Collection of papers and recommendations - legal capacity and community life: the protection of the rights of persons with disabilities, MDRI-S, 2014, available at:http://www.mdri-s.org/wp-content/uploads/2014/12/Zbirka-radova-SRB.pdf (accessed on 29/12/2016).

all the patients who were on long-term hospitalization in "Gornja Toponica", being able to leave the hospital and live in the community, where they receive appropriate support from members of the multidisciplinary teams of the Centre.

After 3 years of work, the staff of the Center reached the conclusion that, despite their enthusiasm, a small number of users with schizophrenia, with more difficult clinical background and less favorable course of illness, without relatives, without adequate housing and regular monthly income, cannot get out of hospital and be treated in the community unless protected housing is offered within mental health care.

The need for long-term hospitalizations in psychiatric hospitals could be eliminated by creating protected apartments, which could be the responsibility of Social work centers, with different levels of support provided by multidisciplinary teams of mental health care services in the community (only home visits, morning presence of therapists, daily presence of therapist or 24 hour presence).

Unfortunately, for the operation of this Pilot Center, further funding is not ensured, and the new Law on the Protection of Persons with Mental Disabilities[34] provides for the establishment of community-based mental health centers that resemble those that exist in Montenegro. However, the experience of this Pilot Center from Medijana remains a valuable example to be considered in the further development of services provided to persons with mental health problems.

Within the project "Open Arms", supported by the European Union, two more community-based centers for mental health were launched in Kikinda[35] and Vršac[36]. Now it remains to be seen how their operation will be organized through bylaws and in practice.

34 "Official Gazette of Republic of Serbia no.45/13, available at: http://www.zdravlje.gov.rs/downloads/2013/Jun/Jun-2013ZakonZastitiLicaSaMentalnimSmetnjama.pdf (accessed on 28/01/2017).

35 http://www.spbnoviknezevac.rs/centar-za-mentalno-zdravlje/.

36 http://www.cmzvrsac.org.rs/index.php/component/content/?view=featured.

The situation in Montenegro: institutionalisation and a vision for change

Strategic framework

In 2009 Montenegro ratified the Convention on the Rights of Persons with Disabilities and its Optional Protocol[37], and assumed an obligation pursuant to the provisions of Article 19 of the Convention to carry out deinstitutionalization and to enable all people with disabilities to live in the community.

As for the strategic framework, the first Strategy for the integration in society of persons with disability in Montenegro was adopted in 2007, being recently replaced by a new Strategy, for the period up to 2020. Unfortunately, the new Strategy does not offer detailed information on future steps to be taken. I do at least refer to the European Strategy 2020, which is its most positive feature.[38]

Even though the Strategy recognizes the importance of developing community services, the main form of care for persons with disabilities remains oriented towards residential institutions, with a tendency of expanding their capacity. Deinstitutionalization is not even explicitly mentioned. Although the Strategy states that mental health, as an important component of overall health, deserves particular attention, none of the measures that are listed is explicitly applicable to this area, nor to persons with mental disabilities, or to people who are in the Special psychiatric hospital in Kotor due to social reasons – the so-called "social patients".

In addition to this Strategy, the situation becomes even more problematic considering Article 40 of the Law on Protection and Rights of Mentally Ill Persons[39] which allows for the transfer of people from psychiatric institutions into social care institutions. Accordingly, there is a real danger that the "deinstitutionalization" of the Special Psychiatric Hospital in Kotor would lead to people being sent not to live in communities, but to social care institutions.

On the other side, the Mental Health Improvement Strategy for the Republic of Montenegro[40], passed in 2004, provides for the (re) organization of services and institutions as one of the priority areas for action:

> „It is necessary to reorganize the system of mental health so that treatment of patients is shifted from large psychiatric institutions and clinics to out-patient psychiatric services, mental health services are developed at the local level which will provide overall, less restrictive mental health protection which is closer to community, and mental health protection included in the primary health care."

37 „Official Gazette of Montenegro-International Agreements" 2/2009.

38 http://www.disabilityinfo.me/component/k2/item/1445-osvrt-na-novu-strategiju-za-integraciju-osoba-sa-invaliditetom (accessed on 30/12/2016).

39 "Official Gazette of the Republic of Montenegro", no. 32/2005 and "Official Gazette of Montenegro", no. 27/2013.

40 http://www.mzdravlja.gov.me/ResourceManager/FileDownload.aspx?rid=217288&rType=2&file=Strategija%20unapre%C4%91enja%20mentalnog%20zdravlja%20u%20Republici%20Crnoj%20Gori.pdf.

This strategy has been accompanied by action plans. The Action Plan for the Promotion of Mental Health in Montenegro 2017-2018 contains very important objectives and activities that confirm the positive direction of the reorganization of the mental health system towards the development of community-based mental health services. Of particular importance are the activities of expansion of service and capacity building of professionals in primary care, community-based mental health centers and work on the de-stigmatization of people with mental disabilities. The measure that envisaged the division of costs between health and social care sectors has been confirmed also with this Action Plan (Objective 4 Activity 5), by which the Ministry of Labour and Social Welfare should take over part of the financing. Considering the difficulties in implementing these measures, it would be necessary to adopt a binding relevant document at the highest executive level.

The process of deinstitutionalization is recognized as one of priorities of the European Union within Chapter 23 and is accordingly mentioned in the respective Action Plan involving implementation of recommendations of the European Committee for the Prevention of Torture CPT.[41] The Action Plan for Chapter 23, stated in 2013: "Improvement of conditions require multi-sectorial approach to the category of social cases that have nowhere to go and stay in the hospital, and for whom there is no need for further treatment. Therefore, the Action Plan recognized multi-sectorial approach whose implementation will enable the improvement of material conditions of hospital, as well as treatment of residents. At the same time, it will effect on citizens' awareness in order to reduce stigma."

The Action Plan then envisaged measures for the transformation of the social care home "Komanski most", which however were not entirely aimed to a full transition from institutional to community based care. On the other side, the Action Plan does not include any measure for the deinstitutionalization of chronic patients from the Special Psychiatric hospital in Dobrota.

Basic facts

The exact number of persons with mental disabilities in Montenegro is not known, nor the exact number of persons on institutionalized care, given that these persons are placed in the Special Psychiatric Hospital in Kotor (240+) and hospital departments in Nikšić (20) and Podgorica (30), as well as in social care institutions – the Public institution "Komanski most" for the accommodation of persons with special needs (115)[42] , and homes for the elderly in Bijelo Polje (total of 120) and Risan (total 317).

41 Action Plan for Chapter 23, pp. 168, available in Montenegrin at: http://www.ujn.gov.me/wp-content/uploads/2015/03/AP23-CG.pdf.

42 Source: Interview with the representative of MLSW.

Report from monitoring 2013:*

Unfortunately, despite a noticeable improvement, we wish to note that some of the most important recommendations have not been met, including the recommendation to the Ministry of Labour and Social Welfare to address the issue of hospital stays of several years (even decades) of the so-called social patients, people whose health condition does not require further hospital treatment, but who continue their stay at the Hospital because they could not be provided with adequate social care otherwise, as well as the issue of the shortage of medical staff, which is the responsibility of the Ministry of Health. Recommendations on the need for adequate social care of patients were also set forth by the CPT and Protector of Human Rights and Freedoms of Montenegro. Although the funding for hiring five nurses has been approved, this is still not satisfactory. Also, the existing staff is not sufficiently stimulated to work with psychiatric patients (e.g. they are not entitled to an early retirement plan). Lack of staff also results in a failure to meet the CPT recommendation to increase the offer of therapeutic and rehabilitative activities to patients.

**Report of NGO monitoring team Human Rights Action (HRA), Centre for Anti-discrimination "EQUISTA", Centre for Civic Education (CCE) and Women's Safe House*

On the websites of relevant institutions (Ministry of Labour and Social Welfare, Department of Social and Child Protection, etc.) there is no data on the number of persons deprived of their legal capacity. In addition, an article that was published on the portal Dan Online states that information on the number of persons deprived of legal capacity in Montenegro was requested from the Secretariat of the Judicial Council, but it was not obtained, as there are no specific records of persons deprived of legal capacity. The lack of this data was also emphasized in a report of the Association of Youth with Disabilities of Montenegro[43]. Also, in the annual report of the Ministry of Labour and Social Welfare for 2015[44] there is no data on the number of persons deprived of their legal capacity, nor on the number of those over whom parental right has been extended and they were subsequently placed under guardianship.

The Special psychiatric hospital in Kotor

In addition to the persons with mental disabilities in social care institutions, where they are not provided with adequate treatment, a large number of people with disabilities are also placed in the Special Psychiatric Hospital in Kotor, although they do not have a condition which would require hospitalization. Patients from the chronic male department (46), the chronic women's department (45) and the department for extended therapy (52) - in total more than 140 people - "are the main category of patients to be included in the process of deinstitutionalization with reintegration in the social community."[45]

43 Human Rights of Persons with Disabilities, Report for Montenegro, 2010, Association of Youthwith Disabilities of Montenegro, http://umhcg.com/wp-content/uploads/2013/11/izvjestaj-eng.pdf (accessed on 30/12/2016).

44 Report on Work and Status in Administrative Areas under the Ministry of Labour and Social Welfare for 2015, March 2016, available at: http://www.mrs.gov.me/informacije/planrada/159582/Izvjestaj-o-radu-Ministarstva-rada-i-socijalnog-staranja-za-2015-godinu.html.

45 http://psihijatrijakotor.me/mn/index.php?option=com_content&view=article&id=4&Itemid=117 (accessed on 30/12/2016).

The deinstitutionalization of people from the Special Psychiatric Hospital in Kotor should not involve sending them to social care institutions or any other type of institutional settings. To be particularly forbidden is the opening of such institutional settings for this purpose.

Another problematic ward of the Special Psychiatric Hospital in Kotor is the forensic ward, which is not specifically designed for its purpose, i.e. is unable to provide an adequate level of security; while the hospital cannot meet the safety standards for the care of forensic patients, it also jeopardizes the safety and freedom of movement of other patients. The capacity of this department is of 20 beds. This number is far from sufficient comparing to the number of forensic patients reaching the hospital; therefore an additional 50 patients with the imposed measure of compulsory treatment are deployed in other wards of the hospital. There is also a waiting list of people with the imposed measure who, for objective reasons, cannot be referred to the hospital. There are therefore 70 forensic patients who are being held in an inappropriate environment. A solution for them must urgently be found. It is necessary to involve the Ministry of Justice without delay in solving this problem. The experience of other countries in the region should be taken into consideration.

In Montenegro there are already some community-based mental health centers. They are a good starting point for deinstitutionalization. In the same time however, further work is needed, to improve their expertise so they can offer adequate support to patients hospitalized and institutionalized for long periods of time. They should also get support from other services at local levels, which will meet other needs of these persons that go beyond health care delivery system – social, educational, cultural etc. This could be achieved through creating action plans at local level which should provide adaptation of planned measure to the local context and matching the real needs of local population.

Conclusions and recommendations

The information presented above indicates that deinstitutionalization processes are complex. They took place at different pace across Europe, but what remain certain is that continues work needs to be devoted to development of adequate community-based services. Our goal was to show that the process of deinstitutionalization is based not only on principles and binding human rights standards, but also on the experiences of other countries, which shows how important it is to develop good quality services, which ensure the good quality of life of people they are intended for.

The philosophy of the reform in psychiatry in all European countries is directly or indirectly based on several key principles of social psychiatry, following these trends:

- **closing of old asylum-type psychiatric hospitals and other institutional settings;**
- **development of alternative services and programs in the community;**
- **integration with the general health care services;**
- **integration with social and other services in the community.**

Mandatory elements of the process of deinstitutionalization are, on the one hand**, prevention** through the *development of appropriate services and the ban on new admissions* to institutions, and, on the other hand, the creation of conditions for the **discharge of people from institutions** while *ensuring alternative forms of housing with appropriate support* for those who do not have own income, housing or family environment to which they could return. In addition to the development of specialized services to respond to the specific circumstances and needs of each target group, it is essential that the existing services for the general population are made available to all citizens with disabilities, regardless of the level and type of their support needs. Considering the examples of good practice presented above, we developed the following proposal for priority steps to be taken in Montenegro in the process of deinstitutionalization (i.e. transition from institutional care to community care and support).

1. **Adopt a strategy and action plan for deinstitutionalization.** A strategic document must be approved by the highest executive body in order to ensure active participation of all departments in its development and implementation. The strategy, *inter alia*, must include the questions of prevention and discharge of people from institutions, financing, development of quality standards of new services, necessary amendments to legislation, strengthening of human resources, public awareness campaigns and fighting prejudice, the ban on new admissions and participation of service users. Follow the example of Italy and the UK, whose reforms were both based on a good strategic framework.

   A good action plan should have clearly defined steps and answers to most questions, with realistic, but not lengthy implementation deadlines. The plan must be revised on a regular basis.

   It is also possible to revise the Strategy for the Promotion of Mental Health in Montenegro in order to raise it to a higher level, in terms of transferring of responsibilities from the Ministry to an inter-ministerial body, and include activities to be undertaken by other departments.

2. **Delegate the management process or establish a new body to coordinate the process of deinstitutionalization.** The body for coordination must be above-ministerial given the complexity of the process and necessity to include different departments at different stages of the process. Coordination should take place on two levels - vertically (among administrative bodies at the national, regional and local level) and horizontally (among different departments i.e. ministries at the national level, and at the local level among their branches - sectors of local governments for education, social and health care, finance and justice and other authorities). Therein it is possible to use the example of France and Hungary.

3. **Develop a transformation plan for the Special Psychiatric Hospital in Kotor.** Priority issues concerning this hospital are:
   a. ***Finding a solution for people accommodated in chronic wards and extended treatment ward.*** Given that the problems faced by these persons are mainly social in nature, it is necessary to map their social needs and opportunities for community living. Due to the overlapping of departments in funding care for these people, we suggest using the model from Spain *(in terms of establishing a public (state) foundation funded equally by four state departments most relevant for providing support for the mentally ill (health, social welfare, employment and technological development and economy and finance, joined subsequently by the education sector),* as well as the experience from France *(where, at the very beginning, a medical-psychological centre and a centre for housing and deinstitutionalization were created, specializing in the rehabilitation of chronic, long-term institutionalized patients; thereafter, co-operation with local authorities and contacts with managers of social housing were initiated in order to establish common and "therapeutic" housing, and then in order to access the support and housing units distributed throughout the community).*
   b. ***Shutting down the forensic psychiatric unit*** and including the judiciary in the founding of a special facility for serving the measure of mandatory treatment, which may be part of the Administration for Execution of Criminal Sanctions. The Organization for Security and Co-operation in Europe (OSCE), has initiated series of discussions among professionals in this area in Serbia, which were implemented together with the Serbian Ombudsman. Since the Ombudsman of Montenegro has been warning the Government about this situation in Montenegro we suggest to the Ombudsman and the Government to request assistance from OSCE, both technical and financial, in the way it was provided to Serbia.
   c. ***Education of personnel*** who should provide support to people with mental health problems in the community. At the same time, staff at the Kotor Hospital are an important resource to support other health workers who do not have sufficient experience with people with severe mental illness.
   d. ***Acute wards are needed until psychiatric wards or units for hospital treatment of small capacity are formed*** in local general hospitals; experiences from Italy may be used to that end.

4. **Strengthen the capacity of local mental health care centres.** Teams at mental health care centres must be interdisciplinary and trained to provide support to people in crisis, including those with serious psychological disabilities. This is important both for the prevention of hospitalization as well as monitoring of patients in order to timely respond to the deterioration of their mental health condition and prevent re-hospitalization.

Services in the community-based mental health care centres should be extended from solely inpatient treatment to outpatient treatment (crisis situations team, monitoring of patients after discharge from hospital (see example of the United Kingdom). Community mental health care centres can be improved based on the experience of the Centre for Mental Health in the Community that functioned in "Medijana",Niš, presented in the section on Serbia, as well as the two newly opened center for mental health in the community in Kikinda and Vršac.

5. **Develop new, innovative services provided in the community for people with mental disabilities.** Private legal entities, civil society organizations and existing state services, such as social welfare centres, should also be allowed to provide these services. Of particular importance is the inclusion of user associations in the provision and planning of support. As regards the development of innovative services it is possible to utilize the presented examples from Bulgaria, Greece and Finland. Examples of such services are set forth in the description of all the models presented in this document.

6. **Make existing services for the general population available to persons with disabilities.** Ensuring inclusive public services (education, health care, vocational training and support in finding and maintaining employment, transportation, etc.) is a key component for achieving full social inclusion. The more inclusive these services are, the lesser the need for the development of specialized services provided to a person, while the whole society benefits from it. Critical reassessment of the existing spectrum of services creates an opportunity for these services to become more inclusive and to respond better to the needs of people with disabilities, but also all other persons in the general population.
   For example, the training of primary health care providers to provide this service to people with different types of disabilities (e.g. training of all general practitioners on how to communicate with a person with intellectual disability) reduces the need to create specialized services for persons with disabilities. Such practice is both cost effective and reduces the risk of segregation and provision of lower quality services in the context of specialized services. In the employment area, rather than developing special workshops for people with disabilities, it is possible to achieve inclusion in regular working environment with the support in the workplace and informal support of colleagues. Strengthening these types of support is useful for the recruitment and integration of other marginalized groups.

7. **Revise the model of funding of social services. One of the key principles of adequate support for people with disabilities is that the money follows the person. In this way, the means to provide support to a person outside the institution are provided. Also, a person is thus provided with a possibility to choose** the service/s they want to use. In the meantime, it is certainly vital to continue the basic funding of institutions, without major investments, to the extent to which such action is necessary until all users have transitioned to alternative forms of support.

8. **Revise regulations governing the issue of legal capacity so as to be in accordance with the Convention on the Rights of Persons with Disabilities. Persons with disabilities should be able to live independently in the community and to make choices and have control over their daily lives, on an equal footing with others, as required by Art. 19**[46]. Recognition of legal capacity is a fundamental prerequisite for full social inclusion in community life.

46 General Comment No. 1 to Art. 12 of the Convention on the Rights of Persons with Disabilities, § 40.

In order to conform with the Convention and respect the human rights of persons with disabilities, it is necessary to implement deinstitutionalization and restore the legal capacity of all persons with disabilities, who must be able to choose where and with whom they live (Art. 19). The choice of a person where and with whom they live should not affect his or her right to access to support for the realization of his or her legal capacity.[47]

The reform currently implemented in Bulgaria represents a good model applicable in Montenegro, too, following the establishment of services that can provide support in decision-making to people with mental disabilities.

9. **Work on dismantling prejudices through campaigns and public debate.** Individual incidents and "severe" cases should not be used as an excuse for inaction. It is particularly important to work on the attitude of health care personnel who should take care of these persons as much as possible in primary and secondary health care institutions. It is advisable to make use of many years of experience of colleagues from the Special Psychiatric Hospital in Kotor in working with people with severe mental disabilities by making them mentors or advisers to colleagues with less experience in dealing with such persons.

10. **Revise the Action plan for chapter 23.** This Action plan needs to contain measures directed to support deinstitutionalization of chronic patients from Special psychiatric hospital in Kotor and measures that are to ensure full social inclusion of this group of people. Measures should also address the stigma surrounding persons with psycho-social disabilities especially those living and returning from the Special psychiatric hospital to the community.

    The most effective way to fight prejudice is through personal experience acquired by involving people with mental disabilities in the community, while providing the necessary support. The experience of all countries shows that support provided in the natural environment allows timely response to potential worsening of the disease, reduces the need for medications, prevents involuntary hospitalization and contributes to the recovery. It is important to bear in mind that each person requires an individualized approach and that the support provided must be based on trust and respect for personal autonomy and dignity.

The right to live in the community is equally valid for all persons with disabilities. Regardless of the intensity of support required, everyone - without exception - has the right and deserves to be included and to be allowed to participate in the life of the community. It has been proven time and again that people who were considered to be "too distracted" to benefit from inclusion in the community thrive in the environment where they are valued, where they participate in everyday life of the immediate environment, where their autonomy is fostered and where they are given a choice. Programs being implemented around the world have shown that it is possible to respond to all the needs for support and that this is best done in a natural environment which allows for the expression of individuality and provides better protection against abuse.

47 Ibid, § 42.

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