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## **THE HIDDEN AND FORGOTTEN**

Segregation and neglect of children  
and adults with disabilities in Serbia

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and adults with disabilities in Serbia

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## **SKLONJENI I ZABORAVLJENI**

**Segregacija i zanemarivanje dece sa smetnjama u razvoju  
i odraslih osoba sa intelektualnim teškoćama u Srbiji**

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The MDRI-S is exclusively responsible for the content of this document.



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# INTRODUCTION

The history of neglect and the locking away of persons with intellectual disabilities is long and shameful. Much like the majority of other countries, Serbia has failed to correct this injustice imposed upon this group of people who are part of our society. Despite the constitutional guarantees granting the protection of disabled persons and the new and the amended laws which are, in most part, in accordance with international human rights standards, children and adults with intellectual disabilities remain isolated from the rest of society.

The general public is unaware of the lives lead by children and adults with intellectual disabilities residing in institutions. This is due to institutions being closed, the access of interested visitors being often denied and the movement of the residents being restricted. Certain institutions might be self-described as open. The interaction between residents and the wider community is, nevertheless, always limited. The situation is not much better for persons with intellectual disabilities who live with their families. They are being deprived of the systemic support that would enable them to develop social skills and to lead, as much as possible, an independent life. They are excluded from the education system, and completely absent from the labour market. For all these reasons they are under the genuine risk of being placed in an institution the moment their relatives lose the ability to take care of them.

In 2007, Disability Rights International (DRI)<sup>1</sup> published a report that illustrated the disastrous state of social care institutions and of psychiatric hospitals in Serbia. The physical conditions in these establishments were often very bad, but the most problematic aspect was found to be the manner in which residents were treated. The report revealed that both children and adults were subjected to prolonged physical and chemical restraint. When immobile, they were not taken into the fresh air or even out of their cribs/beds. Also, due to the lack of any type of recreational or educational activity, children and adults in need of the most support spend their entire time in beds. The Serbian government was recommended to act in accordance with its international obligations and intensify the efforts to implement reforms in the field of social protection, health and education. This would lead to establishing support services as the primary answer to the needs of persons with disabilities. By creating the possibility to live in the community, further institutionalization would be prevented and the closing of institutions would be made possible.

Almost five years later, the question remains: what was specifically done to improve the conditions of life inside and outside the institutions? Serbia did acknowledge the difficult situation of children and adults with intellectual disabilities and a range of measures were put into action. However, it is yet to be established whether their lives actually improved as a result of

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<sup>1</sup> Disability Rights International was then known as Mental Disability Rights International. DRI is an international organization that has for more than 20 years worked on the promotion and protection of the rights of individuals with mental disabilities around the world.,

these efforts. This was precisely the purpose of our monitoring research. The key questions that the monitoring team asked were:

1. Which are the problematic aspects of the respect of the rights of residents in institutions – both children and adults with disabilities?
2. What are the effects of the welfare system reform on residents and staff?
3. What are the effects of the education reform on young residents?

Recognizing that the effects of long-term residence in institutions are the most distressing for children, the focus of recent reforms in Serbia were welfare institutions for children, including children with disabilities. At the international level, the institutionalization of children is also recognized as a critical issue that should be addressed immediately, with the aim to ensure that children remain with their families or in the least restrictive environment.<sup>2</sup> DRI is calling the governments of the countries that are parties and signatories of the Convention on the Rights of Persons with Disabilities, or/and the Convention on the Rights of the Child, as well as international donors to stop directing resources towards institutions and, instead, to direct them towards community-based support services and education.<sup>3</sup>

Because of the aforementioned reasons, MDRI-S decided to target this research on the institutions where children with disabilities are placed. Due to the nature of the system, the social security network and the manner in which they function, apart from two institutions, children and adults are placed together. In effect, there were no significant differences in “residential services” in terms of the residents’ ages. Thus, many children who grew up in one facility would remain in that same institution even after turning 18, because it was deemed “most appropriate.” Consequently, even though young residents were the intended focus of this research, the monitoring team recognized the fact that the age factor did not play a significant role in life in the institution and therefore could not neglect the position of adults with intellectual disabilities who resided there.

We would like to point out that the purpose of this report is not to provide an exhaustive review of all the aspects of the institutions’ work and functioning. Factual data is already provided in various government documents and reports, and the data is used here merely for the purpose of clarifying issues, reaching conclusions and giving recommendations. We would also like to emphasise that the report is not a comparative review of institutions, as every institution has its own story, with different residents, staff and management. Nevertheless, the reviews of each individual institution can certainly serve the staff and management of the system for the purpose of the development of ideas, the mutual coordination of future actions, etc.

## METHODOLOGY

The report is based on the monitoring team’s visits to welfare institutions for children with disabilities. During the course of the project, seven institutions were visited:

Centar za zaštitu odojčadi, dece i omladine (Centre for the Protection of Infants, Children and Youth), Belgrade (hereinafter referred to as *Zvečanska*)

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<sup>2</sup> OHCHR *Forgotten Europeans – Forgotten Rights* and UNICEF *At Home or in a Home – Formal care and adoption of children in Eastern Europe and Central Asia (June 2011)*.

<sup>3</sup> <http://www.disabilityrightsintl.org/learn-about-the-worldwide-campaign-to-end-the-institutionalization-of-children/>

Dom za decu i omladinu ometenu u razvoju (Home for Children and Youth with Developmental Disabilities), Sremčica, Belgrade (hereinafter referred to as *Sremčica*)

Dom *Veternik*, Novi Sad

“Dr Nikola Šumenković”, Stamnica, Petrovac na Mlavi (hereinafter referred to as *Stamnica*)

Dom *Kolevka* (Home Cradle), Subotica

Dom za decu i omladinu sa autizmom (Home for Children and Youth with Autism), part of the Residential and Day-care Centre for Children and Youth with Developmental Disabilities (Centar za smeštaj i dnevni boravak dece i omladine ometene u razvoju), Belgrade (hereinafter referred to as *Stacionar*)

Dom za smeštaj odraslih lica *Kulina* (Residential home for Adults *Kulina*), Aleksinac

Visits were conducted from January to April 2012, based on the agreement signed by the Ministry of Labour and Social Policy and Mental Disability Rights Initiative – MDRI-S in June 2011. At that time, the Ministry forwarded the MDRI-S’ initial questionnaire to all participating institutions. The questionnaire contained basic questions regarding the make-up of the residents and the organization of work in the institution. Every institution submitted its response to both the Ministry and MDRI-S within a month.

In accordance with the agreement, MDRI-S notified each institution about the time of the visit, several days prior to the monitoring. Each visit was conducted by five to seven members of a multidisciplinary team made up of representatives of the residents – parents of the children, i.e. young persons with intellectual disabilities – psychologists, one psychiatrist, a human rights specialist and a special education specialist.

Each visit was structured in a similar way. The team would initially meet with the management of an institution – the director, doctor, head nurse, social worker and special educator (the members of the team varied, depending on the institution). During the brief discussion, the team leader would explain the goal and structure of the visit, as well as the steps that would be followed. That time was also used to clarify the potential questions that may have arisen during the completion of the initial questionnaire. The team would then begin the visit of the institution, led by the staff and sometimes the director of the institution. Our team’s medical doctor was usually given access to the institution’s medical records and to the files of various protocols. The members of the team established contact with residents with the aim of obtaining information. Where possible, due to age and difficulties in communication, the team members gathered information without the presence of the institutions’ staff. One team member would take photographs of the institution and residents. A written agreement was signed through which MDRI-S assumed the obligation to not disclose residents’ identities in any potential publication (apart from one institution, where it was explicitly requested not to photograph in any way the residents). Information was also collected through questions put directly to the staff.

At the end of each visit, the monitoring team held a final meeting with the same individuals that had participated in the introductory meeting. There, they presented the particularities that they had come across during the visit. Through discussion with the management it was tried to identify the causes for the occurrence of certain problems. This report is largely based on the minutes from those discussions, the notes made by the team members during the visits and the conversations with the management, the staff and the residents.



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# FINDINGS OF THE MONITORING OF SOCIAL WELFARE INSTITUTIONS

## SUMMARY

Taking into consideration the total population of Serbia (7,100,000)<sup>4</sup> and the estimated number of people with intellectual disabilities living in Serbia (2% or 142,000)<sup>5</sup>, it could be concluded that the number of institutionalized children and adults with mental<sup>6</sup> disabilities is relatively low (approximately 5,760)<sup>7</sup>. However, there is no official data regarding how many children and adults with intellectual disabilities, including persons with autism, live in the community. The state has no estimate of their number. The results of the 2011 census may be the first available source from which to acquire this information.

The state report on the functioning of social care institutions for persons with disabilities identifies various circumstances that may lead to the institutionalization of children and adults with disabilities. Regarding children, the list of possible reasons for institutionalization is as follows: deceased parents, unknown parents, parents fully or partially divested of parental rights, parents divested of legal capacity, parents who are prevented from exercising their parental rights, parents who are unable to attend to the child's needs and inadequate parental care.

In most cases, parents are prevented from exercising parental rights, or they provide inadequate care for their children.<sup>8</sup>

The main reasons for the institutionalization of adults with disabilities are: the absence of close relatives, the unwillingness of the family to take care of them, socio-economic risks and inadequate care by the family. The explanation that the adult has no close relatives, or sufficient funds, is not an adequate justification for the failure to enable them to live in their own homes in the community. The data also suggests the troubling fact that it is still acceptable in Serbia to be “unprepared” for assuming care of a child or adult with a disability while, on the other hand, the state offers no support and no human rights based alternatives for families facing this challenge.

Placing a person in an institution frequently results in long-term placement which very often lasts for life. Statistics on the length of stay in institutions are very discouraging: only 4 % of children with disabilities and 7 % of adults with intellectual disabilities spend less than 12

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<sup>4</sup> According to the latest data from 2011 census

<sup>5</sup> Since there is no data on the exact number of people with disabilities in Serbia, here we use the estimate used by researchers in this field as well as demographers – which is 2.0 percent of the population.

<sup>6</sup> Term “mental disabilities” here includes intellectual and psycho-social disabilities

<sup>7</sup> According to the latest report published in July 2012

<sup>8</sup> Report on the work of social welfare institutions for the accommodation of persons with disabilities for 2010, p.7 (Document is available in Serbian at: <http://www.zavodsz.gov.rs/PDF/naslovna/god-izvestavanja/OSI.pdf>)

months in the institutions, whereas 55 % of beneficiaries reside in the institutions for more than 10 years.<sup>9</sup> The predominant reason for leaving an institution is death<sup>10</sup> (up to 71% in the institutions for adults and 39.8% in the institutions for children). The second reason is transfer to another institution (22% of adults and 28.4% of children). Thus we get the astounding fact that 93% of people over 18 will, if ever placed in an institution, almost certainly remain there for life.

It is possible to say that despite the government's efforts and on-going reforms, institutionalization remains dominant "service" offered by the state, and the system does not yet offer satisfactory alternative solutions. We encountered children and adults without intellectual disabilities in the institutions, placed there only because the system was unable to find a suitable solution for their problem. We met people who were there only because of the inability or unwillingness of government agencies to provide them with the essential support for living in the community. They were in institutions because they were not able to earn the livelihood which would enable them to secure the necessary means for independent living.

Concerning children with disabilities and adults residing in institutions, it must be stressed that there are significant differences among the institutions that we visited, such as the number of residents, their age, nature of impairment, location of the institution and the size and the structure of the staff. While the situation is significantly better in institutions specialized exclusively for children (because of the location of the institution, as well as its physical conditions and staff structure), institutions where both children and adults reside face greater challenges in securing adequate care and therefore have greater problems.

While there are significant differences among the institutions, there are problems that are universal. Their existence is inevitable in a closed system characterized by unlawful segregation<sup>11</sup> and isolation, depersonalization, lack of privacy, rigid routines and inadequate protection against neglect and abuse. Overcrowding and the lack of privacy remain the basic features of these institutions. The lack of understanding of the needs of the residents is also a fundamental feature, as well as the unequal treatment of residents in relation to the degree and nature of their impairment.

Issues that require immediate attention are over-medication and the withholding of necessary medical treatment by the healthcare system. The adult residents face problems of unregulated use of mechanical restraints<sup>12</sup> and isolation<sup>13</sup>.

Institutions are still dominated by the medical approach<sup>14</sup>, thus overlooking the other needs of the residents which are essential for the development of personality and identity. This approach

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<sup>9</sup> Ibid, p.8 and 15.

<sup>10</sup> Ibid, p.11 and 18

<sup>11</sup> The State's decision to segregate and isolate people with mental disabilities through placement in closed institutions represents a fundamental form of discrimination and is violating the right to life in the community, prescribed by international standards. Discrimination against people with disabilities and their subsequent isolation based on mental disability is prohibited by both domestic and international law. Segregation and isolation alone deepen the stigma that surrounds people with mental disabilities.

<sup>12</sup> Mechanical restraint involves the binding of hands and/or feet to a bed, chair, or wheelchair with bandages, sheets, belts, etc.

<sup>13</sup> Apart from locking away in a special room, isolation also implies leaving a person in a bed/cot out of which they cannot get out on their own.

<sup>14</sup> The medical or traditional model of approaching persons with disabilities focuses on the persons' disabilities as well as on the individual approach regarding the course of the treatment. In the 1980 the so-called social model emerges and becomes dominant. The social model of disability states that impairments and chronic illnesses often give rise to difficulties for persons with disabilities, but that they are not the crux of the problem. The principal problem of the individual becomes not their disability, but the barriers that exist in society.

leads to the residents being identified with their diagnosis, as one of the basic characteristics of the institutional system. The question of the accuracy of the diagnosis becomes a separate and important problem. It was noted that in social care institutions as well as in large psychiatric hospitals, triage and admission are not conducted on the basis of diagnoses prescribed by the current Classification of Diseases (ICD-10), but following other principles, which are known or implied. This is one of the reasons why persons of different disabilities or difficulties are placed in one institution where they require different treatments that are impossible to apply in the existing circumstances.

Due to the physical isolation of residential institutions, educational institutions are not accessible, thus only recently has a small number of children with disabilities been accepted in the education system. In cases when there is a nearby school or kindergarten it is still difficult to include a large number of children with disabilities into a single education facility. Residential institutions also face numerous problems when trying to include children in the educational system, due to the lack of support of the competent systems - education, social welfare and healthcare. The prevailing tendency is to establish departments in the institutions themselves. While this is understandable because of the existence of systemic obstacles preventing the inclusion of children from institutions into the education system, this solution is unsatisfactory since it encourages further segregation and isolation.

The only real way to protect the rights of persons who currently reside in institutions is their deinstitutionalization, as institutions will never be able to fully ensure the respect of human rights. Naturally, it is not possible nor acceptable to toss people out onto the street, without affording them with any kind of support. Therefore, it is necessary to take all the measures to provide maximum support to persons with mental disabilities, at the same time respecting their privacy, personal wishes and needs.

## CONDITIONS IN INSTITUTIONS

Data from the national report on the functioning of social care institutions for placement of persons with disabilities suggests that there is a serious problem of overcrowding and lack of privacy. With the exception of institutions for people with psycho-social disabilities, the number of persons who reside in each type of state social care institution does not exceed the total capacity defined by the ministerial decision on the network of institutions.<sup>15</sup> This information does not say much about the situation in each individual institution, not only because the data is grouped according to the type of institution, but, more importantly, because the determined capacity is approximated to the current number of accommodated persons instead of taking into consideration standards that prescribe sufficient personal space per individual resident.

Therefore, while residents live in common dormitories with a complete lack of personal space, institutions or their departments may be within or below the prescribed limit.<sup>16</sup>

There is a significant difference in the number of residents in the institutions that we visited, and that can also be said about their living conditions. At the time of our visit, there were 2,023 persons in the institutions, 641 of which were children, while the number of residents in

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<sup>15</sup> Report on the work of social welfare institutions for the accommodation of persons with disabilities for 2010.

<sup>16</sup> Helsinški komitet za ljudska prava u Srbiji: Ljudi na margini (4) : izveštaj o stanju u socijalnim ustanovama za smeštaj dece i omladine bez roditeljskog staranja i dece i omladine sa poremećajima u ponašanju, str. 17. The Helsinki committee reports that in Sremčica's children pavilion there are more than 14 children in every room (2009).

seven institutions varied from 49 (Stacionar) to 573 (Veternik). Three institutions are located in a city<sup>17</sup>; three are located in the vicinity of a town<sup>18</sup>, while the Kulina home is completely isolated. Besides the number of residents and the location, there are significant differences among institutions regarding the structure and the number of staff and the physical conditions which the residents live in.

Certain improvements in the physical conditions can be seen in all institutions, compared to 2006 and 2007. Some buildings have been repaired, hygiene has been improved, investments have been made into the interior, decorative details have been introduced in the rooms. However, there are significant differences among institutions in this regard.

Nevertheless, even in the institutions with the best physical conditions, we documented the lack of privacy and the lack of choice by residents, even on the most basic life issues. Everything is decided by the institution, who tells residents when and what they should eat, what is their bedtime, when should they receive medication, etc. A fact which is of special concern is that not all residents living in one institution receive equal treatment. Thus, more skilled children receive more attention and reside in better conditions than those with a higher level of disability. Even though they require greater stimulation and support, the latter often remain neglected. The numerous investments into the improvement of the physical conditions have made this division even more visible, as the funds were directed to the enhancing of areas where the so-called “better children” or “the more capable” beneficiaries reside. This difference can be seen even in the institutions with the best care, such as Zvečanska and Kolevka. Visible efforts have been undertaken in Zvečanska to provide the children with the freedom of movement, the possibility to explore space and interact with their carers more easily. Nonetheless, the stimulation seems to be significantly poorer in the departments where children with more complex disabilities reside. Correspondingly, it was also noted in Kolevka that children with more complex disabilities spend most of the time in their rooms, playpens and wheelchairs, deprived of stimulation or structured activities.

The director of Zvečanska points out yet another problem, which is the inability to establish a balance between privacy and security. In Zvečanska institution, rooms have glass walls so the children are deprived of any privacy. While the director is aware that glass greatly threatens children’s privacy, she says that the children’s safety is more important – above all, it prevents neglect and abuse, as the staff is well aware that everyone can see what they are doing. She does not see it to be a big issue for younger children, but it is a problem for teenagers, whose privacy and dignity is jeopardized:

*“It is difficult to balance privacy and protection from neglect and abuse (the control of the staff); this is a characteristic of institutions in general. You need to be careful when placing teenagers in glass rooms.”*

The conditions in Sremčica are somewhat poorer, especially for children and adults with more complex disabilities. Rooms where the caring groups (groups of users assessed to be with most significant disabilities that are taken care of by non-qualified staff called carers) stay are meagrely equipped and they lack the dynamic of life as the residents are not included in any kind of activities.

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<sup>17</sup> Zvečanska, Stacionar and Kolevka

<sup>18</sup> Sremčica, Stannica and Veternik



Adult dormitory, "Pink" pavilion, Kulina



Adult dormitory, Lower Zone, Stannica

However, in institutions such as Veternik, Kulina and Stamnica there are still conditions unworthy of human beings. In contrast to parts for the “most functional” residents, such as the facilities for “assisted living,” where residents enjoy all the benefits offered by the institution, pavilions A, A1 and A2 in Veternik house children and adults with the most complex disabilities, who reside in conditions which can be characterized as inhuman and degrading.

The rooms are bare, stripped of everything but a television set with poor reception and folk music. All the residents are in a very poor state, many of them sitting or lying on benches or squatting on the floor. The dormitories contain only beds. Many users have no toilet habits (during conversation, it was discovered that they had never been given toilet training). With many residents, because of their clothing and hairstyles, it is impossible to tell whether they are male or female. The bathrooms and toilets have no doors and the bowls have no seats. They have been installed in inappropriate places, even centrally (A1 and A2), without natural ventilation. They spread a specific odour throughout the entire pavilion. The rooms where men are housed are much more poorly furnished. There are several rooms in the area with iron doors, bars and a padlock, with a mattress on the floor, reeking of urine. We were told that those rooms serve to isolate distressed residents, but the residents revealed to us that some of those rooms, to which they refer to as slums, actually belong to a certain user.

*“This is where people who have been forgotten are, those who live in a vast void.”* - MDRI-S associate, Pavilion A, Veternik

*“My impressions from here can hardly be expressed in words. Here, you have the “pink,” but also the “family corner.” The thing that characterizes them is contrasts. That is, I guess, why I find it so hard.”* – Member of the MDRI-S team, following the visit to Kulina.

The same contrast is apparent in Kulina. There is the “family corner,” which houses 10 residents, but also the “pink” pavilion where immobile users reside. The former pavilion for men has been renovated and it now houses female users, since they are “tidier”, according to staff. The renovated pavilion is nicely decorated and the rooms are much more pleasant. Nonetheless, there are two squatting toilets and two potties. The attending nurse says that it is “hard for them to squat, so they prefer to use the potties.” It is also confusing that in the pavilion for women, all of whom are mobile, there are beds for immobile users. On the side, residents who are in fact immobile reside in the “pink” pavilion and are still sleeping in cribs which are far too small for them.

The construction of a new building which should relieve the current overcrowding has started in Stamnica. This raises the question of staff numbers, since current staff is hardly able to function adequately in the present space. There is a significant difference in the appearance of the central building and the garden around it in relation to surrounding structures.

In the facility for children, the so-called “French” facility, there are group dormitories without any personal touch. Children spend their time together in the common areas furnished with benches and some tables, covered with identical-looking stuffed toys and blocks. Children with serious impairments have only a few toys at their disposal, so they spend most of their time sitting on the benches or lying on the mats, more or less without any direction. In that same institution we saw children rehearsing a theatre performance. It was very lively in the room and some children were drawing. An unpleasant smell was coming out of the rooms and dormitories.

Immobile and semi-mobile residents with serious health problems reside in the recently renovated blocks C and D. Some of them have outgrown their little beds. Notwithstanding, compared to several years ago, the rooms have been renovated and a significant number of beds have been replaced.



Children's dormitory, Kolečka



Children's dormitory, Zvečanska

In the “Upper Zone,” reserved for adults and elderly users, conditions are still quite poor. The pavilions are small and overcrowded. The dormitories contain beds that are set out in a way that leaves it unclear how residents manage to get into them. The living and dining rooms are also very cramped. During our visit, the residents were sitting outside idly. Old building blocks seemed to be put before them primarily because of our announced visit. This is just one more illustration of the wrong approach towards adults with intellectual disabilities. Regardless of the fact that they are older than 30, 40, 50, etc., they are seen as children. The question which naturally arises is what the life of these residents looks like in winter, when they cannot go out.

The pointlessness of investing in the renovation of facilities within institutions is evident in Sremčica. The example in question is the “Children’s pavilion” which was completely renovated five to six years ago. The roof has since started to leak. Bringing this structure to the adequate shape and condition requires the same funds that were invested in its renovation, because according to the director “it was poorly done from the very beginning.” Constant investing into the facilities significantly diminishes the funds available for the development of appropriate services which would enable children with disabilities to live in the community, thus reducing the need for the existence of these institutions.

The recently renovated facility of the Home for Children and Youth with Autism (Stacionar za decu i omladinu sa autizmom) 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. There are eight dormitories in this institution with three to seven beds per room. An absolute lack of personal items, clothes, footwear, personal hygiene items, is notable (if there were any personal items, they were locked in the storage facility). Residents have no right to privacy, because as staff claims “everything is potentially dangerous” for them. Surveillance cameras are set up in the institution (with the exception of the toilet cubicles). Despite good hygiene, the toilets have no doors or toilet seats and the showers have no doors, which the staff justified by saying that it is because of the “residents’ condition” and “bad experiences” that they had a few years back. Men and women share dormitories. When asked to comment, the psychologist said that they had no awareness of their sexuality, and that they were placed in rooms on the basis of their level of disability.

We may conclude that even after the physical conditions were improved, the quality of life and the infringement of human rights in closed institutions still remain matters of great concern. The majority of the residents spend their time without any worthwhile activities. They are either lying or sitting on beds, chairs and/or floors, not doing anything. Residents who cannot stand up on their own, never go outside nor do they have any type of activity, aside from occasional verbal communication.

In all institutions housing adult residents, which are five out of seven institutions we visited, the privacy of the residents is violated to such an extent that in certain cases it could be deemed inhumane and degrading. Apart from the toilets without the doors, squatting toilets, or toilets without seats, showers without screens or the group showering of residents with a hose, the issue of sexuality and sexual relations among residents, which will be discussed later, also calls for special attention.



Feeding the children, Kolevka



Activities for children, Zvečanska

## ACTIVITIES AND REHABILITATION

To a greater or lesser extent, institutions offer modest rehabilitation programmes, such as crafts or so-called creative workshops. Only a limited number of residents are involved in such programmes, allegedly because some lack the ability to participate in such activities. For a large number of residents there are no such types of engagements and rehabilitation programmes. They are left to wander the yard or corridors, or to remain in their rooms.

Some of the institutions that we visited, like Sremčica, Veternik and Stamnica, provide modest opportunities for different kinds of work engagement and rehabilitation. In Sremčica and Veternik there are special facilities with workshops for weaving, sewing and pottery making. There is also a carpentry and machinery workshop, printing presses, etc. Yet, these facilities are only rarely used. Female beneficiaries mostly do handcrafts such as embroidery, knitting or weaving on the loom. During our visits we noticed that many of the available machines were not in use. In Veternik, we encountered a number of residents sleeping on the workshop floor.

As far as children are concerned, there is a noticeable lack of toys and other equipment that could be used in working with them. We found in all institutions a large number of toys still in their packaging. They were not given to the children because “they will destroy them.” In Stamnica there is an area equipped with a Montessori room and a computer centre with adapted keyboards and mice and special learning software. There is a computer centre in Sremčica also, which, according to the staff, it is rarely used. A small number of residents work in the kitchen, laundry room and in agriculture (growing vegetables, raising poultry, etc.) While some institutions have an internally regulated system of rewarding, residents are not formally compensated for their work.

In Kulina and Stacionar there are no such forms of working engagement and they have quite poorly developed occupational programmes for a limited number of residents. It is also surprising that whereas all the residents of Stacionar are mobile, they still spend the vast majority of their time in confined spaces. There is an established formal structure of work in this institution, but it does not meet the needs of the residents.

The paucity of activities which engage the residents in Kulina may be explained (but not justified) by the alarmingly low staff-to-beneficiary ratio. The structure and training of the staff are also problematic. However, there can be no explanation found for Stacionar where the number of employees is higher than the number of residents. Here, it seems that the staff structure and working habits are altered. For example, the staff speaks about certain “specialized individual treatments” in their work with residents, but when asked about group activities, refers to showering and eating. This kind of explanation reflects the erroneous or complete lack of understanding of group-work possibilities by the members of staff.

In every institution that we visited, the employees’ relationship with the residents varies. Residents with fewer disabilities are “privileged” and they are included in more activities. Residents with more serious disabilities are merely “taken care of”, which in fact means that they are merely supervised. These residents drift around the common rooms or sit in beds completely aimlessly. For the majority of residents, life in the pavilions is reduced to eating, sitting and sleeping. The majority of the staff behaves well towards the residents, showing care and attention, but also displays a great deal of disbelief that persons who have major disabilities can in any way be engaged in any kind of activities. Therefore, a high number of residents have developed



Multipurpose workshop, Veternik



Sewing workshop, Veternik

passive (also known as institutionalized) behaviour<sup>19</sup>, in that way adapting to the routine, boredom and lack of purposeful activities. Even the staff who takes care of these residents with time becomes more and more “institutionalized.”

All five institutions with adult residents that we visited have formed special groups (so-called “caring groups”) where 15 to 20 residents spend time exclusively with a carer who, in most cases, is not trained for educational and occupational work, so the entire activity boils down to “caring.” When we asked about the activities of the residents within one of such groups, we were told that those activities included “feeding and bathing,” even though it was evident that each resident in this group is mobile. Persons who are constantly in bed and with whom the staff was not able to establish any type of communication are referred to as children, regardless of the fact that they are adults.

It seems as if the carers are not sufficiently empowered (or motivated) to try to perform other activities with the residents, apart from taking care of their hygiene and diet. However, the current situation where one carer comes on a large number of users with complex disabilities raises the question whether any type of meaningful activity could be performed under the circumstances. We also noticed the weak interaction among residents and carers, who keep moving from department to department. The carers know only a few details about the residents, such as where they came from and what their ties with their families are like. So, the residents have no opportunity to create any kind of bond with individuals that would take care of them.

As with the adults, a certain number of children are placed in so-called caring groups. In the pavilion for children in Sremčica, the caring group of children spends time in the room with mats, with barely any toys. A nurse that worked there for a long time, but in a different pavilion says that the “children are in that room all day long,” and that the special educator leads the children one by one upstairs to work with them. The general impression is that the present nurses are not aware of how certain children function, what their specific disabilities are, why they act in certain ways, what their capabilities, skills and interests are; and regarding children that have arrived from other institutions, they have no knowledge of when and where they came from. Additionally, there is a complete lack of understanding of children with autism and a certain fear of interacting with them.

The situation is better in Zvečanska, where the atmosphere in the rooms is much livelier, due to the presence of volunteers, from whom the majority of children get direct support in communication and in play. It is also worth mentioning that the staff and the director, unlike in other institutions, are well acquainted with all children. Immobile children with more disabilities regularly spend time on the balcony, while the children who have arrived from other institutions, for the most part from Kulina, begin to be taught how to master the inside space, as they are still afraid of going out due to having been denied that experience for a long time. There are rooms dedicated to educational work with children of school age in Sremčica and Kolevka, while in Stamnica there are specialized rooms for occupational therapy where the atmosphere is lively, but only a smaller number of children are involved.

The most drastic example of unequal treatment was discovered in Veternik, in the facility where children with the “most severe disabilities” are housed. Of the 72 residents, only 14 are

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<sup>19</sup> They have slid into a monotony, sitting aimlessly, without the desire to be included in any type of activity, while the users that are lying in beds cease to react to any stimuli; they are afraid of sounds, light, touch.

included in group-work taking part in the newly equipped room. Others spend time without any activity. During the day, 2 medical nurses and 4 carers spend time with them, while at night there are only 2 carers to tend to 76 residents. In Kulina, one nurse in the daily shift takes care of 20 to 34 residents with the most severe impairments. This situation represents a security risk not only for the residents, but also for the employees who are under the high risk of violent situations.

The basic reasons for this state of affairs are, above all, prejudices towards children with the most severe disabilities. They are reflected primarily in the problematic conditions and regulations prescribed by the state.<sup>20</sup> Therefore, in institutions for young children the emphasis is on health care while the activities relative to psycho-social rehabilitation, at least for the children with more serious disabilities, are unjustifiably neglected.

On the other hand, in institutions where there are both children and adults, and which are according to the Decision on the Network of Social Welfare Institutions, dedicated to the care of children and/or adults with “severe and most severe disabilities”, the emphasis is placed on basic care. A very small number of expert and basic nursing staff (the staff who directly works with the beneficiaries) is engaged. This has direct adverse impact on the possibilities of children’s rehabilitating activities and educational work. Also, even though they spend most of time with the residents, the carers do not go through any training, so their job is mostly reduced to provision of basic care.

For many decades the presence of the medical model of care for persons with disabilities has led to the situation that residents are seen through their diagnosis. This approach has remained with the staff, regardless of their profession or the level of education:

*“He is a Down; combined risk.” – Kolevka*

*“Hydrocephalus lives for 4 to 5 years; this means that we are doing a good job.” – Kolevka*

*“There are no plans for all the children, because there are children who do not react to emotional, tactile, visual and auditory stimuli.” – Kolevka*

*“The TV set is only for children who can understand something.” – Veternik*

*“Some of them can no longer go to the common room [rooms where the educational work is conducted] because they deteriorate no matter how hard you try.” – Veternik*

Often, the children and youth are referred to in a negative context right before them, as if they are not even present (“He was one of the most aggressive kids here,” “He is a moderate,” “She is borderline retardation and she really does not belong here among the moderates”), which causes residents to feel shame and humiliation.

In Stacionar, it is particularly noticeable that the employees see the residents as persons who cannot do anything, who are “gone-for-good”. They consider that everybody among the residents has problematic behaviour, that they are prone to running away, aggression, breaking things, eating inedible objects; that they are persons to whom nothing can be explained and that nobody would be able to “deal” with their unwanted behaviour. Problematic behaviour is perceived as an integral part of the residents’ condition, or of their “disorder” and not as a con-

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<sup>20</sup> Pravilnik o bližim uslovima za početak rada i obavljanje delatnosti i normativima i standardima za obavljanje delatnosti ustanova socijalne zaštite za smeštaj dece i omladine ometene u razvoju (Official Gazette of the Republic of Serbia, no. 88/) and Pravilnik o bližim uslovima za početak rada i obavljanje delatnosti i normativima i standardima za obavljanje delatnosti ustanova socijalne zaštite za smeštaj (Official Gazette of the Republic of Serbia, no. 88/93, 53/05)

sequence of their unsatisfied needs, lack of activity and the length of institutionalization. The condition of persons with autism, according to the staff, is correlated with “psychiatric problems” such as psychosis. The staff fails to see the relation between these types of behaviour, the treatment, and the consequences of being institutionalized.

It is certain that a number of children, due to various impairments, initially require training in basic life skills, such as standing, walking, using hands, eating independently. This process sometimes can be long, for example mere transition from pureed to solid foods, may become a process that can take months. Nevertheless, a significant number of children can do more than that. It is necessary for them to have individual activities devised in a way that helps them develop their potential to the maximum. It is also necessary to consider the increase of staff and when this is not possible, to work on educating the entire staff, regardless of profession and formal education, on the needs of the beneficiaries. Zvečanska is an example of a successful reorganization of work and other institutions should draw from this experience. The exchange of experiences among institutions should be encouraged.

## NEGLECT AND ABUSE

Today there is a large number of scientific studies that confirm the exceptionally negative effects that institutionalization has on children and adults. These studies refer to the residential staying in institutions as an extreme example of social deprivation (the lack of human contact) and corroborate the negative outcomes of early institutional care on mental health.<sup>21</sup> The developmental outcome for children who experience institutionalization depends on the length of stay, where longer periods of institutionalization are connected to atypical limbic development and difficulties in controlling emotions, including anxiety. Apart from increased emotional sensitivity, studies show a wide range of effects that institutionalization leaves on a child’s physical development and motor skills.<sup>22</sup> These effects include stereotypical behaviours, such as rocking back and forth and self-injury. Hearing and sight may be impaired due to inadequate diet and/or lack of stimulation.

The scarcity of occupational programs for persons with the most complex disabilities, or their complete lack leads to a weakening in social and psychological functioning. Due to inactivity, persons tend to express the “unwanted” behaviour – ripping off their clothes, destroying things, rocking back and forth, self-injury, aggressive behaviour towards other residents and staff, all of which inevitably leads to the frequent resorting to the use of isolation and chemical and mechanical restraints.

Insufficient staff, despite presence of good will, is not capable of adequately taking care of the residents who have the most complex disabilities and demand the most attention. The only solution available to the staff remains the use of antipsychotic medication<sup>23</sup> and the limitation of movement either by isolation or mechanical restraint. Since this treatment only leads to the deterioration of the residents’ psychic condition, as stated by numerous sources, the use of these measures often increases and sometimes turns into abuse.

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<sup>21</sup> Bos K, Zeanah CH, Fox NA, Drury SS, McLaughlin KA, Nelson CA. Psychiatric outcomes in young children with a history of institutionalization. *Harv Rev Psychiatry*. 2011 Jan-Feb;19(1):15-24.

<sup>22</sup> Browne, Kevin: *The Risk of Harm to Young Children in Institutional Care*, Save the Children (2009), p.10

<sup>23</sup> Medication used in the treatment of mental illness that targets the central nervous system



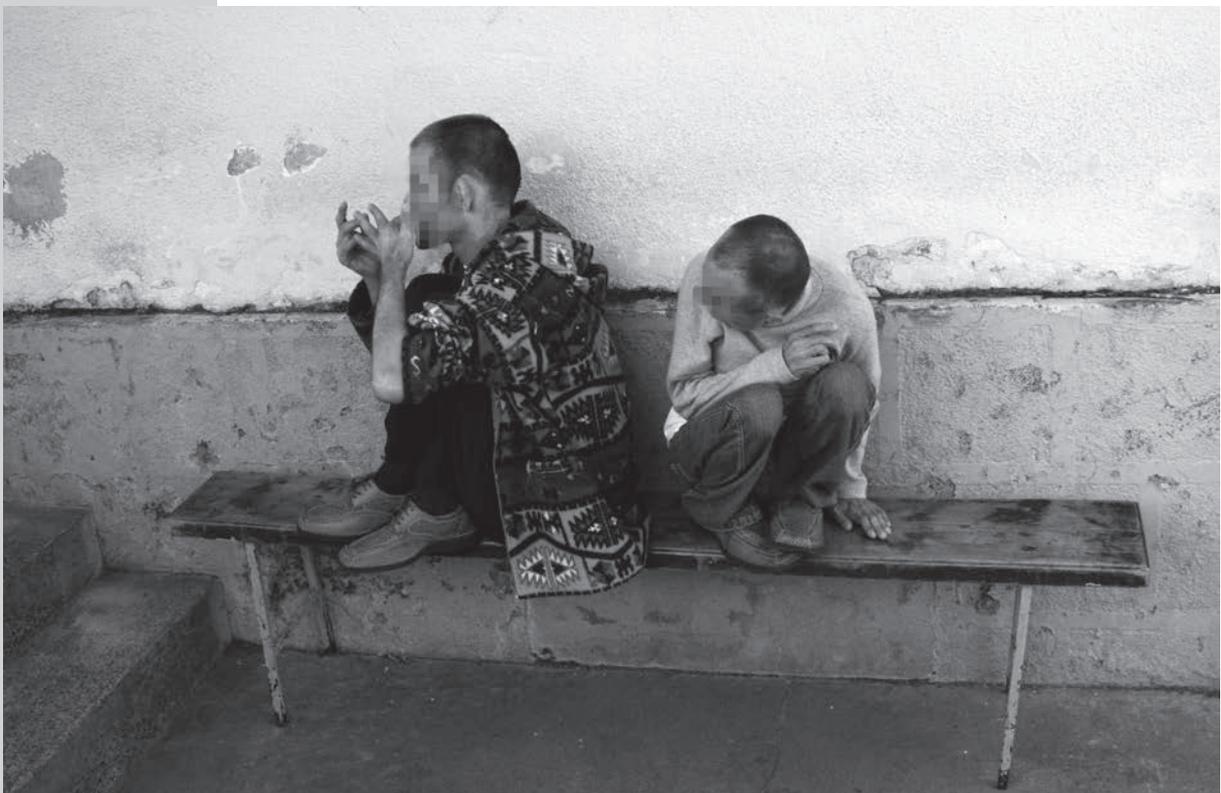
Common room for children with severe developmental disabilities, A pavilion, Veternik



Common room for women with severe disabilities, A2 pavilion, Veternik



Common room for men with severe disabilities, A1 pavilion, Veternik



Residents in the Upper zone, for adults with severe disabilities, Stannica



Children's pavilion, Sremčica



Common room for children with severe developmental disabilities, A pavilion, Veternik

Neglect is additionally caused by negative attitudes of the employees towards the residents – which in fact emerge from the experts and public opinion – i.e. their inability to recognize the needs of the residents and to respond to them. The staff often interprets the unwanted behaviour as a necessary consequence of the clinical features, based on the diagnosis of the residents and not as a consequence of their devastating frustration ensuing from unsatisfied needs.

## **Abuse of medications**

Among the visited institutions, abuse of medication is the most alarming in Stacionar, where only three out of 49 residents are not on antipsychotics. Long-term use of these medications causes a range of side-effects affecting motor function, metabolism, cognitive ability and many others. This is why there is a common misconception amongst the staff that “these persons age more rapidly.” The rapid ageing is linked to the diagnosis and not to the drugs whose use has such consequences.

*A day before our visit, a young woman was admitted to the institution, without being prepared in any way. She was visibly upset, shivering, sweating, and standing in a corner terrified. We found out from the staff that her therapy had been increased eightfold because they “needed to divert her thoughts” so that her adaptation could begin. – Stacionar (Home for Children and Youth with Autism)*

In Veternik, there are hardly any residents who receive only one type of medicine. Most often, residents receive a combination of several drug groups, as well as combinations of older and more recent medication in dosages that cause considerable side-effects – something that can be concluded based on the appearance of the residents (excessive salivation, slow motion, lack of expression.) Keeping people constantly on antipsychotics, especially when failing to keep proper records and register side-effects, may lead to disability, irreversible damage to the nervous system or sudden death.<sup>24</sup> Out of 573 residents, about 400 are on psychiatric therapy, with or without internist therapy.

Among them there are 170 residents who were diagnosed with epilepsy, so they also receive medication for this condition. Medical records reviewed in Kulina showed that, in most cases, older medications with more prominent side-effects were prescribed.

Although over-medication is more prominent among adult residents, it is worrying that antipsychotics are very much prescribed to children too. Justification for this practice is questionable when we look at the children’s diagnoses – severe disability, autism, behavioural problems. In Zvečanska 20-30% of children receive neuroleptics.<sup>25</sup> The staff claims that the “children are flooded with diagnoses, check-ups and medications.” It is commendable that the employees in this institution carefully monitor how children react to medication and point out problems, when and if they occur.

Apart from Stacionar, no other institution has a full time psychiatrist, so there is no continuity in monitoring the condition of residents. Psychiatrists who decide on the administration of medication are for the most part unfamiliar with the life context of the residents in question.

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<sup>24</sup> Sudden unexplained death in psychiatric in-patients, Appleby et al (2000) (Iznenadna neobjašnjiva smrt kod psihijatrijskih pacijenata)

<sup>25</sup> Type of medication used to treat psychosis



Isolation room, A1 pavilion, Veternik

Taking this into consideration, engagement of a full-time psychiatrist in an institution could be thoroughly justified. Nevertheless, as experience from Stacionar tells us, the mere presence of a psychiatrist in an institution is not a guarantee that cases of over medication will not occur.

## **Physical restraint and isolation**

The abuse of medication, isolation and restraint are often used to keep residents under control and to provide respite to the alarmingly meagre staff. The problem of inadequate numbers of employees is compounded by inadequate staff structure – the absence of employees with the skills needed to work with beneficiaries.

During the visits to the institutions, no restrained residents were noticed, but many were found in isolation. The staff at Stacionar and Veternik confirmed that restraint was regularly administered. In Stamnica and Sremčica, employees and the management claim and information from the institutions' records show that restraint was rarely used.

This measure, according to the employees, is not used in Zvečanska and Kolevka. In other institutions there is, in most cases, a protocol on use of restraints which is adopted by the institution. Still, Veternik only has a rulebook on working with beneficiaries and there is no official protocol on restraint. Employees consider a major problem the fact that this issue is regulated by each individual institution:

*“It is still an unresolved issue; it is more improvisation than the official protocol.” – Veternik*

*“Despite our numerous pleas to the Ministry of Health, there is no official protocol that would regulate use of restraints.” – Stacionar*

Apart from the lack of clear and unified criteria for the use of restraints, the length of the application of this measure, as well as its poor record keeping are also problematic. Additionally, residents are often restrained in front of other residents, for example in the common room.

Although the medical doctor in Veternik denies that restraint is commonly used with extremely agitated residents, the other employees confirm that this is practised, especially in pavilions A1 and A2. The restraint mechanisms include belts with magnets and special sheets with leather belts that fixate the entire body. No adequate records about this exist. The last measure of restraint recorded in the “notebook of fixations” was in early 2011. There were around 50 restraints recorded in 2009 and 2010, and only two in 2011. Regardless of the fact that the registered duration for each recorded restraint was two hours, we were told that, if needed, a person can be restrained much longer, according to findings of MDRI-S team medical doctor.

According to the staff statements collected from Kulina, “there is no need for restraint,” and the last time a resident was physically restrained was in March 19, 2009. Considering that from January 1, 2009 to March 19, 2009, 34 fixations were recorded, it is likely that this measure is still conducted, albeit with poor record-keeping. An isolation room existed, but it was not shown to us, despite the insisting of the doctor on the monitoring team and contrary to the agreement signed with the Ministry of Labour and Social Policy.

In Stacionar there is no special room for isolation, so the residents are restrained in the common room, in the presence of other residents (the procedure is performed with leather belts or belts with magnets). Some residents are restrained on a daily basis. In the opinion of the doctor on the monitoring team, that number is quite high compared to the total number of residents. Since this procedure causes great psychological pain to the person, a more strict control of the utilization of this procedure is required.



Fixation equipment, Veternik



Fixation equipment, Sremčica

In Zvečanska and in Kolevka this procedure is, according to the staff, not used. They say that when children show anxiety and distress other measures are undertaken – analysing the causes of such behaviour, and more attention and physical contact is given to the child.

*“We are trying to understand the function of [such] behaviour; that behaviour [self-injury] comes as a result of deprivation. Children have their phases and then we do everything to help them – we give them more attention, more physical contact, and that calms them.”* – Director, Zvečanska

In Kolevka, a boy with HIV was found in permanent isolation, without adequate stimulation. He was placed in a special room within the semi-intensive unit, where there are children who are seriously ill. This boy’s situation requires serious attention from the competent services, since this isolation has already taken its toll on his development. What is particularly worrying is that these consequences affecting his development are not perceived as consequences of isolation, but as inherent characteristics of his condition.

Frequent isolation of residents in Veternik, of which there are no records, is highly troubling. Although some employees say that isolation is used for no longer than 2 hours, the staff who works at particular wards and the residents themselves told us that some of the isolation rooms are de facto “the permanent place of stay” for some of the residents. These rooms, which the residents call “the slums”, are small, with one or two iron beds. Some are covered with tiles, others are not. Contact with staff is made either through bars or through a little opening with bars in the middle of the door. In the A1 pavilion for men, we found two young men in separate rooms with bars and a mattress on the floor. In pavilion A, which is reserved for children, we found four children locked in the rooms with bars on the windows, and without any openings on the door through which the staff could see what was going on inside. One of the rooms held a young man who suffered from epilepsy and was “prone to impulsive actions, so it was safest for him to be there.” Putting him in that type of restrictive surrounding is very risky and can be, considering his seizures, life-threatening.

*“Z. is an antisocial being, cannot stand anyone in his vicinity, so he is permanently kept under the lock.”* – Veternik

Long-term antipsychotic therapy, the use of physical restraint and isolation causes enormous suffering for these persons and is very dangerous. The monitoring team concluded that these measures are used mostly because there are not enough employees who can provide different types of treatment in situations when residents engage in undesirable behaviour, either towards themselves or to others. Another reason is that it is easier to give a person a tranquilizer instead of searching for the causes of their troubled behaviour, which is usually a reaction to frustration. Keeping people medicated, in isolation and restrained gives rise to feelings of humiliation and makes people vulnerable and susceptible to neglect and abuse. Such measures should never be justified by the staff being overburdened or unable to provide adequate treatment. According to international standards, the wide-spread misuse of medication and leaving people in long-term physical restraint and isolation represents cruel, inhuman and degrading treatment or punishment. In some cases, the long-term use of these measures may reach the level of torture.<sup>26</sup>

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<sup>26</sup> Charles H. Zeanah et al., 2010.

## Health and Life Risks and the Denial of Health Care Treatment

*“One can take a perfectly healthy human being, tie them to a wheelchair, and they will die if you leave them immobile for long periods of time. Everything shuts down. All body systems are dependent on movement.”* – Karen Green McGowan, expert for practical work with children with developmental disabilities

A large number of children and adults from the visited institutions require more intensive medical care and nurture. However, focusing exclusively on primary health care of residents, while no expert staff and no stimulation are provided to them, leads to the worsening of the residents’ condition and may have adverse consequences on their health and life.

Apart from the use of physical restraint and isolation, we came upon a large number of children and adults who could not move and who were restrained by the very fact that they were left to lie in cots or beds with iron bars, from which they could not leave without assistance. Many of these people suffer from cerebral palsy which, without proper treatment, leads to the dislocation of limbs.<sup>27</sup> A person who is unable to move because of the state of their limbs and joints is under great risk of scoliosis or spinal bending. Stretching and correct positioning are crucial for the prevention of deformities.

*“You have noticed that a large number of them have secondary contractures<sup>28</sup> because of lying. And we have only one physiotherapist for all our residents.”* – Kulina.

There were a large number of people with secondary contractures in Kulina. This is the consequence of long-term recumbence. Even though one physiotherapist works at the infirmary, the institution does not have a full time physiatrist. The room for physiotherapy is not used and it is completely inaccessible to those who need this treatment. These persons are placed in isolated wards which they cannot leave.

*“They are immobile and semi-mobile, we do not take them outside. There are children upstairs who can get out.”* – Kulina, central pavilion

Providing adequate care is additionally altered by placing immobile residents on the upstairs floors without elevators, thus effectively divesting them of the possibility of any movement. The low-numbered staff is unable to carry the residents outside or to the physical therapy room. Thus, the residents are kept in multiple isolation and without opportunity to even leave their beds.

Long-term physical inactivity and recumbence is dangerous both for the physical and mental health of every child and adult.<sup>29</sup> Due to long-term recumbence, the head becomes flat, and the bones do not develop properly because of inadequate effects of gravity force. In Kulina, we discovered a young man, seemingly jointed with the bed mattress. His body was thin and the bones had no muscles on them. Many children who grow up in beds experience limited growth. There are a lot of teenagers and adults in the institutions that look like they are three to five years old, not because of some “inborn” condition, but because of long-term recumbence and the withholding of the treatment they need.<sup>30</sup>

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<sup>27</sup> Sanda M. Nettina, Lippincott Manual of Nursing Practices 194 (9th ed.), 2010.

<sup>28</sup> Bending, dislocation of joints which is the result of the permanent recumbence

<sup>29</sup> Carter, 2005; Mulheir and Browne, 2007; Smyke et al., 2007

<sup>30</sup> Charles H. Zeanah et al., 2010.

Apart from not receiving adequate treatment within the residential institution – due to the lack of staff, but also due to their poor training in the field of working with persons with complex disabilities – the most alarming fact is the discrimination of the residents by the health system. One of the most common problems that institutions mention is the discrimination of children with disabilities and adults with mental disabilities in the general healthcare system and the hardships they have to undergo in order to receive necessary treatment outside the institution.

For instance, there are cases when children come to the social welfare institutions after the hospital ethical committees have labelled them as “cases for palliative care,” essentially writing them off; yet we can see that they live in the institutions for a long time and sometimes even recover or their condition improves. The situation is critical in institutions such as Zvečanska and Kolevka, where children are often directed shortly after they have been born.

*“Doctors have great power. Children who come from hospitals are practically just forwarded here to die. They didn’t even send us the necessary therapy for this little girl, because she would most likely not make it until the next morning. We managed to save these children from critical state and right now they are improving well.”* – doctor, Zvečanska

Even following placement in an institution and despite the requests sent by the institution, hospital ethical committees further refuse to approve provision of proper treatment for a child which would either keep them alive or at the minimum, ease their suffering.

In Zvečanska, in the semi-intensive unit, we find a boy with hydrocephalus. He is lying on his side, facing the wall and weeping – obviously suffering from pain – while the nurse is trying to calm him by cuddling him. In his case, the ethical committee decided not to operate on him because of the great risk factor and to perform only palliative care. Two years have passed since the ethical committee’s last decision and his situation has deteriorated. Nevertheless, despite all the predictions, he is still alive and in great pain.

In cases like this, the first question is why the boy did not receive the necessary treatment immediately following his birth or after the illness was diagnosed and subsequently, whether it is more humane to undertake the risk and give him the indispensable treatment or to leave him lying for years in insufferable pain.

The situation seems to be worse for adults. Employees tell us that they encounter big problems when trying to obtain appropriate specialist treatments. A significant problem is that these persons are reluctantly admitted to the hospital, even when they are in critical danger. It is not rare that in these situations the continuous presence of the medical nurse from the institution is required by the hospital.

*“There is a horrific stigma in the healthcare system, because hospitals do not want to admit our patients”* – staff, Stacionar

*“We have to deal with the lack of understanding from our colleagues, and due to the high dosage of medications, the residents are returned in sedated state, with comments such as: ‘Unlike our patients, the quality of life of your residents cannot be improved.’”* – staff, Stacionar

The staff in Stacionar gave an example of a young man who was diagnosed with acute kidney insufficiency with critical vital signs. In that state, he was discharged from the hospital with the recommendation that he should continue his treatment in the institution. Considering the fact that there are no adequate conditions for such treatment, in this case the prognosis is very bad.

*“Cooperation is generally poor, because they are afraid of our beneficiaries and if hospitalization is needed, they ask that our nurse be present.”* – staff, Stacionar



Semi-intensive care, Zvečanska



Isolation room, A pavilion, Veternik

Considering the fact that all institutions that we visited had a large number of residents who were using antipsychotics, a big problem is that the Republic Healthcare Fund (RFZO) provides only 1.8% of its funds for this type of medication. Thus, this population is denied treatment with newer generation of medicines with fewer side-effects because it is more expensive.

The situation is additionally exacerbated by a dispute concerning financing, i.e. the territorial jurisdiction of the healthcare centres. Namely, the residents are placed in institutions that are normally outside of their place of residence, so a question emerges on who approves and who pays for their medical treatments. The healthcare insurance fund that has competence over the institution refuses to cover medical expenses. So, usually the service is then, following a complicated procedure for obtaining of approval, paid from the fund tied to the beneficiary's earlier place of residence, even though they may have left long time ago or have never even lived at that address. Months can go by until medical treatment is approved. Thus, valuable time in providing healthcare can be lost or alternatively, the treatment is simply paid by the institution.

A doctor in Sremčica gave an example of the health centre which cannot charge the expenses for persons who are not insured in Belgrade, therefore it refuses to perform laboratory analyses for them. Patients are then referred to private labs and the expenses are covered by the institution. It is the same with consultations in the Clinical Centre of Serbia.

Even though the majority of institutions have equipped dental offices, the labour systematization does not allow for the employment of a dentist. That is the reason why an inspection of the Ministry of Health ordered that this service should be otherwise arranged. Since then, the majority of institutions started cooperating with the Faculty of Dentistry, where the residents are sent only for complicated procedures that are most often conducted under general anaesthesia. Conservative care is almost never performed. Health of residents is therefore additionally jeopardized by this ministerial decision, particularly if we consider the generally bad condition of residents' teeth and frequent gum inflammations.

It was mentioned above that the majority of residents have extreme problems with muscular-skeletal-joint system, which is in part a consequence of inborn deformities and in part the consequence of inactivity or inappropriate positioning. Some institutions have (scantly) equipped rooms for physical therapy (Sremčica, Stamnica, Zvečanska, Veternik use them according to their original purpose, while other institutions use them as storage closets). In most cases there is one physio-therapist on staff, who performs the therapy following the orders from a doctor or less frequently, of a psychiatrist. The insufficient number of mobility and support aids that the immobile or semi-mobile residents need makes the situation even worse. Considering that the system does not include physiotherapy as necessary healthcare for persons with intellectual disabilities, the often-present dysfunction of their musculoskeletal system additionally complicates their disabilities.

## **PROTECTION OF THE RIGHTS OF RESIDENTS**

The basic characteristic of the institutional system is the inability to respect the privacy and at the same time provide safety to the residents. In the existing physical conditions and with the rigidity of the routine, social exclusion and overcrowded facilities, it is not possible to ensure the respect for privacy of residents. On the other hand, it is necessary to establish mechanisms for protection of residents, so that the risk of their exposure to neglect and abuse is minimized.

## Arbitrary Detention and Freedom of Movement

Institutional placement is still the only alternative to the life within a biological family offered to children and adults with disability. Even though the new social welfare law suggests a wide range of services that should encourage and enable life in the community, these services are not yet institutionalized within the system and are not available to the residents. At the same time, the competence for developing these services has been transferred solely to the local level. This gives rise to potential for much discrepancy among the municipalities with regard to the services they would provide.

The predominant reason for institutionalization is the mere existence of disability, or certain types of disability and impossibility to receive adequate care within the family. The main problem is that children and adults are still placed in institutions according to their “category”, meaning type of disability instead according to their place of residence. This represents yet another form of discrimination and makes maintaining contact with family relatives and return to the natural surroundings much more difficult. Only 10 to 15 percent of residents come from the municipalities where the institution is located, or from the surrounding municipalities.<sup>31</sup>

We learn from the employees in all institutions that a large number of residents have no adequate diagnosis and that they are often ascribed to certain categories in order to obtain the right to be placed in a certain institution. Consequently, among children and adults categorized as having “a severe and very severe disability” there are persons who could with minimal support immediately leave the institution to become included in the community. Yet, with the loss of that categorization, they would also lose the right to placement to any institution. At the same time, categorizing a person within a certain category leads to them not being able to exercise numerous rights, above all in education and employment.

Aside from being fenced and locked, the majority of institutions are outside residential areas or are far away from the centre of the residential area. This additionally complicates leaving an institution and maintaining contact with people outside the institution. The residents are banned from freely moving outside of the institution, unless they are granted permission by the authorities. It is important nonetheless to note that this restriction has no basis in judicial or administrative decisions, considering the fact that the resident has not violated any laws. The freedom of movement and meeting people outside the institution is the first mechanism of protection, because it enables residents to make complaints and to point out potential problems they might encounter in their everyday lives in institutions.

The institution in Kulina is so far from the nearest town that contact of the residents with the outside world can only be established if someone comes to visit. However, the geographical position of the institution makes it harder for relatives to come. A small number of users may leave the institution with consent. Denying them legal capacity further complicates the freedom of movement, because for every leave, consent of a guardian is needed. Thus, residents become prisoners who cannot freely leave upon own decision. To illustrate this, the director gives an example of a young man who is capable of independent movement outside the institution. He often visited fairs in the nearby places, but now, because of his guardian’s decision, he is not allowed to leave the institution.

*“We are not ready to undertake risks of that nature.”* – the answer of the staff of Stacionar when asked if the residents are allowed to move freely.

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<sup>31</sup> Izveštaj o radu ustanova socijalne zaštite za smeštaj osoba sa invaliditetom za 2010. godinu (Report on social welfare institutions for persons with disabilities, 2010)

Additionally, the users are frequently denied freedom of movement within the institutions – locked wards and locked rooms are common during the day. In Sremčica, we encountered locked doors of the residents' rooms. It was explained that this was a way to provide safety for the residents and that sleeping during the day brings no therapeutic benefits to their psychological condition. However, with such restriction, residents have no privacy and possibility to rest during the day. Thus, we found residents napping, leaning against the table or the radiator in the common room. In view of the information provided to us by the staff, management and residents on occurrence of intimate relations, the question arises where this occurs and how the privacy for these people is secured. They are locked out of their rooms during the day, and are in the company of other residents during the night.

We encountered locked dormitories in Kulina and Veternik as well. In Veternik, in a special locked area, the doorknobs were taken off from several rooms so that they could not be opened from the inside. Almost every door had bolts on the outside as well. We were told that this was done for the security of the residents due to a small number of staff. This explanation might appear logical, but it is not justifiable from the human rights perspective. Once again this points to the defects of the institutional system – even when the best physical conditions are met, it cannot ensure both privacy and security to their residents.

## **Personal Contacts and the Right to Privacy**

People living in an institution do not have the right to choose with whom they will live, and they cannot attain the levels of privacy that other people enjoy in the comfort of their homes. Considering that the institution is intended for large numbers of people, especially if those are people that need significant support in everyday life, the residents are exposed to the restrictions that diminish the possibility for self-determination, including the rules on when, with whom, how often they can leave, and when will they return. These restrictions especially limit the possibilities for establishing intimate relationships and the expression of sexuality.

As mentioned above, only a small number of users keep contacts with their families (including visits and phone contacts), which is additionally made more difficult because of an institution's geographical location, but also the limited visiting hours (for instance, visiting hours in Veternik are until 3pm on weekdays). Institutions' staff also told us that a large number of families are not at all acquainted with the possibility for reimbursement of travel expenses by social work centres. In the majority of institutions the residents have no possibility to contact dear persons at the time of their choosing. The only phone booth noticed during visits was the one in front of Stamnica. Rare contacts with significant persons, without predictable dynamics are maintained by only 20% of the residents, while 8.8% of residents have continual contact, albeit with frequency of less than once a month. The structure of the residents according to the manner of keeping contact with family and relatives shows that the majority of residents have no contacts with their relatives – 53 percent.<sup>32</sup> Of all the residents, 12.5 percent have no relatives.

Contact with people outside the institution is crucial for the protection of the residents' human rights, but it is also a prerequisite for de-institutionalization or the return to their natural surroundings. Only the openness of the institution can lead towards the effective protection of rights. If we want to work on the inclusion of people into the community, it is necessary to first

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<sup>32</sup> Ibid.



Residents socializing in C block, Stamnica



Residents socializing in C block, Stamnica

encourage the creation of social networks of current residents and the establishing and maintaining of contacts with people living outside the institutions.

Considering that a large number of residents spend their entire lives in institutions, it is impossible to prevent or prohibit them from having intimate relations with other residents or persons living outside institutions. It is especially important to ensure that the residents are not exposed to violent behaviour or abuse, which essentially means that these relations must be voluntary.<sup>33</sup> It is difficult to establish a formal system for “approving” intimate relations between the residents, particularly because it probes into the privacy of an individual, so again we encounter the inevitable question of balancing the right to privacy with the efficient protection against abuse. The ability to voluntarily enter into sexual relations requires an open discussion with residents, so that their individual rights are respected, while they are at the same time protected from potential sexual abuse. This is especially significant since persons with mental disabilities, particularly women, are subjected to higher risk of abuse and violence on the part of other residents as well as members of staff (this includes the violation of privacy, acts of restraint, undressing, isolation, rape, forced abortion or sterilization).<sup>34</sup>

In four out of five institutions visited where the adults are accommodated, intimate relations are considered natural and the employees do not attempt to curb the residents’ behaviour in this area. In Stamnica, there is a detailed record of monthly menstrual cycles and contraception, while in Sremčica they claim to dedicate special attention to the sexual education of the residents. Still, special attention should be dedicated to the issue of contraception, as there is reasonable doubt that contraceptives are provided non-selectively, or in a sufficiently effective manner.

*When asked whether they have intimate relations with other residents and if they have their privacy, one resident in Sremčica responded that they manage to perform it in agreement with roommates, who “go somewhere to do something.” Contraceptives, such as the diaphragm and pills are provided to the female beneficiaries, while the males are provided with condoms. Yet, they tend to have unprotected sex. One male resident told us that his girlfriend already had two abortions (“one time it was twins, one time it was a boy”).*

In Veternik, awareness of the employees about which and how many residents practice sexual relations is significantly lower than in Stamnica or Sremčica, the danger of abuse being therefore higher. In Kulina, apart from the confirmation that residents do have sexual relations, we could not obtain any additional information. The combination of lack of knowledge on this and small-numbered staff give rise to an extremely high danger of sexual abuse.

While awareness about sexuality of the residents exists and is not negated in the mentioned institutions, a complete lack of understanding of the sexuality issue was encountered in Stacionar. Its employees think that the residents’ sexuality is “turned off” and they exhibit no awareness that this kind of a need has to be taken into consideration. They believe that the residents are unaware of their sexuality, and feel no shame. Correspondingly, young men and young women sleep in the same rooms, while video surveillance is installed even in the bathrooms. The employees do not seem to realize what the residents could possibly gain by gender separation since “they are not aware of anything.”

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<sup>33</sup> For more information on the consent to sexual relations by persons with disabilities see: The Notion of Consent to Sexual Activity for Persons with Mental Disabilities, Suzanne Doyle (<http://www.inter-disciplinary.net/wp-content/uploads/2010/04/sdoylepaper.pdf>)

<sup>34</sup> International Network of Women with Disabilities (INWWD), Document on Violence against Women with Disabilities, 2010, p. 8.

If some residents do not exhibit any sexual needs or frustrations as a result of inability to express them, naturally, they must not be forced to enter into sexual relations. Nevertheless, the staff must bear in mind that if such a need exists, their inadequate response or dismissal can lead to much frustration and unwanted behaviour. Special attention needs to be dedicated to this issue, which means education of both residents and staff. It is especially important to keep in mind that denying existence of residents' sexual needs will not prevent potential cases of abuse.

## **Mechanisms for the Prevention of Abuse and Neglect**

The Ministry of Labour and Social Policy forwarded the Special protocol for the protection of children in social welfare institutions from abuse and neglect<sup>35</sup> to all institutions. The protocol was adopted by the Serbian government in 2006. It established the procedure to be undertaken by the competent persons and institutions when suspected neglect and abuse are occurring inside a residential institution. This mechanism introduces special protection of children in institutions, but it fails to protect them from neglect that occurs as a result of the system's inability to provide them with adequate care. Also, it is uncertain to which extent the employees in the institutions are willing to report their co-workers.

Whereas the special protocol offers a certain extent of protection from abuse and neglect to children, the mechanism of protecting adult residents is still solely in the hands of individual institutions. No unified criteria are established on the central level which would, for instance, regulate the use of restrictive measures towards the residents, such as the use of chemical and physical restraint and isolation. Record keeping about the use of these measures is also left over to the institutions and, for the most part, it is completely inadequate and superficially run. Therefore, adult residents in social care institutions are placed under a high risk of neglect and abuse resulting from violent acts committed by both other residents and the staff, but also from the inadequate treatments and procedures.

The establishment of independent control mechanisms for the violation of rights is one thing that leads to ensuring full protection from abuse and neglect. However, it is essential that the institutions themselves have effective internal mechanisms which would serve as the first safeguard in the prevention of abuse and neglect. Such system of protection has not been established in any institution yet, this being frequently justified by "the residents' incapacity to formulate and file a complaint."

*"There are no mechanism for filing complaints because our residents are not verbal"* – Stacionar

The disability of the residents is often stated as justification for the lack of complaints procedures for abuse and neglect, or it is stated that the only mechanism to bring forth a complaint is to express the problem at the so-called therapy groups. In Sremčica, for example, residents' parliament exists. It is composed of one member representing each of the residents' groups, while the residents who are in "caring" groups are represented by their carer. Still, the readiness of residents to report cases of violence and abuse to a great extent depends on the sensitivity of the problem they are faced with, fear of the consequences of reporting the abuser, as well as the extent of perceived mutual protection of co-workers.

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<sup>35</sup> <http://www.minrzs.gov.rs/cms/sr/briga-o-porodici-i-socijalna-zastita>

If a person has no family or friends to help them and cannot contact an organization for protection of victims of violence and abuse, there is absolutely no mechanism they can use to protect themselves. They are left to the conscience of employees to report such cases. This is especially problematic when the abuser is a staff member, against whom co-workers will rarely file charges. The director of Zvečanska confirms that “empathy is stronger in the relationship with one’s co-worker, than it is in the relationship between a staff member and a resident.” It would be useful to establish specialized treatment or counselling for residents, especially for women, that would take place within and outside the institutions. It is also necessary to establish protocols for reporting cases of abuse to persons outside of institutions. Frequently conducted visits to the institutions by members of the civil society and independent human rights state mechanisms, such as the Ombudsman, are yet another way to secure better protection of the rights of the residents.

### **Loss of Legal Capacity and Freedom**

The Convention on the Rights of Persons with Disabilities states that even people with the most severe type of mental disabilities are capable of making certain decisions. Article 12 of the Convention was created with an aim of ensuring to the persons with disabilities an access to adequate support in overtaking maximum control over own life, even when they have significant difficulties in understanding or communicating their choices.

A disturbing practice emerged in Serbia which conditions one’s placement in a residential institution and one’s access to social welfare services with the deprivation of one’s legal capacity. The existing legal frame which regulates deprivation of legal capacity of a person is inadequate because it divests that person of almost all of their rights. In Serbia, persons who are “incapable of reasoning” – as the law states, are provided “protection” in the paternalistic manner, nowadays abandoned in the international standards of human rights of people with disabilities. As expected, this kind of “protection” is often abused and violated by those who are given the authority to protect the interests of persons deprived of legal capacity.

Employees in the institutions that we visited point out that because the residents are deprived of legal capacity, they encounter more problems in realization of their rights, especially the right to work and pay, as well as freedom of movement.<sup>36</sup>

*An adult resident of the institution in Kulina was deprived of his legal capacity. He has the habit of going independently to a nearby town and spending his pocket money. The team of experts estimates that it is in the young man’s interest to sustain his habit, and since the appointed guardian of the beneficiary is employed in the Centre for Social Work, the team asked the centre to provide their formal legal approval. But the centre refuses to issue the approval, regardless of the fact that going out to town is the beneficiary’s regular activity and that the institution is prepared to take responsibility. The institution has no means of changing the guardian’s decision nor of filing a motion for the return of legal capacity to its resident. The Centre for Social Work has the authority to initiate the proceedings for the restoration of legal capacity. In case other persons file the motion, the centre’s approval is a requirement for initiating the proceedings.*

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<sup>36</sup> To find out more about the removal of legal capacity see the MDRI-S report „Univerzalnost prava u praksi“ (Practicing universality of rights) <http://mdri-s.org/files/Univerzalnost%20prava%20u%20praksi.pdf>

According to the information about institutions for children and youth with disabilities (apart from Kulina, all of visited institutions belong to that category)<sup>37</sup>, 76.2% of adult residents are deprived of legal capacity. While the remaining have legal capacity, apart from one resident, none gave a personal statement of voluntary institutionalization. This tells us that all the adult residents, apart from a single one, are placed in institutions against their will. The majority of residents in the institutions (including children and adults deprived of legal capacity) are under the immediate guardianship of the Centre for Social Work – 621 residents (41%), while relatives or other close persons are guardians to 403 residents (27%).

Put into practice, the situation is such that people with intellectual disabilities are not even consulted on whether they want to be placed in an institution as a consequence of a belief that they cannot choose for themselves. The decisions are being made by their guardians, usually in cooperation with Centres for Social Work. The residents are not free to move unless they have their guardians' approval, nor do they have any kind of power to decide about their everyday lives. This practice is in contrast with international regulations. The European Court of Human Rights has emphasized a need to establish procedural safeguards in order to avoid simultaneous deprivation of freedom and deprivation of legal capacity.<sup>38</sup>

## LEAVING INSTITUTIONS

Death is still the most common way out of the institution.<sup>39</sup> Children from Zvečanska, Kolevka and Sremčica are transferred to other institutions (which cannot be considered to be deinstitutionalization) or seldom into foster families. The most common causes of death are old age or illness (death by natural cause) or in the younger population “congenital anomalies incompatible with life.”<sup>40</sup> There was not a single case where a clinical autopsy was requested and performed, so it is impossible to determine whether there were cases of negligence during the treatment. For instance, sudden death can occur as a result of medication therapy, as long-term and over-medication with antipsychotics could lead to disability, irreversible damage to the nervous system and sudden death.

In Kulina, apart from the transfer of children to other institutions and group homes, based on the institution's transformation plan, the most common reason for “leaving the institution” is death. Based on the data gathered through the questionnaire, there were 16 deaths in Kulina in 2010. In all 16 cases stated cause of death was a natural cause, but not in a single case was an autopsy requested, because, as explained, “the guardians did not want this.”

In Kolevka seven children died of natural causes during 2010. Only in certain cases, when such an outcome was not clear, was an autopsy requested. It is well known that children with various impairments live shorter, but the autopsy would still show whether all the medi-

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<sup>37</sup> Izveštaj o radu ustanova socijalne zaštite za smeštaj osoba sa invaliditetom za 2010. godinu, (Report on social welfare institutions for persons with disabilities, 2010) str.10

<sup>38</sup> *Varbanov v. Bulgaria* (31365/96, ECtHR 2000-IV), *Shtukaturov v. Russia* (44009/05, ECtHR 2008-I), *Salontaji-Drobnjak v. Serbia* (36500/05, ECtHR 2009-II)

<sup>39</sup> 36 Izveštaj o radu ustanova socijalne zaštite za smeštaj osoba sa invaliditetom za 2010. godinu, Republički zavod za socijalnu zaštitu, (Report on social welfare institutions for persons with disabilities, 2010) str. 11 i 18

<sup>40</sup> The term that we came upon in the institutions, which means a genetic disorder with inevitable (rapid) fatal outcome

cal measures were undertaken in order to prolong a child's life. It is hard to determine without talking to a doctor or looking at the medical files (none of these was provided during our visit) whether this was the expected outcome, especially when taking into consideration the improper behaviour of the local hospital employees (for example, a child who was sent back from hospital died in the institution less than 24 hours after being dismissed).

Such situation confirms that residents are “written-off” by the system as soon as they enter an institution. In 2010, there were 277 deaths in 20 institutions of social welfare. Of all the 277 deaths, only six were identified as violent (five suicides and one homicide), while three deaths remain undetermined. The report on social care institutions alleged that most deaths (268 out of 277) resulted from an illness and they were pronounced natural, without any additional information being provided. This leads to question whether any additional investigations have been initiated concerning the cause of deaths which are assumed to be non-violent.

According to the information gathered and published by the state organs, the mortality rate in social care institutions is almost 48 (out of 1,000.) In comparison, according to the data of the Statistical Office of the Republic of Serbia, the mortality rate in Serbia in 2010 was 14.2 (out of 1,000)<sup>41</sup>. Such differences are a cause for concern and should open up some important questions: is the right to life being appropriately protected in the institutions for persons with disabilities in Serbia? Can the mere existence of a disability justify a mortality rate which is more than three times higher than the country's average? And finally, is the life of a child with a disability less worthy than the life of other children?

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<sup>41</sup> According to the data of the Statistical Office of the Republic of Serbia, Basic demographic pointers of the population (Osnovni demografski pokazatelji stanovništva)

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# ANALYSIS OF THE REFORM OF SOCIAL WELFARE IN SERBIA

## LEGISLATION AND POLICY ANALYSIS

### New principles in social welfare

Right to living in the community for persons with disabilities is not addressed in the Constitution of Serbia. However, art. 69, which addresses social protection, states that social protection is provided based on principles of social justice, humanity and respect of human dignity and that “invalids”<sup>42</sup> are entitled to special protection, in accordance with the law.

Regulations that should give effect to the persons with disabilities right to community living are contained foremost in the new Law on Social Protection.<sup>43</sup> Principles of the law are in line with the concepts of community living and social inclusion of vulnerable persons including persons with intellectual disabilities. For instance, the principle of least restrictive environment mandates that social services are provided primarily in a direct and least restrictive environment, where those services which enable a user to remain in their community are chosen.<sup>44</sup> The law further introduces the principle of accessibility (physical, geographical and economical) and individual approach.<sup>45</sup> As the law does not couple these principles directly with the operative provisions which regulate provision of social services, it is not evident how these principles will be translated in practice. A system of rulebooks under the law is expected to regulate all issues more specifically.

### Institutionalization

With the new Law on Social Protection, institutional placement became only one form of social services. Placement in a residential institution is provided for those persons for whom it is not possible, or is deemed not in their best interest to remain in their family, receive community-based services or be placed in a family<sup>46</sup>. A child under the age of three cannot be placed in residential care except in cases of particularly justified reasons for this course of action. Even in this case, a child cannot stay in an institution for more than two months except with the approval

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<sup>42</sup> Most legal terminology that refers to persons with disabilities, especially to persons with psycho-social or intellectual disability is archaic and politically incorrect. In most cases, the authors replaced such language with non-stigmatizing terminology. In other cases, the authors place outdated terminology in quotation marks.

<sup>43</sup> Law of Social Protection (Official Gazette of Republic of Serbia, No.24/2011)

<sup>44</sup> Art.27 Law of Social Protection

<sup>45</sup> Art.33 Law of Social Protection

<sup>46</sup> Ibid, article 52, section 1

of the relevant ministry<sup>47</sup>. The ambiguity of the expression “particularly justified reasons” leaves much room for arbitrary assessment of a child’s need for institutional care, and thus requires particular attention and scrutiny.

The article on institutional placement must be read in conjunction with the right to participate in decision-making on the use of social services and the right to a free choice of services.<sup>48</sup> The relevant provisions state that users have a right to participate in an assessment of their own situation and needs and to decide whether to accept services – based on the receipt of timely and necessary information. This is a huge step forward as social services are now oriented towards the user. Nevertheless, the right to participate and freedom of choice as guaranteed by the law do not apply to persons without legal capacity, since by law these rights are exercised by the legal guardian.<sup>49</sup>

The legislation seems to attempt to protect legally incapacitated persons from their guardians’ wanting to place them in institutions. Article 78 states that direct contracting of services<sup>50</sup> cannot be done for residential placement of persons without legal capacity – instead, a referral by the intermediary centre for social work or decision of the court is needed. In order to make this provision operational, we need to strengthen centres for social work, in particular by finding ways of issuing referral for services in non-restrictive environments.

## **New community-based services, financing and standards**

Article 40 of the Law on Social Protection provides a list of social services. These are grouped into: assessment and planning services, day community services, independent living support services, counselling and socio-educational services, and accommodation services including placement into residential institutions. Specific services that fall under these five groups are:

- assessment of condition, needs and strengths of and risks to users and other significant persons within their surroundings; assessment of guardian, foster parent or adoptive parent; development of an individual or family plan for the provision of services; legal protection measures and other assessments and plans;
- day-care stay, help in the household, drop-in centre, other services that promote the individual remaining within the family and direct surroundings;
- supported living, personal assistance, training for independent living, other types of support necessary for active participation in society;
- intensive support services for families in crisis; counselling and support for parents, foster parents and adoptive parents; support for families caring for children or grown family members with “developmental disabilities”; preservation of family relations and reuniting families; counselling and support in cases of violence; family therapy, mediation, SOS phone-lines, and other counselling and educative services;
- placement among relatives, within a foster or other family, residential placement, placement in a drop-in centre and other types of placement.

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<sup>47</sup> Ibid, article 52, section 2 and 3

<sup>48</sup> Ibid, articles 35 and 36.

<sup>49</sup> Ibid, article 35, section 2: “Without the consent of the beneficiary, i.e. their legal representative...”

<sup>50</sup> Ibid, article 77 regulates the direct provision of services.

One positive aspect of the law is that it recognizes that the quality of care and services is crucial. Therefore, each of the above-listed type services requires a defined set of standards and accreditation.

The law introduces procedures for the accreditation of programs and training sessions for service providers. Previously, institutions were seen as the only social service for persons with psychosocial and intellectual disabilities. As a result, the standards were contained in two rulebooks focused only on standards for institutions for adults with psychosocial and intellectual disabilities<sup>51</sup>, for institutions for children with developmental disabilities<sup>52</sup> and for institutions for children. These rulebooks prescribe the necessary number of professionals and other staff in institutions,<sup>53</sup> and lay down requirements for the physical space, equipment, food, cupboards and personal belongings, objects of everyday use, etc. However, these standards do not mention what treatment and care is to be received by the residents. Moreover, the required number of professionals and other staff is far from satisfactory. The accreditation includes the development of standards for each particular service recognized by the law. These should relate not only to the operational standards contained in these two mentioned rulebooks, but should also address the substance of service provision such as individual approach, the user's participation, etc.

The funding of social services, including community-based services is assigned to various levels of government. Most services are within the responsibilities of local governments, which is logical inasmuch as the local authorities are most familiar with the needs of the members in their local community. Central and regional governments finance the largest expenditures such as social benefits and institutions. One positive factor is that the central and regional governments are also responsible for financing new supported living services for persons with disabilities in those counties whose index of development is below the nationwide average. Also, the law envisions allocated transfers for social services for these localities. These transfers are also foreseen for the transformation of residential institutions and for innovative local services and social services that are of significance to the country as a whole.

## **Future direction of de-institutionalization in law and policy**

The future of residential institutions for persons with disabilities in Serbia remains unclear. The law defines the capacity for social care institutions as 100 adults and 50 children (Article 54). Institutions have a maximum of three years to adjust their capacity to this standard (including all other prescribed standards).<sup>54</sup> A ministerial order that used to prohibit the placement

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<sup>51</sup> Official Gazette of the Republic of Serbia, no. 88/93 and 53/2005. Rulebook on the specific conditions for establishing and the regulations and standards of practice concerning social welfare institutions for adults with developmental, mental and physical disabilities.

<sup>52</sup> Official Gazette of the Republic of Serbia, no. 88/1993. Rulebook on the specific conditions for establishing and the regulations and standards of practice concerning social welfare institutions for children without parental care and children with behaviour disorders.

<sup>53</sup> These standards specify less closets, less resources and equipment, as well as less professional staff for children categorized as severely disabled, compared to children with fewer disabilities (article 21, 23 and 25 of Rulebook on the specific conditions for establishing and the regulations and standards of practice concerning social welfare institutions for children and youth without parental care and children and youth with behavioural disorders.)

<sup>54</sup> Ibid. Article 223, section 2. Social welfare institutions and the providers of social welfare services are required to submit a request for granting of a license for providing social welfare services within the next three years.

of children under the age of three into institutions except in unusual cases and with the approval of the relevant ministry has been turned into law, thus giving it statutory strength. Whether the exception to the rule will remain an exception in practice is yet to be seen. It is highly alarming, however, that Article 10 and Article 113 provide for the establishment of new institutions within the social care without exception, which implicitly includes residential institutions for persons with intellectual and psychosocial disabilities.

The main document which directed the reforms of the system of children's institutions is the Master Plan of Transformation of Social Welfare Institutions for Children (2009-2013), developed within the project *Transforming Residential Institutions for Children and Developing Sustainable Alternatives*, implemented by UNICEF in partnership with the Ministry of Labour and Social Policy and with support of the European Union. The document is based on the principle of providing the least restrictive environment, giving priority to the natural family environment, and is concerned with the redistribution of human resources as well as the redirecting of material resources to alternative forms of accommodation and the slowing down and halting of the process of institutionalization.

The Master Plan provided an overview of the situation concluding that strengthening of fostering (around 4200 families) and monitoring of the work of referral centres considerably decreased the number of children in residential care. However, the decrease mainly referred to children without parental care, i.e. children without developmental disabilities. In this initial phase of the reform, children with disabilities living in institutions have been marginalised, which is something that the plan is attempting to remedy. However, the shortcoming of the plan is its assumption that community services would be unable to answer the needs of children who have multiple or severe developmental disabilities and that these children should remain in residential institutions<sup>55</sup>. This assumption is used to justify the survival of the residential system and further implies development of an expensive and unsustainable parallel system. Furthermore, it curtails the efficiency of community-based services by presupposing their inability to provide support to those children who need them the most. It is vital to emphasise that the underlying principle of community-based services is responding to individual needs (and not group needs, as so far has been the case), regardless of the type or level of these needs.

From the Plan it therefore follows that children with severe developmental disabilities require continuous residential placement<sup>56</sup>. Consequentially, the Plan envisages the creation of new services within residential institutions, in accordance with a needs assessment. This poses the question whether such direction of the system's development will thwart the growth of community-based services for children and adults with more complex disabilities. In such conditions, if their disabilities are assessed to be "severe or complex", children might continue to be directed towards institutionalization from the very start.

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<sup>55</sup> Master Plan of Transformation of Social Welfare Institutions for Children (2009-2013), footnote 51, p. 17 (Sveobuhvatni plan transformacije rezidencijalnih ustanova socijalne zaštite za decu 2009-2012)

<sup>56</sup> Ibid., footnote 32, p. 7.

## THE REFORM IN PRACTICE

### Plans for transformation of institutions

*“Becoming a day-centre in which children with developmental disabilities can stay before and/or after kindergarten or school. Taking children to and from kindergarten and school. Providing children with additional activities during the time when their parents are at work or are for other reasons (e.g. health) unable to be with their children. Providing support to families so that separation does not happen.”* – The management envisions that this type of functioning could be implemented in Zvečanska in the period over the next ten years. Current facilities for accommodation would be kept only for the provision of respite services and joint accommodation of parents and children. – Vision of the transformation of Zvečanska.

Our interviews with the management of institutions, made evident that the reform of the system of social welfare for persons with disabilities is not deemed to be of vital importance by the institutions and in some cases merely carries a symbolical significance. In all of the institutions, the management is aware that the Ministry of Labour and Social Policy has been for some time implementing a system reform. However, this knowledge is not in any way linked to the awareness of what should be its final effect on the institution – the staff, services and foremost, the residents. Generally speaking, among the staff, understanding of these matters is at an even lower level.

Most surprising is the fact that majority of institutions do not have an individual transformation plan. Indeed, it is inconceivable that in the midst of the institutional system reform, the institutions as the subjects of the reform do not have a written action plan (or staff is not aware of its existence). Such action plans must describe the specific steps towards the reduction of the institution’s capacities, methods of identifying and transferring children or adults to less restrictive forms of care, what these forms of care would be, what is the preparation that children or adults have to go through and how the preparation would be carried out, what are the mechanisms of control and, last but not least, what are the required funds and timeframes.

Only two institutions are exceptions in not only having an individual plan, but also with greater or lesser successes, working on its implementation (Zvečanska and Kulina). Only in these two institutions concrete results are noticeable in the reduction of number of child residents (Kulina) or the quality of programmes provided (Zvečanska). Two other institutions (Kolevka and Stamnica) have stated that plans for their transformation were developed several years ago, but that their implementation was halted due to a lack of funding and other forms of support on the part of the system.

The lack of clearly defined goals and plans for their realisation is evident from the vision and perception of the institutions’ needs as stated by the institutions’ management teams. The needs that have been expressed are varied but they do not primarily concern the reduction of the number of residents and the opening up of an institution to its community and public (with the exception of Zvečanska and partially Kulina and Stamnica). The managements mainly see the need for development of new services exclusively within the confines of the institution itself. For the most part, these new services include sensory rooms or new classrooms, farms and the expansion of the institution’s economy, work centres and day-care facilities. The idea that some services might be established within the community, for example, in the centre of the neighbouring town, mainstream school, kindergarten, or local business, was completely absent.

Furthermore, the desire of the managements to transform these institutions into medical and social institutions in accordance with article 60 of the Law on Social Welfare was clear (especially in case of Kolevka and Stacionar). The belief is that this will greatly facilitate the work and functioning of an institution, thus improving the treatment received by the residents with medical problems. It is still unknown what this type of institution will exactly bring (purpose and organisation should be regulated by subordinate acts that have yet to be passed). This could be a recommendation to the system - if the aim is to make the two systems – social and health, more complementary and better functioning, and as a result increasing the benefits to the users. However, although a great number of residents indeed need a higher standard of health care, a change of function of the institution should be done cautiously so that it does not result in neglect of the social and educational needs of children and adults, as the medical approach has for many years been firmly embedded within the system.<sup>57</sup>

### Exercising the right to education

An important aspect of the reform that has been neglected in social welfare institutions for many years is exercising the residents' right to education. This right is guaranteed by both national law and international documents. Article 72 of the Constitution of the Republic of Serbia<sup>58</sup> states that everybody has the right to education and that primary education is free and compulsory, whereas secondary education is free. The right of children with developmental disabilities (including children with intellectual disabilities) to receive free education is therefore implicitly contained in the Constitution.

The Law on the Fundamentals of the System of Education and Upbringing<sup>59</sup> further regulates education of all children in Serbia, including those with developmental disabilities. It defines general principles of education, such as quality and availability of education, focus on a child, equal opportunities and non-discrimination, as well as the general objectives and standards of education. The law contains a non-discrimination clause, which is introduced as the first general principle guiding the education system. That stresses that the educational system must provide all children, students and adults equal right and accessibility of education and upbringing, without discrimination and segregation on the basis of gender, social, cultural, ethnic, religious or other background, place of residence, material or health status, developmental disabilities, impairments and disabilities, as well as on other status<sup>60</sup>. The law also emphasizes that children, students and adults with developmental disabilities and disabilities have access to all levels of education, **and that children and persons placed in social welfare institutions, sick children and students – realize the right to education during their placement in an institution, or while receiving treatment in a hospital or at home.**<sup>61</sup>

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<sup>57</sup> The medical or traditional model applied to persons with disabilities focuses on the impairment of the person and has an approach towards an individual is through medical treatment. In contrast to this model, during the 1980, the social model was developed and has gained dominance since then. The social approach to disabilities states that impairment and chronic illnesses often present a difficulty for persons with disabilities, but that they are not the main problem, i.e. the problem for an individual person is not the disability in itself, but rather the social and other barriers that exist in the environment.

<sup>58</sup> Official Gazette of the Republic of Serbia, no. 98/2000, Constitution of the Republic of Serbia, article 72.

<sup>59</sup> Official Gazette of the Republic of Serbia, no. 72/2009 and 52/2011, Law on the Fundamentals of the System of Education and Pedagogy.

<sup>60</sup> Ibid., article 3 (1).

<sup>61</sup> Ibid., article 3 (4).

Of the 641 children who were on institutional stay at the time of monitoring visits, only 167 children (26%) were receiving education. It is important to mention that only one institution – Sremčica, near Belgrade – claims to have included *all* the resident children in primary or secondary schooling<sup>62</sup>. However, three institutions do not have any practice of including children in education (Stamnica, Kulina and Stacionar), while three do so to a lesser extent (Veterinik, Kolevka and Zvečanska).

It is certainly positive that almost all institutions (with the exception of Stacionar) have taken initial steps towards including all their resident children in education – contact and communication have been established with local schools and education authorities. It is immediately apparent that these institutions predominantly opt to place children in special schools or in kindergartens' developmental groups. The percentage of children attending mainstream schools is negligible. This is a negative state of affairs as kindergarten or school can be very important (if not the only) places where children living in institutions can come into contact with children without developmental disabilities. Additionally, this practice of unselective placement of children with developmental disabilities into special education is not in accordance with international standards which state that children should be included in mainstream education, and only exceptionally be placed in special classes.

In most institutions it was apparent that staff foremost considers provision of education for children with minor disabilities and then, as was stated, exclusively in special schools. If no difficulties from the side of schools' administration are encountered, children are included into education. When there are obstacles identified (to be discussed further on), not much effort is put into overcoming them. It must be said however, that inability to realize the resident children's right to education is not only the responsibility of the institutions themselves, but is also the result of large number of barriers existing in other institutions and systems responsible for education.

Firstly, the very location of institutions impedes on outside movement of children including in accessing a school. Obstacles of this sort are felt most strongly in Kulina, which is very far from the nearest town. This does not only raise the question of transportation, but also the ability of schools to receive a significant number of students coming from this institution. However, as the institution in question has begun the process of transformation, it is expected that children will be moved either to foster families or to small group homes (in Aleksinac, Nis and Negotin) in the near future and that they will be enrolled into local special schools. The director predicts that by the end of 2012 there will be no more children in Kulina, which means that their greatest problem (the distance) concerning inclusion into education will no longer exist.

Similar problems are encountered in other institutions, despite them being closer to towns and cities. Schools in the institution's area do not have the capacity or ability to include large numbers of institutionalized children and to provide adequate support required by these children.

The problem of transportation, i.e. taking the children to and from school, also arises. Additionally, in the majority of cases the schools insist that the institutions provide companions or some form of assistance for the children, which places further burdens on the already insufficiently staffed institutions.

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<sup>62</sup> However, during the visit and in conversation with the management and staff it was discovered that the situation was not as previously described. Not all children (minors) were receiving education, whereas some adult residents were.

Even in the event that children are enrolled into schools, there is often inadequate cooperation between the teams of specialists which results in children later dropping-out of schools for various reasons. The most common is certainly the excuse of a school that the child cannot follow the curriculum or that they have behavioural problems. The question emerging from these situations is whether the schools have fulfilled their legal obligations and have taken all the necessary steps to provide the children with adequate support.

Children from institutions who have been enrolled into special schools are often placed in special classes so that they have no contact with other, non-institutionalized children. In this way they are deprived of the whole purpose of inclusive education, which should be that they are given the opportunity to be in the company of their peers and become socialized, something of a great importance for children in institutions.

The institutions are not empowered enough to demand inclusion of children in education. The same is true for the aforementioned post-enrolment exclusion of children from schools, by which schools are directly violating the law. One such example can be found in Zvečanska, where a special primary school for the visually impaired children explicitly refused to enrol three blind children on the basis that it is equipped to educate visually impaired children only. Considering that transformation plans for institutions are only just being put into practice, the question of education has not yet become a priority, especially in the case of children in need of intensive support. There are still large numbers of children in residential institutions who are not receiving adequate support for learning and development even in the institutions themselves, many of them being so-called “recumbent” children who require intensive medical treatment and care. In this context, institutions and the system consider the education to be an issue only for a small number of children deemed not to have severe developmental and behavioural problems.

In several institutions (Kulina, Sremčica, Zvečanska, Veternik) the management had plans to organise education within the institution. The director of Kulina stated: “The educational system has closed the door on us (...) I have no means to force them [to accept the children]. So we have a plan to bring them [teachers and special educators] here. We are imitating education until the authorities remember us.” In Sremčica there are plans to provide this type of education to children who were excluded from schools because they were unable to adjust, could not “follow the curriculum”, or had behavioural problems. In Veternik, a class has been put together for children with physical disabilities. The management of Zvečanska has conducted interviews with the school “Dragan Hercog” on this topic, with the aim to provide education for children for whom they are unable to organize transportation or who are not in a position to leave the institution, due to serious health concerns.

Realization of the right to education for children who are living in social care institutions requires careful and intensive cooperation of all relevant sectors – education authorities and social and healthcare services. In the current context where even children living in families encounter significant obstacles in receiving support for basic functioning, we are aware that the complexities faced by the managements of institutions are even greater. We acknowledge the efforts being made and we believe that the aforementioned systems will intensify inter-sectorial cooperation so that all children will be able to exercise their right as prescribed by the law and the Constitution.

## The right to adequate health care

In the visited institutions we encountered serious infringements of the residents' rights to adequate health care. These originate from bad practices within the institutions themselves, but also from serious obstacles faced by the institutions in provision of the essential medical supplies and outside treatments for their residents. This state of affairs requires serious reorganisation within the healthcare system, which would enable a more efficient realization of the right to healthcare of the residents of closed institutions.

Some of the failures of the institutions are:

- Excessive use of drugs that act upon the central nervous system, even in the case of children;
- The lack of procedures and poor keeping of records concerning the use of chemical and mechanical restraint, and the negative effects of certain medication;
- The ascribing of symptoms to the residents' "diagnosis", which can lead to the failure to provide special treatment, and the lack of investigation upon deaths not caused by violence;
- The keeping of incapacitated residents without stimulation and necessary rehabilitation, which aggravates their condition and endangers their lives.

However, many serious failures are the responsibility of the healthcare system, and they include the complicated procedure for gaining healthcare services outside the place of residence (i.e. principle of the territorial belonging in provision of services), which is crucial for persons permanently institutionalized away from their place of residence, as well as the withholding of necessary specialist treatment by healthcare institutions, which can endanger the life of a resident.

The healthcare system refuses to accept its responsibility for persons living in social welfare institutions, although many of the residents require intensive healthcare. This is manifested not only in the withholding of necessary treatment and complicated procedures required to receive necessary treatment, but also in the denial of financial means necessary to cover all healthcare needs of the residents of institutions. Furthermore, evident is an unequal status of medical staff under the jurisdiction of the Ministry of Health.

While medical staff employed in social welfare institutions is paid less for the same amount of work in relation to their colleagues employed by the healthcare system, additionally problematic is the content of specialised training necessary for maintaining professional licenses. Thus, the unregulated licensing system of the two sectors is a serious obstacle in providing of adequate training of the care staff. Consequently, this has a visible effect on the quality of care for residents by the staff.

The solving of this problem requires serious discussions on the state level as the competent ministries, for a number of years now, have not been able to overcome the aforementioned problems. The institutions are often left to cope to the best of their abilities and try to provide the means to satisfy the most basic health needs of their residents.

## Staff training

*"If there were more staff in institutions that were foreseen to work directly with the residents, psycho-social rehabilitation would be more comprehensive and efficient. Despite the fact that the work within the institution has been going through changes in recent years, the support from the Ministry of Labour and Social Policy has been scarce, which means that the structure of the personnel has remained the same. The regulations put forth by the*

*Ministry can only be changed through examples of good practice, accompanied by detailed argumentation.” – the director of Kulina.*

The question of staff training in the institutions is one of great importance, not only from the perspective of the monitoring team, but also according to the managements of the visited institutions. Fundamental changes on the systemic level cannot take place without a change of thinking of the staff directly working with residents. Even with current capacities, directed and concrete education could considerably improve the treatment received by the residents. Additionally, it is necessary to attend to the education of all the staff, as it was apparent that some of the personnel – in particular, those who were in direct contact with the residents – were being neglected by the system.

According to the institutions’ staff, the most useful type of training is on the spot, “hands-on”, which is reasonable taking into account the fact that in all institutions there is a general lack of staff working directly with residents. As already stated, personnel simply cannot leave their workplaces in order to participate in training given that there is no-one to substitute them while they are away. Most of the employees mentioned that the most useful training would be one that would help them deal with difficult situations, for example, when residents are in distress and causing harm to themselves or others. All the carers in the institutions are working in difficult circumstances, with persons who are utterly neglected by the system and who need the most support, for which they have not been empowered nor adequately trained. Consequently, it is necessary to provide them with support in the form of intensive and continuous skill development.

According to the staff, the second stage of education should be implemented on the level of the collective institution’s staff. This exposes the need for a healthy working environment, for accepting the reform processes and adequate resident care. At the same time, the need reveals that in some institutions problems exist regarding these matters. It is necessary to empower the staff in order for them to acquire “ownership of the changes”. The staff mentions some examples of such training: education in communication, techniques of assertive communication, tolerance.

In addition, the assessment of the monitoring team is that the need exists for education of all personnel in the subjects of human rights, alternative forms of communication with the residents and methods of identifying the psycho-social needs of individuals with intellectual disabilities or communication difficulties.

The key problem in this area, recognised as such by all those who were interviewed, is the question of whose responsibility is staff training and education. The budget does not allocate funds for any additional education because it is interpreted that in this case, the employer is the institution, and not the state. Therefore, the institution bears legal responsibility for financing this important aspect. Continuous professional improvement indeed is the key aspect of the systematic reform, and the relevant ministries would have to invest into it if they expect any positive change to occur in treatment of residents and changing the roles in the system.

## **Gatekeeping**

*“The shelter is full, which is a sign that there’s something wrong with the system.” – Director, Zvečanska*

*“I love my child but I do not have the means to provide him with adequate health care and medication. That’s why my only option is to leave him in an institution.” – mother who contacted MDRI-S*

The managements of all institutions emphasized that the lack of support given to a biological family is a great problem besetting the system. The fact that fosterer and special foster parents receive special training, whereas nobody educates or gives support to the biological parents of children with disabilities, was identified as a shortcoming. Full institutions are an apparent sign that “something is wrong with the system”, right in the midst of the reform. It is also apparent that parents are not informed about their rights, including the benefit to financial assistance from the centres for social work, for travel expenses incurred when visiting their children in an institution that is far away from their place of residence. Engaging with the biological families would open up the opportunity for a child to return to the family and would prevent their institutionalization in the first place.

The institutions’ managements informed us that children are still being accepted for stay with the referral of the competent ministry.<sup>63</sup> According to the data collected in the institutions during the course of the project, in the period of just one year (2010) the institutions admitted 87 children. Out of the seven institutions monitored, only Kulina did not have new admissions. This fact is also made evident in the reports on the analysis of the measures to eliminate malpractice in the placement of children and youth into social welfare institutions run by the Republic bureau for social protection. Particularly alarming is the fact that according to the most recent Analysis of implementation of measures for the period from 1<sup>st</sup> January 2012 to 30<sup>th</sup> June 2012<sup>64</sup>, only in the first six months of 2012, a total of 126 children were admitted to social welfare institutions, a number double that of previous years. These were predominantly younger children (90% of the children were under the competence of the Belgrade centre for social work). According to the authorities, this situation requires immediate investigation as to the causes.

A compounding problem is the practice of the centres for social work, following the ministry’s recommendation, to divest the parents of children with developmental disabilities of their parental rights during the process of placement in social welfare institutions. The assumption is that this recommendation was put into place in order to protect the children whose parents did not waive their parental rights despite failing to provide them with care, and taking into consideration that many children were unable to be placed in alternative care due to the lack of consent from the biological parents. Nevertheless, it is necessary to consider the effect that divestment of parental rights can have on a child’s possibility of returning to its biological family. A blanket divesting of parental rights from parents who are perhaps temporarily unable to care for the child does not aid the future return of the child to the family. Therefore, it is advisable to analyse reasons behind this practice, as well as its effects.

Furthermore, an alarming practice has been noticed recently and it involves conditioning the placement of adults in institutions and the receiving of other types of social services with the removal of legal capacity. The instructions to operate in this manner came after a controversial interpretation of the report of the European Committee for the Prevention of Torture (CPT), which following its visit in 2008 ordered the reassessment of the status of the residents of social welfare institutions who were there without their consent. However, the practice that ensued is contradictory to international regulations and the European Court of Human Rights

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<sup>63</sup> A child under the age of three is not placed in a residential institution, except in special circumstances and if there are particularly justifiable reasons. Even in this case the child cannot remain in care for more than two months, except with the approval of the competent ministry. (Law on Social Welfare, article 52, section 2 and 3).

<sup>64</sup> <http://www.zavodsz.gov.rs/PDF/mere/Izvestaj%20do%2030.06.2012.pdf>

stressed the need to establish procedural measures, which would prevent the concurrent loss of freedom and legal capacity.<sup>65</sup> According to the staff of the institutions visited, the practice of the removal of residents' legal capacity greatly hinders the exercise of their rights, in particular, the right to work and freedom of movement. The exercising of the right to work is the main prerequisite to life in the community<sup>66</sup> as it empowers the person to make decisions on the most important aspects of their life – the right to decide where and with whom to live, to work and earn a living, to have a family, to vote, etc. In order for this to change, it is necessary to think in the direction of establishing communication with the residents, providing them with the relevant information and support, instead of curtailing all their rights.

## Funding the institutions

*“The ministry allocates considerable funds. I cannot say that they are insufficient for maintaining basic standards.”* – Director, Sremčica.

*“A lot of money came [to Kulina] since 2000, but there was no vision or concept. Six and a half million euros came in three years and we do not know where they went. Now we are working with much less.”* – Director, Kulina.

The success of the reform will certainly depend on the funding allocated. However, the most important factor is purpose and manner of its utilization. There has been an increase in the investments put into institutions recently. For this reason, a closer attention is required to the way they are spent. Experience has shown that most of the funding is used to renovate the institutions and their strengthening, i.e. the development of additional services on the premises of the institutions themselves. Such spending has the potential to considerably slow down the reforms and produce negative effects.

During the visits to institutions, the improvements of the physical conditions were noticed, yet regrettably, those residents who are in the worst-off position experience the least benefit from these changes. Namely, the new nicer-looking facilities house the more “able” residents who can preserve the conditions, whereas those “who know nothing and destroy things” (as well as the staff working with them) are still placed in conditions that could be described as inhuman. Thus, we were able to see examples where staff considers their assignment to such wards as a form of punishment, which consequently has an effect on their treatment of the residents. However, it is necessary to keep in mind that a move to a more favourable accommodation will not fundamentally improve the position of the residents, as the crux of the problem lies in their segregation, isolation and the limitation of their rights.

Moreover, there are examples of renovated institutions which are in need of further investments only several years after reconstruction (for example, the children's pavilion in Sremčica). For this reason, the process of transformation requires that a serious cost-benefit analysis be performed in order to evaluate the viability of further investment in the institutional system.

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<sup>65</sup> *Varbanov v. Bulgaria* (31365/96, ECHR 2000-IV), *Shtukaturov v. Russia* (44009/05, ECHR 2008-I), *Salontaji-Drobnjak v. Serbia* (36500/05, ECHR 2009-II)

<sup>66</sup> Hammarberg, Thomas: The right of people with disabilities to live independently and be included in the community, CommDH/IssuePaper(2012)3, <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

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# INTERNATIONAL OBLIGATIONS

The Constitution of the Republic of Serbia stipulates that “the generally accepted rules of international law and ratified international agreements will be an integral part of the legal system in the Republic of Serbia and will be directly implemented”. The Republic of Serbia ratified all major international and regional instruments for the protection of human rights, including the International Covenant on Civil and Political Rights<sup>67</sup>, the International Covenant on Economic, Social and Cultural Rights<sup>68</sup>, the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment<sup>69</sup>, the Convention on the Rights of the Child<sup>70</sup>, the Convention on the Rights of Persons with Disabilities<sup>71</sup>, the European Convention on Human Rights, etc. The Serbian Constitution considers these instruments part of the state legislation and gives them precedence over national laws if there are discrepancies between the two. This means that the Republic of Serbia committed itself to harmonising its laws and practices with the international obligations.

The UN Convention on the Rights of Persons with Disabilities (hereinafter: the Convention) provides a valuable framework for the protection of the rights of children with developmental disabilities and adults with disabilities who are locked up in Serbian institutions. The Convention does not bestow any new rights, but reaffirms that all present rights are applicable to persons with disabilities<sup>72</sup>. It emphasises the principle contained in international law, but often neglected in practice, that under international agreements persons with disabilities enjoy the same rights as persons without disabilities. As stated in article 1 of the Convention, “The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”<sup>73</sup> This implies that “discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person.”<sup>74</sup>

Article 19 of the Convention clearly states that unjustified segregation of persons with disabilities in institutions is in itself a violation of their rights.<sup>75</sup> The placement of people in in-

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<sup>67</sup> Official Gazette of SFRY (International agreements), no. 7/1971.

<sup>68</sup> Official Gazette of SFRY (International agreements), no. 7/1971.

<sup>69</sup> Official Gazette of SFRY (International agreements), no. 9/91.

<sup>70</sup> Official Gazette of SFRY (International agreements), no. 15/1990.

<sup>71</sup> Official Gazette of RS (International agreements), no. 42/2009.

<sup>72</sup> Gerard Quinn, *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, 1 European Yearbook of Disability Law 89, 100 (2009)

<sup>73</sup> Convention on the Rights of Persons with Disabilities, article 1.

<sup>74</sup> *Ibid*, Preamble (h)

<sup>75</sup> Camilla Parker: An overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities, in European Coalition for Community Living: Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities, p. 13 (2009).

stitutionalised care on the basis of their disability and the administering of so-called block treatment is at odds with the principles that stipulate respect of dignity and autonomy of individual persons with disabilities. Additionally, this sort of grouping isolates these people from the rest of society and focuses the attention of the community on the disability itself<sup>76</sup>. In this sense, it is possible to conclude that grouping of persons with disabilities is not in accordance with the obligations of the state, which require that positive attitudes towards persons with disabilities be promoted. Having this in mind, it is important to stress that the improvements of the conditions and services within the institutional system does not satisfy the standards introduced by article 19, which is wholly directed to the inclusion of persons with disabilities in the community. This argument needs appropriate consideration when drafting state policies concerning children and adults with disabilities and especially when national and foreign funds are allocated for development of the services.

Additionally, denying the right to life in the community and segregation on the basis of disability also entails the curtailing of a wide array of other rights such as the right to life (art. 10), equality before the law (art. 12), freedom and security (art. 14), protection from torture or cruel, inhuman or degrading treatment or punishment (art. 15), the right to health (art. 25), the right to habilitation and rehabilitation (art. 26). Infringements of these rights were noticed during our visits and have been outlined in this report.

While certain rights demand immediate realization and their restrictions cannot in any way be justified – such as protection from discrimination, the right to life and the freedom from torture or cruel, inhuman or degrading treatment or punishment, the exercise of certain other rights requires progressive realisation (i.e. their gradual adoption), especially in the cases where greater funding and/or significant changes in practice and legislation are required. Nevertheless, in these cases, the rights guaranteed by the Convention contain the element of so-called immediate obligation which implies taking decisive and clear steps towards their fulfilment, together with providing of the necessary funding and clear timeframes for realisation.

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<sup>76</sup> Hammarberg, Thomas: The right of people with disabilities to live independently and be included in the community, CommDH/IssuePaper(2012)3, <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

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## CONCLUSION AND RECOMMENDATIONS

The criticisms regarding the lack of achievement of concrete results in the process of reform is not directed to the institutions themselves as much as to the central government whose responsibility is implementation of the reform. Without setting up clear goals and steps and lacking continuous support, but also control, it is impossible to obtain any satisfactory results. Consequently, even where willingness exists to improve the functioning of the institutions, this has been left to the enthusiasm and initiative of the individuals that head the institutions. This enthusiasm may sometimes be based on the genuine intention to improve the position of the residents, but in other cases the vision of the management is not attuned to long-term plans or, in the absence of these, to the international obligations taken on by the state to close down the residential institutions and to form a community-based support system. Even defining the most acute problems represents a challenge for the management of institutions, the reasons for which partially lie in lacking knowledge of the basic needs of the residents.

It is understandable that the management must operate within the setting which they have encountered and with means that are at their disposal in the institutions, and it is expected that they are motivated to improve the institution. Notwithstanding, it is necessary to redirect the focus from the actual buildings, the physical conditions and increasing capacities of the institution to issues that will actually add to the wellbeing of the residents and promote freedom of movement, life in the community, alternative forms of housing, interaction with the community, the learning of skills and finally, the establishing of a system which will be able to support all these changes. This is impossible without the support of the wider system, in other words, the competent ministries. The ultimate goal must not be the creating of “premium hotel accommodation”, but life in the community, in private apartments or houses with the help of competent services. When children are concerned, the primary aim must be ensuring they receive education with their peers and their return to community, with either their biological, adoptive or foster family.

The reform of the institutional system for children with developmental disabilities on the whole did not meet expectations. A clear new strategy is necessary, with an action plan, allocated funds and set timeframes. Also, inter-sectorial cooperation and flexibility are much required, especially in changing regulations which have proved to be inadequate. A comprehensive reform of discriminative system that violates many of the rights of persons with disabilities is not merely a responsibility of specific ministries, but of the whole state. The state is, in accordance with the international obligations assumed, obligated to undertake all the necessary steps towards ensuring that children with developmental disabilities and adults living in institutions, are able to live in the community. Life in the community is itself the essential prerequisite for the effective protection of human rights of these persons.

## RECOMMENDATIONS

In accordance with the findings from the monitoring of conditions in institutions and the corresponding reform, we recommend the following:

- 1. To create transformation plans for each institution with clearly delineated steps, timeframes and allocated funding.** In order for the reform to fully comply with the requirements of article 19 of the Convention, its final aim must be the closure of institutions. The residents of institutions must be actively involved in the planning, realisation and overseeing of the process of reform. The plans must establish the responsibilities of particular sectors for specific steps, contain a clear timeframe for the realisation of foreseen activities and the exact costs that each of the steps requires.
- 2. Until the final transformation, to organize institutional system in a manner that will be able to provide services to residents living in their proximity (the territorial principle), instead of the current practice of placing persons in institutions based on the level of their disability.** This is especially important when taking into consideration the arbitrariness evident in the assessment of children and adults, which is seldom reviewed despite the insistence of the institution staff. The proximity of the local community and family relations will greatly ease the establishment of contacts with the environment and the return of children/adults into society. At the same time, segregation, i.e. the institutionalization of persons based on their disability is an apparent form of discrimination, forbidden by both national and international regulations. Therefore, the mere existence of developmental difficulties or disabilities (which includes the inability of the family to take care of its member due to the disability) must not be the basis or excuse for institutionalization.
- 3. To undertake efficient measures that will prevent future institutionalization, primarily by devising a support network for the primary families.** The providing of support for the family must include training, counselling, empowerment, access to services and education. Additionally, the absence of a family or its inability to provide adequate care must not be accepted as a reason to exclude a child/adult from the community by placing them in an institution.
- 4. To immediately establish efficient and independent mechanisms for the protection of rights.** This could be achieved through the nurturing of contact with families and relatives and frequent visits of volunteers, non-governmental organisations and independent state mechanisms. Article 16 of the Convention demands that states create independent supervising bodies which would protect children and adults with disabilities from exploitation, violence and abuse. These mechanisms are important not only for children in institutions, but also those benefiting from community-based services and they must be age, gender and disability-sensitive, in other words, responsive to the functioning of persons they aim to protect.
- 5. To immediately provide those residents who are currently bed-ridden with adequate accommodation and necessary rehabilitation.** This includes moving the residents to larger beds and enabling them to be taken out of them regularly. It is necessary to provide essential equipment which will permit them to be placed in an upright

position and prevent deterioration brought on by continuous immobility. Based on the examples of good practice, it is apparent that this does not require great financial resources, as it is primarily dependent on good will and an openness to accept alternative forms of work and care for residents.

6. **To immediately stop the practice of ill treatment and torture ensuing from the misuse of medication, restraint and isolation.** Immediate action needs to be taken in order to protect residents in institutions from conditions and treatments that are life-threatening. This includes the establishing of procedures on the systemic level which will regulate the use of restrictive measures, i.e. restraint, and forbid its use for the purpose of punishing residents and easing the work of the staff. In the cases where such measures are unavoidable for other reasons, it is necessary to provide adequate conditions for their implementation in accordance with international standards, with continuous supervision and for a limited amount of time. In the short term, this might require an increase in the number of staff in institutions, but this must not be the excuse for additional investment in the infrastructure.
7. **To introduce changes in the law regulating legal capacity deprivation.** In the meantime, it is necessary to re-examine and abandon the current practice of the removal of parental rights and legal capacity for the purpose of institutionalization, as well as setting that as a condition to receive certain services within the social welfare system (financial benefits and access to social welfare services, such as day-care). Article 12 of the Convention guarantees that persons with disabilities enjoy the right to legal capacity. It is necessary to establish support programmes which will empower persons to make decisions on matters that affect them.<sup>77</sup>
8. **To review the current regulations concerning professional work, the providing of continuous training for employees and the adjusting of the licensing criteria between the health and social welfare systems.** Special attention needs to be placed on the competencies and duties of staff, which should be adjusted to the actual needs of the residents and not to the arbitrary criteria based on diagnosis. Care for the residents must be organised according to their needs, and not according to the professional skills or formal education of the employees. As part of continuous professional training of healthcare workers it is necessary to improve instruction on the subject of mental health and support in the community. In this way, consequently the concept of “de-institutionalization” and the detrimental effects of living in an institution will be better understood.
9. **To allocate funding for institutions of social welfare on the basis of the needs of an individual beneficiary, instead of on the capacities or needs of an institution.** The main obstacle to the implementation of policies and goals of de-institutionalization is the manner of funding. To date, funding is based on the “number of beds”, and not the actual needs of the residents or standards of practice. The funds should follow the user and not the other way round, as only in this case, a person with a disability will

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<sup>77</sup> Further information on these programs can be found in MDRI-S: “Legal capacity as a fundamental human right – A guide to national practices and possible alternatives to guardianship”, August 2012.

be able to receive support regardless of where and with whom they live. Additionally, this type of funding provides flexibility to the system, as users would be able to leave institutions knowing that they will continue to be financially supported by the system.

10. **To immediately re-examine the responsibility of medical doctors who refuse to provide treatment to residents of institutions.** It is necessary to introduce compulsory procedures with the aim of determining the causes of death, even when they appear to be “natural”, so as to avoid possible cases of malpractice and determine whether every possible measure was taken in order to prevent death.
11. **To provide access to education for children living in families, as well as children in institutions of social welfare.** The inclusion of children into the education system not only has a positive effect on the child and its development, but it also provides a form of respite for the family (in the sense that members are able to keep employment), or for the staff in institutions who can then, when the children are in school, devote their time to attending to residents in need of intensive support.
12. **To re-examine the practice of automatic placement of children with developmental disabilities in special schools.** Institutions which are far away from towns often do not have special schools in their vicinity, therefore, local schools might be much more accessible. At the same time, the inclusion of children from institutions in neighbouring schools would solve the problem of special schools which are struggling to accept all children from institutions.
13. **To re-examine the forming of a parallel “specialised” system for children and adults with disabilities and to stop further investment into residential institutions.** The maintaining of parallel systems is expensive and leads to further segregation of persons with disabilities and it is therefore necessary to redirect the focus on the accessibility of existing services while new services are being established. If the conditions in an institution are a health hazard, it is essential to make urgent interventions. However, large-scale investment in new infrastructure is inexcusable. Experiences from other countries point to the dangers of continual investment in these institutions.<sup>78</sup> Larger investments which include the building of new structures or the execution of new programmes on the premises of institutions and which therefore continue isolating persons with disabilities from society are contrary to the article 19 of the Convention. In situations where, in the opinion of the authorities, large-scale investment is necessary to improve conditions, the possibility of moving of the residents, i.e. the relocation of services, should be considered first. With the aim to establish more efficient planning and execution of the process of transformation, it is necessary to conduct a detailed cost-benefit study which will provide additional arguments in favour of redirecting funding towards the setting up of community-based services, as opposed to maintaining an expensive institutional system which infringes on the rights of its residents.

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<sup>78</sup> Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, 2009.



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