

***Advocacy and self-advocacy of people with
autism in Serbia
- best interest or human rights***

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Introduction

The subject of our paper deals with the problem of advocating best interests for people with autism by others, in other words we would like to draw attention to the fact that until people with autism do not advocate for themselves, the issue of denying their human rights is still present.

Legal Capacity in Serbia

Many people with autism and intellectual disabilities in Serbia are completely deprived of their legal capacity. Thus, they are deprived of any possibility to speak for themselves, to make a choice, or to make decisions related to their own future.

In 2012 MDRI-S has monitored seven institutions of social care. Among 5,364 adults residing in social care homes 3,493 (66.4%) of them are under guardianship. The residents who are not formally deprived of their legal capacity basically have no power to decide about their everyday lives, what makes them equally deprived of their basic human rights.

Low expectations

Primarily due to the influence of professionals who conduct a medical model of disability, many parents have low expectations of their children with autism and believe that they cannot be included in society on equal bases: that they cannot be educated, especially in regular schools, be independent, work, be employed and have families.

Since they accepted the attitude that autism is an illness, they see their children end in institutions and always with antipsychotics to control their behavior.

Parental associations in Serbia act as relevant representatives of people with autism.

Stationary - Home for Children and Youth with Autism

During our participation in parental associations, the largest attention was focused on conditions in the only specialized stationary institution for autism, which is located in the suburb of Belgrade. The demands of parents were primarily directed to improvement of the physical state of the facility, hygienic issues, improvement of feeding, clothing, acquisition of medicaments and video surveillance. The questions of programs, possession of personal items and protection of their privacy were not raised.

Stationary institution for autism is by capacity the smallest institution in Serbia, but in relation to the number of residents – 49, has the biggest number of employees - 52.

Hidden and Forgotten - Segregation and Neglect of Children and Adults with Disabilities in Serbia

“The recently renovated facility of the Home for Children and Youth with Autism shows to what extent investing in the outward appearance fails to positively reflect on the quality of life of the residents. Furthermore, the impression is stronger due to existing contrast between the condition of the facility itself and the state in which the residents were found.”

“Residents have no right to privacy, because as staff claims “everything is potentially dangerous” for them.”

“It is particularly noticeable that the employees see the residents as persons who cannot do anything, who are “gone-for-good”. Problematic behavior is perceived as an integral part of the residents’ condition, or of their “disorder” and not as a consequence of their unsatisfied needs, lack of activity and the length of institutionalization.”

De-institutionalization

Due to the MDRI Report on monitoring of institutions from 2007 - *Torment not Treatment: Segregation and Abuse of Children and Adults with Disabilities in Serbia*, the disastrous position and state of people with disabilities in institutions were publicly exposed.

In respect of European standards, the issue of de-institutionalization is forced upon our society. The Government was forced to enable new kinds of support which would stop further institutionalization.

Services for people with autism and intellectual disabilities in Serbia

- Day care centers for daily stay
- Sheltered homes for permanent departure from their families
- “Respite“ service or weekend program

Day care

The number of day care centers in Serbia is in permanent growth. Positive aspect of day care centers is to decrease the number of new applications for setting in stationary institutions or, on the other hand, to enable people from institutions to return to their families.

Programs within day cares do not enable training for independent life in the community. By structure, profile of employees and approach towards residents, day cares *are* institutions. That is why it is absurd to speak of them as means of de-institutionalization.

We would also point out that existence of day cares for children is not in accordance to their right for education.

Sheltered homes

Parents constantly request for the opening of new institutions for permanent residence, and since that is not in accordance with the proclaimed policy on de-institutionalization, new stationary institutions, essentially based on segregation, will be re-named into sheltered homes or centers for autism.

Sheltered homes can be treated as an inclusive mean of support only if the principle of will and preference is respected.

On which parameters was it found that people with autism want to live in that kind of community? It is their right to make a decision upon living within their families or independently, with a friend or a partner.

“Respite” service or weekend program

Here it is clear that this service is aimed to satisfy needs of the parents. What is questionable is that the only given solution in supporting people with autism when their parents are prevented to take care of them, is their stay in institutions (day care or stationary). This approach is clearly contrary to the declared commitment of government to de-institutionalization.

Employment

In 2009, the new Law of Vocational Rehabilitation and Employment of People with Disabilities was passed. This law significantly discriminated people with intellectual disabilities and autism because the criteria for employment can not be fulfilled by people with autism. The law regulates that the assessment of work capacity of a person with disabilities is brought out by the Commission, mainly based on medical records. The Commission has the competence to declare a person incapacitated, thus denying any employment opportunities.

During the process of passing this law, our organization lobbied to enable people who were deprived their legal capacity, to get employment in the open market. Many parental associations, however, claimed that the best interest for people with autism is to work in isolated sheltered workshops.

Education

The new Education Law from 2009 prioritizes inclusive education for all children. However, the medical approach, maintained by professionals, still strongly influences parents and teachers, who therefore expect from schools to provide treatment and cure, without understanding the essence of inclusive education.

In spite of this, inclusion of children with autism – among which the non-verbal too – into regular schools, gave good results. This influenced many parents of younger children to have better expectations from their children.

Conclusion

Together with partner organizations, MDRI-Serbia is actively involved in changing legislation on legal capacity, and in the process of capacity building of people with autism, intellectual and mental disabilities for self-advocacy.

We also work on arising awareness that social model of disabilities, social inclusion and de-institutionalization can be carried out only if the principle of self-advocacy is respected.

As parents we strongly support the change of the paradigm – not interpreting best interests of people with autism, but creating conditions which would enable them to realize their human rights.

Literature

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