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DIMITRI BARTENEV

Comparative Analysis of the Legal and Political Measures Ensuring Participation of the Mentally Disabled in Policy Making

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Research context

Russia is undergoing a significant reform of its healthcare system in consistency with building the rule of law and democracy. Mental health legislation provided for the background of this reform[1], but enforcement mechanisms are almost absent[2]. The provisions of the law on psychiatric care requiring mental health care facilities to establish services for protection of the rights of the mentally disabled have not been implemented in any hospital or other facility. Hence the Government itself admitted that enacting of these acts had not resulted in positive changes in the state policies affecting people with mental disabilities[3].

Although the situation in mental health care in Russia has changed considerably since the collapse of the Soviet Union[4] advocacy for the rights of the mentally disabled still remains quite a new issue and does not receive the required amount of attention either from health authorities or from the local NGOs.

People with mental disabilities still remain invisible and excluded from the society. Mental disability is still considered to be almost entirely medical problem and social, cultural and other interrelated implications are not taken seriously. The Russian psychiatric practice

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[1] Psychiatric care and rehabilitation in modern Russia is based on two major acts: "The law on psychiatric care and guarantees of the citizens' rights in its provision" and Federal program "Urgent measures of improving psychiatric care".

[2] "The lack of state legal aid systems, the problems of access-to-justice by those under guardianship housed in remote institutions, the few lawyers willing to represent people with mental disabilities, coupled with the unwillingness of domestic courts to hear ECHR points and the grinding slowness of the Strasbourg Court all combine to produce a pessimistic situation in which the realization of human rights seems a long way off." Oliver Lewis, "Mental disability law in central and eastern Europe: paper, practice, promise", (2002) 8 *Journal of Mental Health Law*, 293-303/

[3] The report on the rights of the mentally disabled prepared in 1999 by the Russian ombudsman. Available at www.ombudsman.gov.ru.

[4] It should be admitted that during the last years the conditions of Russian psychiatric inpatient hospitals have been improved and in many of them patients no longer suffer from malnutrition, they are provided with the essential medicines and treatment.

places no emphasis on community-based care initiatives[5]. Consequently there are no alternatives to the existing system of psychiatric hospitalization. The experience of other countries has proven that there are strong medical and economic incentives encouraging the movement of persons with mental disabilities out of large residential facilities into smaller home-like settings.[6]

At the same time there are virtually no mental disability advocacy NGOs in Russia[7], nor there is significant public discussion about relevant governmental policies or strategies for deinstitutionalization of mental health care and strengthening equal participation of people with mental disabilities in society[8].

There is an increasing number of non-governmental organizations in other post-communist countries in Europe providing services to the mentally disabled based on the principle of inclusion and offering alternatives to institutionalized care. Their experience does not receive sufficient attention in Russia and the policies behind this movement have not been studied yet.

It is indicative that a detailed report of the Russian Ombudsman on the rights of the mentally disabled does not address the issues of deinstitutionalization, mental disability advocacy and the most important demand of the advocacy group: transition from segregative care to community-based services. These issues are not addressed by Russian NGOs either. Understanding policies fostering participation of the mentally disabled and their integration into society is an important first step in designing the system of health and social care based on universal human rights values.

Thus, the overall **goal** of the present study is to identify and comparatively review the best practices ensuring participation of the mentally disabled and mental disability NGOs in policymaking in Western countries (the UK, the USA) and selected CEE countries in transition and analyze their applicability to the situation in modern Russia.

Research objectives

1. Review and analyze comparatively provisions of foreign laws designed to strengthen the individual's position in mental health care (analyze existing ways of setting up and developing structures for citizens' and patients' participation in mental health care decision-making process and policy).
2. Review and analyze mental health care reforms aimed at bringing national legislation in conformity with international human rights standards in terms of building the culture of respect for participation and inclusion of the mentally disabled.
3. Identify possible benefits and applicability of the gained results to reforming Russian legislation in the field of mental health within the framework of providing mental health treatment in the most integrated setting appropriate.
4. [Review legislation and policies explicitly prohibiting discrimination against people with mental disabilities in education, housing, employment.]

Introduction

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[5] According to Russian Academy of Medical Sciences it sees "no ways of adopting the ideas of integration and deinstitutionalization under current circumstances in Russia".

[6] See: Davis, DeWayne, Fox-Grage, Wendy, and Gehshan, Shelly, *Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators, National Conference of State Legislatures*, Washington, D.C. Institute on Community Integration, "*Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted between 1980 and 1999*," Policy Research Brief, v10 n1, University of Minnesota, Minneapolis, Oct, 1999.
Bogdan R., Taylor S.J. *Building stronger communities for all: Thoughts about community participation for people with developmental disabilities*. Prepared for the President's Committee on Mental Retardation's Forgotten Generations Conference, February 21-22, 1999. World Bank (2000), Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union.

[7] Gushanskii E. Is there a need for human rights advocates in psychiatry? (in Russian).

[8] The report on the rights of the mentally disabled prepared in 1999 by the Russian ombudsman.

Key points: Historical perspective

- Deinstitutionalization has not necessarily been followed by an adequate provision of alternative community-based resources in developed countries.
- As a rule in developing countries mental health services are scarce, they cover a small proportion of the population and they face acute shortages of financial and human resources.
- A key task for developing countries is to extend the coverage of mental health services so as to reach a substantial proportion of their populations by integrating such services with general primary and secondary care.
- Highly effective psychotropic medications and psychosocial interventions are now available for a range of mental disorders.
- Research has demonstrated the effectiveness of psychological and psychosocial interventions in many mental disorders.

Since the early 1960s there has been a clear international trend to change policies concerning the care, treatment and accommodation of the mentally ill and the intellectually disabled. Those individuals who until this time had been accommodated within an institutional setting were transferred from hospital environments and returned to the family unit, or placed in residential group homes scattered throughout the general community. The process of returning the mentally disabled to the community, commonly referred to as "deinstitutionalization", is purported by most mental health professionals to be a more satisfactory means of treatment for the mentally ill and the developmentally disabled. [AD]

Deinstitutionalization of the mentally disabled has been a trend in western countries for almost three decades now. Bachrach (1976) wrote that the direction in mental health care in the United States has been undeniably in the pursuit of a community mental health care strategy - the provision of services to patients in their home communities. This has led to the devolution of a number of psychiatric hospitals in that country, with over two-thirds of the inmate population being returned to live within the general community environment. The advent of anti-psychotic drugs, together with the criticisms directed at the effectiveness and cost of traditional institutional care, have helped to promote the success of deinstitutionalization programs in many Western countries. However, these same programs have also been the subject of some well-founded criticism in relation to issues such as high recidivism rates, a totally inadequate delivery of programs, supervision and support services to the consumer, and a struggling cost-effectiveness strategy. [ET]

Description and analysis of mental health services around the world [WHO 3]

1. Mental health services integrated into the general health system can be as broadly grouped as those in primary care and those in general hospitals.

Mental health services in primary care include treatment services and preventive and promotional activities delivered by primary care professionals. Among them, for example, are services provided by general practitioners, nurses and other health staff based in primary care clinics. The provision of mental health care through primary care requires significant investment in training primary care professionals to detect and treat mental disorders. Such training should address the specific needs of different groups of primary care professionals such as doctors, nurses and community health workers. Furthermore, primary care staff should have the time to conduct mental health interventions. It may be necessary to increase the number of general health care staff if an additional mental health care component is to be provided through primary care. For most common and acute mental disorders these services may have clinical outcomes that are as good as or better than those of more specialized mental health services. However, clinical outcomes are highly dependent on the quality of the services provided, which in turn depends on the knowledge of primary care staff and their skills in diagnosing and treating common mental disorders, as well as on the availability of drugs and other options for psychosocial treatment. Primary care services are easily accessible and are generally better accepted than other forms of service delivery by persons with mental health disorders. This is mainly attributable to the reduced stigma associated with seeking help from such services. Both providers and users generally find these services inexpensive in comparison with other mental health services.

Mental health services in general hospitals include certain services offered in district general hospitals and academic or central hospitals that form part of the general health system. Such services include psychiatric inpatient

wards, psychiatric beds in general wards and emergency departments, and outpatient clinics. There may also be some specialist services, e.g. for children, adolescents and the elderly. These services are provided by specialist mental health professionals such as psychiatrists, psychiatric nurses, psychiatric social workers, psychologists, and physicians who have received special training in psychiatry. Clearly, such services require adequate numbers of trained specialist staff and adequate training facilities for them.

The clinical outcomes associated with these services are variable and depend on their quality and quantity. In many countries, the mental health services of general hospitals can manage acute behavioral emergencies and episodic disorders which require only outpatient treatment. However, their ability to help people with severe mental disorders depends on the availability of comprehensive primary care services or community mental health services and on the continuity of care that these provide. Mental health services based in general hospitals are usually well accepted. Because general hospitals are usually located in large urban centers, however, there may be problems of accessibility in countries lacking good transport systems. For service providers, mental health services in general hospitals are likely to be more expensive than services provided in primary care but less expensive than those provided in specialized institutions. Service users also have to incur additional travel and time costs that can create additional access barriers in some countries.

2. Community mental health services can be categorized as formal and informal.

Formal community mental health services include community-based rehabilitation services, hospital diversion programs, mobile crisis teams, therapeutic and residential supervised services, home help and support services, and community-based services for special populations such as trauma victims, children, adolescents and the elderly. Community mental health services are not based in hospital settings but need close working links with general hospitals and mental hospitals. They work best if closely linked with primary care services and informal care providers working in the community.

These services require some staff with a high level of skills and training, although many functions can be delivered by general health workers with some training in mental health. In many developing countries, highly skilled personnel of this kind are not readily available and this restricts the availability of such services to a small minority of people.

Well-resourced and well-funded community mental health services provide an opportunity for many persons with severe mental disorders to continue living in the community and thus promote community integration. High levels of satisfaction with community mental health services are associated with their accessibility, a reduced level of stigma associated with help-seeking for mental disorders and a reduced likelihood of violations of human rights. Community mental health services of good quality, providing a wide range of services to meet diverse clinical needs, are demanding in terms of cost and personnel.

Reductions in costs relative to those of mental hospitals are likely to take many years to materialize.

Informal community mental health services may be provided by local community members other than general health professionals or dedicated mental health professionals and paraprofessionals. Informal providers are unlikely to form the core of mental health service provision and countries would be ill-advised to depend solely on their services, which, however, are a useful complement to formal mental health services and can be important in improving the outcomes of persons with mental disorders. Such service providers usually have high acceptability and there are few access barriers as the providers are nearly always based in the communities they serve. Although the services are classed as informal, not all of them are totally free. In many countries, for instance, traditional healers charge for their services and could therefore be considered as providing private formal health care services. Moreover, there are concerns about violations of human rights in relation to the treatment methods employed by some traditional healers and faith healers.

3. Institutional mental health services include specialist institutional services and mental hospitals. A key feature of these services is the independent stand-alone service style, although they may have some links with the rest of the health care system.

Specialist institutional mental health services are provided by certain outpatient clinics and by certain public or private hospital-based facilities that offer various services in inpatient wards. Among the services are those provided by acute and high security units, units for children and elderly people, and forensic psychiatry units. These services are not merely those of modernized mental hospitals: they meet very specific needs that require institutional settings and a large complement of specialist staff who have been properly trained. The scarcity of such staff presents a serious problem in developing countries. Specialist services are usually tertiary referral centers and patients who are difficult to treat make up a large proportion of their case-loads. If well funded and well resourced they provide care of high quality and produce outcomes that are good enough to justify their continuation. Nearly all specialist services have problems of access, both in developing countries and in the developed world. These problems may be associated with a lack of availability, with location in urban centers that have inadequate transport links, and with stigma attached to seeking help from such services. Specialist services are costly to set up and maintain, mainly because of the high level of investment in infrastructure and staff. In many developing countries the cost of specialist units is not necessarily high because staff costs are lower than in developed countries and, in many cases, investments are at a low level and units function in substandard conditions.

Dedicated mental hospitals mainly provide long-stay custodial services. In many parts of the world they are either the only mental health services or remain a substantial component of such services. In many countries they consume most of the available human and financial resources for mental health. This is a serious barrier to the development of alternative community-based mental health services. Mental hospitals are frequently associated with poor outcomes attributable to a combination of factors such as poor clinical care, violations of human rights, the nature of institutionalized care and a lack of rehabilitative activities. They therefore represent the least desirable use of scarce financial resources available for mental health services. This is particularly true in those developing countries where mental hospitals provide the only mental health services. Stigma associated with mental hospitals also reduces their acceptability and accessibility.

Current status of service organization around the world

Very few countries have an optimal mix of services. Some developing countries made mental health services more widely available by integrating them into primary care services. Other countries have also made mental health services available at general hospitals. In some countries there are good examples of intersectoral collaboration between nongovernmental organizations, academic institutions, public sector health services, informal mental health services and users, leading to the development of community-based services. Even within countries there are usually significant disparities between different regions, and both types of service are only available to small proportions of populations, usually in urban areas or selected rural areas.

In developed countries the process of deinstitutionalization during the last three decades has led to reductions in the populations of mental hospitals and to the closure of many of these institutions. However, this has not been accompanied by sufficient provision of community-based services, which are often inadequate and unevenly distributed.

There is insufficient emphasis on developing mental health services in primary care. For example, although depression is a common problem in primary care settings, it is still not identified or is undertreated by primary care practitioners in many developed countries.

Conclusions:

a. mental health services pose challenges in both developing countries and developed countries. However, the nature of the challenges differs. In many developing countries there is gross underprovision of resources, personnel and services, and these matters need immediate attention. In developed countries some of the problems relate to insufficient community reprovision, the need to promote the detection and treatment of mental disorders in primary care settings, and the competing demands of general psychiatric services and specialist services.
b. more expensive specialist services are not the answer to these problems. Even within the resource constraints of health services in most countries, significant improvements in delivery are possible by redirecting resources towards services that are less expensive, have reasonably good outcomes and benefit increased proportions of populations.

Major arguments pro and against deinstitutionalization

Against deinstitutionalization [AD]

Misguided Ideology

Many policymakers believe that the deinstitutionalization process is more than a social policy - it is a 30 year old social movement that appeals to the idealism and ambition of many groups, including public servants, economists, sociologists, lawyers, mental health professionals, patients and their families. But as might be expected of a movement implemented with little forethought, inadequate planning, and no advance scientific study, it has failed to live up to its promise.

Inadequate Treatment Programs

As a result of poor implementation strategies, some serious problems have developed in the care and treatment of the mentally disabled. Opponents of the deinstitutionalization process believe that the community care model has not lessened the incidence of mental illness or the number of mentally ill. Gralnick (1985):

> *'Deinstitutionalization has not reduced the mistreatment and suffering of the mentally ill. Instead of reducing chronic illness, deinstitutionalization all too often has resulted in too-short, ineffective care that leads to repeated episodes of illness and chronicity'.*

Anti-psychotic drug therapy within a community setting does not appear to be as effective as the treatment provided within an institutional environment. Research suggests that following discharge, fewer than 50% of psychiatric patients continue to take their medication, and only 25% will actually participate in some type of aftercare program.

Increases in the Homeless Population

There are increasing numbers of the mentally ill in nursing homes, seedy boarding lodges, hostels, and half-way houses. A great many of the mentally ill live on the street, relying on soup kitchens for food and emergency shelters for lodging (Gralnick, 1985). A study of homeless men in New York reports that there has been a large increase in the number of mentally ill who frequent accommodation facilities for homeless men - the majority of whom are no longer the older alcoholic and black, but instead 'the younger, mentally ill and white'. As a result of these and many other studies, it is suggested that in Australia, as in the United States, deinstitutionalization has produced a **real increase** in the number of destitute, homeless mentally ill persons.

> *'Nothing more graphically illustrates the problems of deinstitutionalization than the shameful and incredible phenomenon of the homeless mentally ill. The conditions under which they live are symptomatic of the lack of a comprehensive system of care for the long-term mentally ill in general'. [BT]*

Increased Crime Rates

Until recently, the mentally ill were considered by mental health professionals to have crime rates no greater than that of the general population. Because there was no research data available to either disclaim or support this hypothesis, the notion was given credence as a consequence. However, a study of New York in 1981, indicated that the deinstitutionalized mentally ill had a crime rate which was 13% greater than that of the general community. When one considers the number of other dispositions which police have the discretionary power to use, and do use to a greater extent (i.e. returning the individual to their family unit rather than putting them through the judicial system etc), the police workload associated with the mentally ill begins to look quite daunting. [AD]

Distribution of Mental Health Funding

For example although in Australia hospital in-patient numbers have been reduced by over 80% since 1963 to resume community living, there remains a constant inference that hospitals have continued to receive a far larger proportion of the mental health budget. This situation has serious ramifications in relation to the distribution of funding and other essential resources into the community to service the mentally disabled consumer. [FR]

Pro deinstitutionalization

For every study that presents the negative implications of deinstitutionalization programs, there is another that espouses support for its many positive features. There is a continual flow of evidence from controlled studies which have consistently shown that the majority of psychiatric patients can be treated more effectively in the community. This is provided of course, that both patients and their families (or carers) are supported with comprehensive and continuous care at the community level.

Community Based Care

The rationale for treating all but the most severely mentally disabled people in a community setting, has as its main premise the proposal that the mentally disabled are optimally treated in an environment that permits contact with the rest of society, and readily available access to mainstream social institutions to achieve a continuity of treatment. Community living demands

independent functioning, is relatively non-coercive, and encourages contact with family, friends and significant others.

WHO's main concerns are summarized as follows: [CP]

- **Human Resources:** they consume most of the available human and financial resources for mental health. There are high rates of staff burnout and demotivation and there is a gradual decline in skills of mental health professionals.
- **Clinical outcomes**: many provide only custodial care of the kind found in prisons, frequently of extremely poor quality. They are frequently associated with poor outcomes attributable to a combination of factors such as poor clinical care, violations of human rights, the nature of institutional care and a lack of rehabilitative activities. The stigma associated with mental hospitals reduces their acceptability and accessibility
- **Acceptability**: *'Significant stigma is associated with segregated mental hospitals, and people are usually reluctant to use these services except as a last resort. This results in delays in seeking treatment from such services which in turn adversely affects clinical outcomes.'*
- **Human rights abuses:** they have a history of serious human rights violations. In both developed and developing countries serious human rights concerns surround the remaining long-stay mental hospitals, despite the improvements made.
- **Access:** they are usually based at some distance from urban areas and have poor transport links. It is often very difficult for residents to maintain contact with their families and the outside world.
- **Financial costs:** *'Mental hospitals are expensive and, in many developing countries, consume a significant portion of the budget meant for mental health services, leaving few resources for community-based initiatives…Many of the hospitals tend to be of a fixed nature with static long-stay populations of patients.' (See organising services 2.3.2 pages 20-21)*

Comparative legal analysis: general remarks

I. International legal background of the rights of the mentally disabled [SP+DB]

!To be added: CP

International instruments which contain general fundamental rights to be enjoyed by all citizens, without exception: UDHR, ICCPR, ICESCR. A number of the instruments adopted by the United Nations Organization are specialized in meaning and are concerned, inter alia, with persons suffering from mental conditions. Those are the 1984 Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment and Punishment, the 1989 Convention On the Rights of the Child, the 1971 Declaration Of the Rights of Mentally Retarded Individuals, the 1975 Declaration Of the Rights of Disabled Persons and the December 17, 1991 Principles of Protection of Persons Suffering From Mental Diseases and Improvement of Health Care In the Field of Psychiatry.

At present, the UN Principles contain a most comprehensive list of requirements regarding the assurance of rights of persons suffering from mental conditions. The document became an outcome of the work started in 1978 by the UN Commission on Human Rights and the Sub-Commission on Prevention of Discrimination and Protection of Minorities. It resulted in the formulation of twenty-five principles concerning individuals with abnormal mental conditions, representing a most vulnerable group of population from the viewpoint of provision of human rights.

It is the comprehensive nature of their content that makes the UN Principles an exceptionally important document, notwithstanding its recommendatory character. In the absence of a special convention or other international treaty on the rights of persons with mental conditions, the UN Principles may provide guidelines in the interpretation of general legal norms applicable to the said group of persons as concerns both the content of domestic laws on mental health (or on psychiatric care) and also their practical application.

The UN Principles are applicable irrespective of whether persons are or are not commissioned to psychiatric institutions, have already been diagnosed or their diagnosis is in the stage of determination (Principle 4 contains the requirements in respect of the latter case). All those persons shall be protected against discrimination, which implies "any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights" (Part 4 of Principle 1). Special measures designed exclusively to protect or promote the rights of persons with mental conditions as well as "any distinction, exclusion or preference undertaken in accordance with the provisions of these Principles and necessary to protect the human rights of a person with a mental disease or other individuals" shall not be treated as discrimination.

The UN Principles contain an extensive list of rights that must be guaranteed to persons with mental conditions. All the rights may, for the sake of convenience, be divided into three groups. The first group includes the so-called civil or constitutional rights that are exercised by all the citizens of a respective state, regardless of the state of their mental health. The second group of rights is set aside specially for the above-mentioned category of citizens, considering that individuals with mental conditions, precisely by reason of such conditions, are not infrequently suffering from maltreatment and derogation from their rights both in social life and in psychiatric therapy. Finally, the third group is made up of rights vested in patients of psychiatric institutions. It seems to be essential to set aside that group of rights as those institutions are most often closed-type establishments with a restrictive regime and, therefore, they call for special attention as far as protection of human rights is concerned.

The suggested classification of the rights of persons suffering from mental conditions is also reflected in the UN Principles. Thus, Part 5 of Principle One stipulates that every person suffering from a mental condition "shall have the right to exercise all civil, political, economic, social and cultural rights as recognized in the Universal Declaration of Human Rights" and in the international covenants on human rights and other relevant documents such, for instance, as the Principles of Medical Ethics devoted to the role of medical personnel, especially doctors, in the protection of prisoners or detainees against torture and other cruel, inhuman or degrading treatment or punishment which Principles were adopted by the UN General Assembly in March 9, 1983. They set forth in detail the rights that shall be vested in persons suffering from mental conditions as a vulnerable category of citizens. Among those rights are the rights to the best available psychiatric care as part of the system of medical and social assistance (Part 1 of Principle 1), to humane and respectful treatment (Part 2 of Principle 1), to the protection against economic, sexual and other forms of exploitation, physical and other abuses (Part 3 of Principle 1). That group also includes the right to live and work, as far as possible, in the community (Principle 3), the right to the aid of a lawyer and personal representative (Principle 18), the right to file complaints in accordance with the procedure established under the domestic legislation (Principle 21) and some others.

And, finally, the UN Principles formulate standards that must be complied with at all times when persons suffering from mental conditions come into contact with medical officers. The determination of mental abnormality shall be carried out in compliance with the commonly recognized international medical standards and the diagnosis may not be based on any circumstances other than the state of mental health of an individual at the time of making such a diagnosis (Principle 4). The medical examination shall not be conducted in contravention of the procedure prescribed under the domestic legislation (Principle 5). The patients who have been found to be suffering from mental abnormalities shall have the right to receive medical and social assistance as far as possible at the place of their residence (Principle 7) and according to the same standards as are applicable to other patients (Principle 8), in the least restraining conditions and by employing the least restraining types of medical treatment (Principle 9).

Principle 11 regulates in detail a consent to medical treatment, including instances of psychiatric care being provided involuntarily while Principle 13 specifies the requirements concerning provision of rights of patients and conditions of their residence at psychiatric institutions.

In connection with adoption of the UN Principles, the World Health Organization (WHO) has prepared several instruments that would facilitate the understanding and implementation of the provisions of the Principles. First, those are the Instruction "On Assisting the Realization of Human Rights by Persons Suffering From Mental Conditions" and Federal Law "On Psychiatric Care: Ten Basic Principles." The Instructions were drafted with a view of making a substantive assessment of the terms of each of the principles formulated by the United Nations and, therefore, it refers to the issue of "basic guarantees of quality, setting thereby a basic standard with the help of which politicians and officers involved in psychiatry may assess programs of mental health at the local, regional and national level." The aim of the second document was to describe the basic legal principles "in the field of mental health with the minimal possible inclusion of factors of individual culture or legal traditions." Thus, those WHO instruments may be used as reference material in assessing a degree of protection of the rights of persons suffering from mental conditions and also a condition of the psychiatric service in a specific country.

Furthermore, in 2001 the World Health Organization released a special document regarding the role of international instruments in the sphere of human rights, specifically dealing with the protection of rights of persons suffering from mental conditions, which may be a valuable source of information for the domestic legislation.

The World Programme of Action concerning Disabled Persons was adopted by the United Nations General Assembly at its 37th regular session on 3 December 1982, by its resolution 37/52. 1/

Participation of disabled persons in decision-making

Member States should increase their assistance to organizations of disabled persons and help them organize and coordinate the representation of the interests and concerns of disabled persons.

Member States should actively seek out and encourage in every possible way the development of organizations composed of or representing disabled persons. Such organizations, in whose membership and governing bodies disabled persons, or in some cases relatives, have a decisive influence, exist in many countries. Many of them have not the means to assert themselves and fight for their rights.

Member States should establish direct contacts with such organizations and provide channels for them to influence government policies and decisions in all areas that concern them Member States should give the necessary financial support to organizations of disabled persons for this purpose.

Organizations and other bodies at all levels should ensure that disabled persons can participate in their activities to the fullest extent possible.

Apart from the international community as a whole, the protection of rights and liberties of the human being, including of individuals with mental abnormalities, is carried out within the framework of regional international organizations. The Council of Europe adopted, within its

confines, two separate documents, similar to the UN International Human Rights Covenants. The November 4, 1950 Convention on the Protection of Human Rights and Fundamental Freedoms is devoted to civil and political rights, while the October 18, 1961 European Social Charter regulates economic and social rights.

According to the principles and aims of Recommendation No. R (92) 6 of the Committee of Ministers on a coherent policy for people with disabilities, a "*coherent and global policy in favor of people with disabilities, or those who are in danger of acquiring them, should aim at*

- *preventing or eliminating disablement, preventing its deterioration and alleviating its consequences;*
- *guaranteeing full and active participation in community life;*
- *helping them to lead independent lives, according to their own wishes.*

It is an ongoing and dynamic process of mutual adaptation, involving on the one hand people with disabilities living according to their own wishes, choices and abilities, which must be developed as far as possible, and on the other hand, society which must demonstrate its support by taking specific and appropriate steps to ensure equality of opportunity.

All people who are disabled, or are in danger of becoming so, regardless of their age and race, and of the nature, origin, degree or severity of their disablement, should have a right to individual assistance, to enable them to lead a life as far as possible commensurate with their ability and potential".

Article 15 of the Council of Europe's Revised European Social Charter establishes the right of persons with disabilities to independence, social integration and participation in the life of the community:

"With a view to ensuring that persons with disabilities, irrespective of age and the nature and origin of their disabilities, can effectively exercise the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular:

1. *to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible, through specialized bodies, public or private;*
2. *to promote their access to employment by all measures which encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialized placement and support services;*
3. *to promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure."*

- *Council of Europe Recommendation of the Committee of Ministers to member states concerning the protection of the human rights and dignity of persons with mental disorder. Rec(2004)10 of 22 September 2004.*
  Article 9:
  EM par. 63-68

II. National laws and policies [IE, DB, AI]

According to [*among others: Inclusion Europe*] the legislative framework concerning community-based support services in the CEE countries is usually very general and not directed specifically to the persons with intellectual disability. Even if the law or national policy plan declare de-institutionalization, in reality the process of transformation from the big closed state

institutions into alternative community-based small living facilities is very slow, if not non-existent. The main role in establishing such facilities, especially group homes and daily activity centers, is played by disability NGOs (Lithuania, Poland, Slovenia). This is a very expensive task to carry out and the financial assistance of the state is rather limited and unstable. Therefore, the majority of intellectually disabled people still live with their families or in institutions.

The best situation is in Slovenia, where the Government since 1999 has started to encourage new forms of community-based support services for intellectually disabled people to be developed by different contractors as part of a framework of public services. But even there the number of services is too small in comparison to the needs of people. The biggest deficiencies are for persons with profound intellectual disability and elderly persons with intellectual disability. In Slovakia where the program of developing small assisted living facilities had already been started, many established facilities have been transformed into homes of social services because of financial reasons. The other countries face the same problems, but to a larger extent. For example, in Romania there is only one day-centre for adults with intellectual disability; in Macedonia there are no residential facilities for intellectually disabled people with less than a hundred inhabitants; in Lithuania only 12 of 1000 disabled people (of different disabilities) residing at home receive any community-based support services.

The financial support received by families with an intellectually disabled member is too low to cover the supplementary costs of the disability in every country studied. Paradoxically, this support is sometimes based on the age of the disabled person, as for example in the Czech Republic, where some benefits are paid till this person is 26 years old. In the majority of countries there is no personal assistance for an intellectually disabled person assured by the social services (even if in Romania the law gives the disabled people the right to get such help). For example the Belarusian social services system, which is responsible among others for covering assistance for home visits of physicians of retired persons, refuses to provide social services to intellectually disabled persons. Therefore, the practice is that one parent resigns from his/her work and stays at home to support the disabled child, even if the pension offered to him/her is minimal.

It is necessary for the governments to prepare, realize and finance a long-term program to ensure the complex support for persons with intellectual disability and their families, which would allow them to live in the open society. Everywhere there should be introduced a legal act on personal assistance to all intellectually disabled persons, adequately financed by the state and ensuring an active participation of the disabled person in the social life of their age group. Protected housing and other forms of community-based services should be one of the main tasks of the local public administration. On the other hand, NGOs must get adequate and stable financing for the services they manage in order to create an open market of such services with the right of concurrence, high quality standards and their control. The state social administration should at the very least change the attitude towards the disabled persons and their families who should become real clients of their services, choosing them according to their needs and wishes.

Nowadays there are many organizations in post-soviet countries working in the mental disability field, also in the intellectual disability field, and most of them provide social services. However, the third sector is still not strong enough. There are three main problems: co-operation between NGOs, partnership with authorities and financial support.

The huge number of disability NGOs means that they are often forced to compete for limited financial resources, trying to protect the specific interests of the disabled group who they represent. This is often the case for small local organizations that are dependent on local authorities. But it is also the case for big organizations that apply to the same sponsors for grants (ministries, international institutions or international grant foundations). Therefore the co-operation between the disability NGOs is not always perfect. However this situation varies from country to country, or even from region to region in the same state.

Such an attitude is justified by need to have one strong representation of the disability field to be recognized by the state authorities on local, national and international level, as up till

now the cooperation with government has been rather poor. The legislation in the majority of studied countries puts the obligation on the government to consult the civil society and its representatives before adopting new laws concerning a specific group of citizens. However, these consultations are usually sporadic, and even if they take place they are only formal – the NGOs have no legal instruments to make their recommendations the government accept their recommendations. The lobbing force of intellectual disability organizations is still too weak.

Continuously changing governments often provoke the NGOs to lobby the same problem over the course of many years, repeating the same actions and the same arguments over and over to different politicians. This is the case because the financial position of the NGOs is not assured and even the limited resources are not stable. The state does not have a legal obligation to finance the organizations of public utility in every country (for example Belarus, Czech Republic, Lithuania; otherwise such a law was recently passed in Poland). Even there where such provisions exist the support is too small to the needs (Romania). Usually, the NGOs have to apply annually to the State and other sponsors for financial support by defining new grant projects, the evaluation of which by the sponsor usually takes some months. The problem with grant financing is also that grants are given with a concrete aim, for example for a particular event or service. Therefore, even the big NGOs with great annual budgets which provide many services have problems to paying management costs, staff salaries, offices costs and member's fees in international organizations, etc.

Legal and political measures promoting inclusion of the disabled in general
Legal and political measures promoting inclusion of the mentally disabled

Country studies

Western European states – the Netherlands, the United Kingdom (DDA 1995, Towards Inclusion 2001, Equality and Diversity 2002, Italy, possibly Sweden and Finland
Central and Eastern European states – Lithuania, Latvia, Poland and Estonia

Situation in the Russian Federation

Legal and political measures promoting inclusion of the disabled in general

The participation of people with mental disabilities is an important principle of the social strategy, meaning that those affected by a decision, or those who use services, may influence the decision-making procedures and the organization of services. In addition to being a democratic right, the participation of people with disabilities is a transfer of experience-based knowledge from a person having a disability to a decision maker or a service provider[9]. It is therefore a substantial contribution to the quality control of services.

The participation of people with disabilities may be practiced at several levels:

- At the individual level, where a person exercises his/her influence on services in co-operation with the service-provider;
- At the service level, where representatives from the organizations exercise their influence on the building up and the organization of services;
- At the political level, where representatives from the organizations exercise their influence on the policy-making and the use of economic resources.

The role of the organizations of people with disabilities is important and the organizations should receive state support for their activities.

[9] RP

Integration Policy: Education and Professional Training

Certain jurisdictions have adopted positive steps to integrate persons with disabilities into the community.

In the United States, the Americans with Disabilities Act (ADA) (1990) provides that public opportunity providers may not discriminate against otherwise qualified individuals with disabilities. An employer violates the ADA if the employer can show that the accommodation would impose an undue hardship on the operation of the employer's business. Further, the ADA prohibits an employer from denying an employment opportunity to a job applicant or employee who is an otherwise qualified individual with a disability, if the denial is based on the employer's need to reasonably accommodate an employee or applicant's physical or mental impairment. The term reasonable accommodation is defined in the ADA to include: making existing facilities accessible; job restructuring; part-time or modified work schedules; reassignment to a vacant position; modification of equipment or devices; adjustments or modifications of examinations, training materials or policies; and provision of readers, interpreters and attendants. The ADA sets forth a three-pronged definition of disability: a) a physical or mental impairment that substantially limits one or major life activities of such individual; b) a record of such an impairment; or c) being regarded as having such an impairment. Evaluating the issue of equal protection, the United States Supreme Court has established major standards.

In the United Kingdom's the 1944 Disabled Persons Act (Employment) originated from the need to make provisions for people disabled in the Second World War. The objective of the Act was to improve the employment prospects of people with disabilities. The Act defined a disabled person as someone who "…on account of injury, disease or congenital deformity, is substantially handicapped in obtaining or keeping employment, or in undertaking work on his own account, of a kind which apart from that injury, disease or deformity would be suited to his age, experience and qualifications." The act provided for the registration of disabled people; the establishment of employment quotas; the designation of certain occupations as reserved for persons with disabilities; sheltered employment; vocational training and rehabilitation; and the establishment of a national body to advise on the employment situation of persons with disabilities.

The U.K. 1995 Disability Discrimination Act introduced a new definition of disability and repealed the quota, registration, and designated employment provisions of the Disabled Persons Act (Employment). For a number of years it had been recognized that these provisions were not working as originally intended. For example, the requirement for employers with twenty or more employees to meet a 3% quota of registered disabled persons proved difficult for employers to fulfill since only a third of those in the workforce eligible to register did so. The quota only took account of recruitment but did nothing to promote effective employment policies by considering issues such as training and promotion.

In the United States, the ADA prohibits an employer from denying an employment opportunity to a job applicant or employee who is an otherwise qualified individual with a disability, if the denial is based on the employer's need to reasonably accommodate an employee or applicant's physical or mental impairment. The term reasonable accommodation is defined in the ADA to include: Making existing facilities accessible; job restructuring; part-time or modified work schedules; reassignment to a vacant position; modification of equipment or devices; adjustments or modifications of examinations, training materials or policies; and provision of readers, interpreters and attendants. Thus an employer may be required to modify a particular job so that a person with a disability can perform the position's essential functions. This can be accomplished by eliminating the job's nonessential elements, redelegating

assignments, exchanging assignments with another employee, or redesigning procedures for task accomplishments.

In India, the Persons with Disabilities Bill ensures free and compulsory education to children with disabilities through different forms of education, such as special, integrated and non-formal education. It also provides financial assistance in the form of distribution of equipment free of charge or at a subsidized cost, promotes research to develop enabling technology and teaching methods for the education of persons with disabilities, and adapts and modifies education syllabi to enhance disabled persons' access to education. The Bill also implemented a scheme of positive discrimination in favor of persons with disabilities through a quota system reserving a certain percentage of places for persons with disabilities in the training and employment programs of public and private sector entities. It also provided incentives to establishments promoting the employment of disabled persons and preferential treatment through tax concessions, subsidies and grants.

Preliminary results of the research

Major obstacles to deinstitutionalization and community-based mental health care [DT+DB] – to be developed in illustrated by the data from country studies and interviews

- *Organizational pressure to maintain residential institutions*
- *Absence of social welfare infrastructure*
- *Absence of a legislative framework*
- *Financial incentives to place individuals in residential institutions*
- *Public opinion*
- *Centralized fragmented bureaucracies*
- *The placement process*

- Russia is one of those countries which do not have a mental health program.
- Lack of awareness among policymakers.
- It is mainly at the initiative of NGOs that alternative living facilities are set up. The legislative framework and the governmental policy in this area are rather declarative. Hence, the majority of people with intellectual disability continue to live in institutions or with their families. The integration of children with intellectual disability in mainstream schools is still limited, most visit therefore special schools. Many children with profound and multiple disability do not attend school at all. Also employment of persons with intellectual disability is problematic. In general, the legislation does not support inclusive employment for people with intellectual disability.
- Disability allowances remain extremely low, which constitutes an obstacle to the provision of community-based living facilities.
- Many of people with intellectual disability in these countries are still forced to live in large residential institutions, which are often overcrowded, understaffed and seldom meet the minimum required living conditions.
- Institutionalized mental health care is used to keep mental health hospitals fully occupied (койко-день) without any medical justifications i.e. to avoid shortages in financing and staffing.
- No substantial attention has been paid to good practices existing in other CEE countries.
- No comprehensive approach has been adopted regarding reforming of mental health care with the aim of promoting inclusion and participation in the society.

Preliminary policy recommendations
Policy recommendations will be presented on the basis of the following general steps towards a comprehensive strategy of deinstitutionalization:

- Changing public opinion and mobilizing community support
- Strengthening the community-oriented social welfare infrastructure
- Creating community-based social service programs as pilot projects, which will in turn reduce the flow of individuals entering institutions and re-integrate them into the community
- Identify priorities for mental health financing having regarded deinstitutionalization options. Initial funding may be obtainable by relocating financing from other sources, and by attracting funds from external donors, Russian charities
- Converting or closing residential facilities. Staff may be retrained and employed in the growing community-based service programs. Institutions may also be converted to more constructive uses; for example, as apartments for young mothers and their infants, or for housing refugees.
- Creating a national system of community-based social services with revised legislation on classification, placement and rights of the vulnerable, new funding streams, monitoring, evaluation, and accountability. Long-term funding must be found to sustain recurrent costs, either by shifting funds from residential care facilities, by reallocating social service funding to localities on a "per client" basis, or other means.

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