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People with intellectual and mental disabilities in the social protection system in Serbia between community and institutionalization[3]

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Abstract

The process of deinstitutionalization is one of the directions of the social protection system reform in Serbia that has started at the beginning of the year 2000 and as one of the reform's priorities is incorporated in strategic documents and laws.

In terms of human rights of persons with intellectual and mental disabilities, the institutions, but also society as a whole, show to a great extent insufficient focus and commitment. Compliance with the standards defined by the UN Convention on the Rights of Persons with Disabilities, ratified by Serbia what makes it legally binding document, has remained just at the level of the governmental formal commitment.

Despite legislative changes aimed at protecting the rights of people with intellectual and mental disabilities, the number of those people in the residential institutions is still high. The key assumption of the deinstitutionalization process - development of community-based services, what should ensure getting the necessary support in the natural

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environment (and prevention of the institutional care as the same time), hasn't kept the anticipated pace.

Keywords: people with intellectual and mental disabilities, institutionalization, the social protection system, community-based services, deinstitutionalization

I Protection of people with intellectual and mental disabilities before the reform process

Despite the promotion of community-based services as the most appropriate and humane form of support and assistance to persons with intellectual and mental disabilities, institutionalization is still very present in many countries, and has been long functioning as a dominant system of care for these people in particular in countries with a socialist past. The legacy of the previous period was one of the reasons why the social protection system in Serbia has a strong tradition of institutionalization.

It was thought for a long time that the institutional setting is the best form of protection for a large number of people whose functioning was limited by some type of disability. Given that these people have usually been deprived of many basic rights and considered as incapable of reasoning and decision-making about their own life, the most common form of protection was the social isolation and "hiding" in the institution (Stankovic, 2014). These institutions were usually outside of towns or at its outskirts, pavilion-type and represented the systems themselves. Spatial segregation has contributed to full social exclusion of their residents. Many of them had been rejected by their families and friends so the contacts and social networks were very limited. The legacy of the previous period was keeping the beneficiaries in passive position.

The basis of such a bulky, institutional and passivating system was the dominant medical model, which was based on deficiencies, diseases and disorders of the individuals, what contributed to the determination for the residential care even in cases when it was not necessary. The full capacity of institutions, among other factors, contributed to the frequent placement of different categories of beneficiaries in the same institution,

what led to the lack of individualized approach and intensification of the negative effects of institutionalization. "In such a milieu "the institutionalized system of protection", based on a paternalistic approach, was developed in which complete control of the services, and therefore lifestyle, exercise experts in specialized institutions" (Brkic, 2014: 25). At the same time, such model was reflecting the attitude of the community towards people with intellectual and mental disabilities.

With the shift in approach from medical to social model within which disability is viewed in the terms of limitations of the environment in functioning and meeting the needs of the individual, the change in the treatment of these people has been made.

Strong criticism of "total institutions" and Goffman's rethinking whether the separation or closure of one part of the population is itself automatically a good move or "garbage storage" of a society, as well as his illustration of the effects[4] of the asylums, in the form of "total institutions", have on their tenants (Goffman, 1961) led to a radical discourse and introduction of the normalization principle and deinstitutionalization in developed countries in 1960s. While many countries have restructured their systems toward protection in the community by reducing the capacity of institutions and developing of community-based services, institutionalized system was maintained for many decades in Serbia, until the democratic changes in the 2000s.

II Actualization of issue of human rights of persons with intellectual and mental disabilities

Political changes, the beginning of the integration and negotiation process with the EU on the *Stabilization and Association Agreement* in

[4]Goffman describes the impact of total institutions on their "prisoners" (inmates) including 'curtailment of self', loss of physical integrity and sense of security, role dispossession, compulsory deference to those who are in power, loss of self-determination, etc. (Gofmann, 1961:24-31)

2005[5] imposed the necessity for reform of the entire social protection system and actualization of question of human rights of vulnerable and marginalized groups where people with intellectual and mental disabilities certainly belong. The existing social protection system had to be reformed with adoption of the international standards in this area. Due to many identified problems such as high centralization and bureaucratization of the system, the primacy of institutional care and lack of social services in the community, deinstitutionalization has been one of the key priorities from the beginning of the reform process. For this reason, the deinstitutionalization and development of community-based services were defined as one of the most important goals of numerous strategic documents starting with the adoption of the *Strategy on Poverty Reduction* (in 2003).

Adoption of *Social Welfare Development Strategy* in 2005 created the basis for further reform in this area. Important strategic directions were defined as:

- decentralization of the social safety net so that local municipalities get back their social protective function for their citizens because "people's needs can be efficiently, economically, timely and rationally met in the immediate environment - the family and the local community" (strategic direction 2.3.2.).
- provision of the quality services in social protection what assumes the development of a variety of community services and support to the family as the best protection framework (strategic direction 2.3.4.).

Focus on development of support system within the community was also highlighted in the *National* ***Strategy*** *for* ***Improving*** *the Position of* ***Persons with Disabilities***, which was adopted in the same year (for the period 2007-2015.), with the aim to provide these services along respect the principle of availability (general objective 3) and the family environment as the best for people with disabilities (specific objective).

[5] The EU and Serbia signed the Stabilization and Association Agreement (SAA) on 29 April 2008. The SAA between the EU and Serbia entered into force in September 2013.

In this period series of legislative acts were passed. The ***Law on Prevention of Discrimination*** *Against Persons with Disabilities* (2006) stressed the duty of local governments to "encourage the establishment of support services for people with disabilities in order to increase the level of independence in daily life and exercise of rights" (Article 32).

The new *Law on Social Protection* in 2011 (Article 27) is considered as extremely important for regulations in this area because it recognizes for the first time the essential services for this category of users - personal assistance and supported housing as daily community-based services. The Law acknowledges the principle of the least restrictive environments as well as services that will enable the users to remain in the community. Therefore institutional care can be used only when it is necessary or only solution, along with the preparation of the user for return in the family or for independent living (Article 52).

The Law on the Protection of Persons with Mental Disabilities (2013) defines "prevention of mental illness, care, treatment and rehabilitation [...] primarily [...] in primary care whenever is possible. Treatment in psychiatric institutions is conducted when it is the only or best way to ensure appropriate medical treatment "(Article 13).

All these legislative changes simultaneously meant incorporation of international standards in the field of human rights. The reasons are twofold - the ratification of a large number of international documents[6] and harmonization of the regulations and standards with the regulations and standards of the European Union due to the integration process.

The adoption of the *UN Convention on the Rights of Persons with Disabilities* in 2006 and the Optional Protocol next year has brought a change of perspective toward disability in general, but also in regulation of human rights issue of this category and their treatment. As Serbia has ratified this Convention and adopted the Act on its ratification in 2009, it

[6]Serbia has ratified numerous acts of international lawin this area: the Universal Declaration of Human Rights, the International Convention on the Rights of Persons with Disabilities, UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (not binding) and others.

became legally binding act. The article 19 of the Convention is of special importance as it provides that the states parties are required to "recognize the equal right of all persons with disabilities to live in the community, have equal choices as others, and should take effective and appropriate measures to facilitate the full enjoyment of those rights for persons with disabilities and their full inclusion and participation in the community" ("Official Gazette of the Republic of Serbia - International Agreements ", no. 42/2009, article 19).

The issue of protection of persons with intellectual and mental disabilities has been set up again on the political agenda by confirmation of this Convention, but with stronger demand for deinstitutionalization of the system than it was the case in the past.

III The institutional character of the social protection of persons with intellectual and mental disabilities in Serbia

While there is no doubt that Serbia has made significant progress in the legislative sphere by adopting the aforementioned documents, it appears that the situation of people with intellectual and mental disabilities has not significantly changed since the institutional care is still dominant and community-based services are not enough developed. Social protection institutions for people with intellectual and mental disabilities continue to have full capacity with often present waiting lists. Thus, for example, of the 15 social protection institutions for adult and elderly people with intellectual, mental, physical or sensory disabilities (according to the governmental Decision on the network of social protection institutions for beneficiaries' accommodation), at the end of 2015 more than half of them had more users than its capacity. Of the total number of accommodated beneficiaries in 2012, even 46.7% were people with mental illness, 31.8% with intellectual disabilities, and 11.8% with multiple disabilities (National Institute for Social Protection, 2013). "Profile of the user in relation to the type of disability, handicap and mental disorders was very similar to the previous 2011 year" (National Institute for Social Protection, 2013: 9). This indicates that the profile of the social protection system of these persons has not been

changed despite the aforementioned regulatory changes because this category of beneficiaries is still the dominant group in residential institutions in the social welfare system. As the dominant reasons for the termination of accommodation are death of users in 70% of cases (National Institute for Social Protection, 2013) or moving to another institution, it is clear that institutional care for the largest number of beneficiaries is durable form of protection despite of the legal determination as a temporary solution until the conditions for a return to the natural environment are created.

Data on social network of the users indicates on their great social isolation. Bearing in mind that one-third of users (33.4%) have no contact with family and relatives, 12.3% of users has no relatives, and that the highest percentage of users (88%) is from the other territory than their municipalities (National Institute for Social Protection, 2013), what makes it impossible to integrate into the local community, it can be concluded that the contacts of these people are very impoverished and reduced only to the staff of institutions and other beneficiaries.

In addition to overcrowding, the institution itself is characterized by lack of privacy, sensitiveness for user's needs and unequal treatment in relation to the level and type of difficulty (MDRI-S, 2012).

At the same time what has contributed to the closure of institutions and moving from institutional toward community care in many developed countries were the high costs of maintenance and operation of the hospitals[7]. However, in Serbia, the funds are often used for investment in facilities, adaptation and renovations instead for the development of non-institutional care or community services.

A reliable record on the existence of local social care services in Serbia does not exist. Many services have been developing as project activities so with the termination of financing local governments do not ensure their sustainability due to limited budgetary resources.

[7]"The increase in costs more than any other factor made the obvious that the support of the public hospitals is politically unfeasible... thisis a major factor of the present pressure to get rid of state hospitals" (Scull, 1977:139).

According to available data, there are 354 community-based services in Serbia. Dominant are daily services (home help services, day care centers, clubs for the elderly), representing approximately 63% of all services. Individually, the most common services are: home help for adults and elderly (in 79 local municipalities), followed by daily centers for children and youth with disabilities (in 62 municipalities), and clubs for the elderly (28).[8] Supporting services for independent living are the second most developed group. However, in this group is dominated supported housing for young people who are becoming independent, which are being provided in 13 cities/ municipalities. On the other hand, supportive housing services for adults and elderly people with disabilities, personal assistance and respite care are just at the beginning of development and provision. In addition, local social services are unevenly established, primarily depending on the level of economic development of the region[9].

These data indicate that not much has been changed in the system, as well as in institutions despite the declarative commitment to deinstitutionalization. "Although many international sources and instances call for urgent leaving the practice of placement and life in institutions, the effects of the intention to carry out the process of deinstitutionalization conscientiously, diligently and in compliance with achieved international standards still don't exist in the Republic of Serbia still does not exist, although some initiatives are visible" (Marković, 2014: 95).

The basis of the social protection system still makes institutional care, while "the medical approach still continues to dominate in institutions and therefore neglects the other users' needs which are necessary for the normal development of the personality and identity" (MDRI-S, 2012: 12). The question is whether Serbia will be able to create a system of services in the generic sense, rather than a system of institutions, that would be available to all people in risk, but at the same time tailored according to the individual needs?

[8]Data base of local services, Republic Institute for Social Protection, available at: www.zavodsz.gov.rs

[9] The services are mainly developed in larger cities/municipalities.

IV Survival of the institutional structure as the legacy of previous policies

Although the experience of many countries shows that the process of transition from institutional toward community-based care can be very long due to needed necessary systemic changes, this transition has been very slow in Serbia even with some already made changes, which are in this case reflected solely in legislative sphere. These changes often have gradually nature due to the so-called "path dependency" (eng. *Path dependency)* (Howlett, 2009) because they follow historical patterns, and once created path is difficult to change. The dependence of the path indicates the temporal nature of politics especially if institutions and policies set up once serve to limit the variety of options/possibilities in later period (Pierson, 2000).

Significant policy changes in any country, regardless of the level of its development, can hardly be achieved when certain policies are institutionalized in society (Tuohy, 1999). Such changes often require significant political changes, regrouping of political parties, the role of interest groups, public opinion or growing policy into the burning question of society. As this category of users is often invisible for society because they have no voting right and therefore does not represent a significant electorate, there is no sufficient critical mass that would put this issue on the political agenda.

To interests for the advocacy for the rights of these people do not show their families, as well as civil society organizations what represent lack of collective action at the macro level which would initiate comprehensive changes in the direction of deinstitutionalization.

As in Serbia the medical approach to disability has had long dominance, as well as deep-rooted belief that institutions are the best form of protection for people with intellectual and mental disabilities, professionals in the social welfare system that work directly with these beneficiaries are still trapped in excessive paternalism. In dealing with a population with intellectual and mental disabilities, professionals

sometimes "empowerment" replace with control, domination and exclusion actions (Morisse et al, 2013).

The transition from a socialist society and ideas on social care into democratic society with the principle of individualization, as well as lack of clear guidelines and devotion for the transition from institutional to non-institutional support, contributed to the copying of institutional patterns of work with beneficiaries in the new period. People act according to the "logic of appropriateness" so that "obstacles for change exist because the institutions produce preferences which are resistant to that change" (Hall and Taylor, 1996:8).

All obstacles and resistances to change of the established institutional policies are not only within the institutions but also in external systems and they are result of lack of catalysts for their closure.[10]

In contrast, a system that is in transition toward non-institutional care of individuals with intellectual and mental disabilities requires a radical change of the approach that will lead to the user *(user-centered approach)* which implies his full and active participation, autonomy and greater satisfaction with services. In the context of deinstitutionalization issue, this approach would involve efforts for reorganizing the services in a way that the users and their rights are in the center of the system.

[10]According to many authors catalysts of the deinstitutionalization were legislative reform, the theory of normalization, the cost of "humanization of the institutions" andanti-psychiatry (and social) movements that were advocating for the rights of these categories of beneficiaries in developed countries (Bigby and Fyffe, 2006).

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