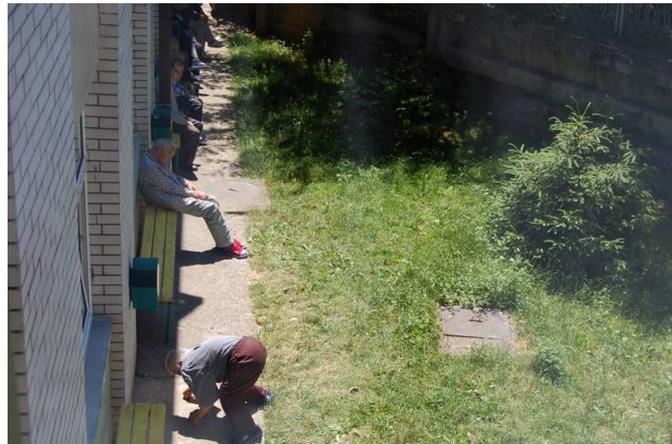




Helsinki committee for Human Rights in Serbia

PEOPLE ON THE MARGINS (part 4)

Social care institutions catering for children and adults with mental disabilities and persons with mental disorders



Begrade, September 2009

Helsinki Committee for Human Rights in Serbia
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with mental disabilities and persons with mental disorders

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Belgrade, September 2009

Findings of the project „Social Care Institutions in Serbia: Support to a Reform-Oriented Strategy“ the Helsinki Committee for Human Rights in Serbia has realized with the assistance of the Open Society Institute and the Royal Netherlands Embassy, Belgrade.



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INTRODUCTION

The third report stemming from the project “Social Care Institutions in Serbia: Support to a Reform-Oriented Strategy” – the Helsinki Committee for Human Rights has realized with the assistance of the Open Society Institute, Budapest, and the Royal Netherlands Embassy, Belgrade – focuses social care institutions in Serbia catering for children and adults with mental disabilities and persons with mental disorders.

Developed countries abandoned the concept of institutionalized protection long ago. However, in Serbia, like in many transitional countries, this is still a reality. Serbia is among the countries that have launched reforms of their social care systems. The process itself is far from being an easy one to be rounded off in short time. Transition to the deinstitutionalized model of protection implies serious preparations and rearrangement of the entire social concept. And it calls for cooperative efforts by all institutions of the governance. Since such cooperation – a key link in the chain – has not been established in Serbia yet, the reform of the social care system is slower than it should be. Many social care institutions will, therefore, remain a major segment of social protection for long and, unfortunately, a lifelong reality for many of their beneficiaries. This particularly refers to persons with mental disabilities and with mental disorders whose ongoing status and potential social reintegration have to be placed high on the list of social and governmental priorities.

The fact that the existing institutions are constantly catering for maximal number of beneficiaries indicates the extent to which the society as a whole is still not ready for integration

of persons with mental disabilities. Therefore, under the newly adopted Decision on the Network of Social Care Institutions Catering for Beneficiaries accommodation capacities have not been reduced at all in most institutions or have been minimally reduced. And have been raised in some.

Overall attitude towards persons with mental disabilities is being changed step by step, but nevertheless painfully slow. As for regulations dealing with position and rights of persons with mental disabilities, several documents have been adopted at national level – Law against Discrimination (an umbrella one), Law against Discrimination of Persons with Disabilities, Law on Professional Rehabilitation and Employment of Persons with Disabilities, Law on Basics of Educational System, Strategy for Improvement of Position of Persons with Disabilities and Strategy for Improved Protection of Mental Health. Unfortunately, a draft law on protection of the rights of persons with mental disorders is still under preparation despite the fact that the National Commission for Mental Health has been working on it for several years. The Ministry of Labor and Social Policies has also adopted relevant regulations and minimal standards for various types of social care services and the Special Protocol on Pro-

tection of Children in Social Care Institutions from Ill-treatment and Neglect. A new law on social protection is expected in near future. It should be noted that Serbia is duty bound vis-à-vis a number of international documents already referred to in relation to this specific project. These documents and domestic legislation provide a solid legal frame for development of a more human and tolerant society. Unfortunately, all these regulations are poorly implemented in everyday life if implemented at all.

The same as earlier reports this one also builds on “case studies,” each implying insights into overall conditions in which four monitored institutions catering for persons with mental disabilities (children and adults) and

with mental disorders operate. Having paid fact-finding missions to these institutions, the Helsinki Committee’s team of experts put forth conclusions and recommendations with regard to departures from domestic and international regulations. The primary objective of the entire project – including the objective of this specific report – was advocacy for improved position of this vulnerable population. Coming from a human rights non-governmental organization, the team, therefore, focused both system flaws and examples of good practice. It also scrutinized overall social backdrop against which these institutions and their personnel function, given that this backdrop preconditions a proper and sustainable reform of the social care system.

We hope this report would contribute to this common goal and help Serbia in its movement towards the standards applied in developed democracies.

We take this opportunity to once again thank the Ministry of Labor and Social Policies, as well as directors, the personnel and beneficiaries of the four institutions for their cooperation that made implementation of this major segment of the entire project possible at all.

SUMMARY

Under the aforementioned governmental decision on the network of social care institutions, four such institutions are designated to cater for children and juveniles with mental disabilities, along with one department of the Center for Protection of Newborns, Children and Youth in Belgrade. Overall accommodation capacity of these four institutions totals 1,400 persons. Nine homes and two institutions – accommodating 2,300 persons – have been set aside for adult persons with mental disabilities. One of these homes, in Starnica, has two separate wards: one catering for children and juveniles, and the other for adults. Persons with mental disorders are accommodated in five social care institutions: three homes, one gerontological center and one of the above-mentioned institutions, the overall accommodation capacity of which amounts to 2,000 people.

The Helsinki Committee's team of experts paid fact-finding missions to two biggest institutions for children and youth with various degrees of mental disabilities – in Sremcica and Veternik – to the biggest institution for adults with “grave” and “gravest” mental disorders in Kragujevac, and to the Home for Adult Persons with Mild and Grave Mental Disorders in Tutin.

The team was composed of one psychologist, a special pedagogue, a specialist in neuropsychiatry, a sociologist and a lawyer. The fact-finding missions were realized in the period May-June 2009. The ensuing case studies deal with the following aspects

of institutionalization: living conditions, institutional personnel, treatment provided to beneficiaries, contact with families and outside community, and guarantees for the rights and freedoms of beneficiaries.

Given that mental health aspect predominates this segment of the project, the report mostly focuses the attitude towards mental problems (all the beneficiaries have diagnoses that – by international classification of illnesses – fall into the category of mental disabilities or illnesses). The report, therefore, opens with a “psychiatric section” that sums up ongoing practices in the treatment of persons with mental disabilities in all the four monitored institutions.

Living conditions – Except for the home in Tutin, the three monitored institutions occupy large areas with several facilities constructed on them. Visually and by accommodation arrangements, they closely resemble specialized psychiatric hospitals: they are located away from urban cores, constructed as pavilions and have long corridors and dormitories. Funds for renovation of premises and equipment were invested in all the four institutions – however, those funds were not sufficient to secure adequate living conditions. Indicatively, renovation of all the facilities accommodating beneficiaries diagnosed with gravest mental disorders waits for “better days.” These facilities are rather ruined with poorly furnished rooms and inadequate communal areas. Living conditions of this category of beneficiaries reflect both professional and social attitude towards them. Nothing is ex-

pected from them and nothing is planned for them. Such living conditions seriously undermine human dignity. Situation in the facilities accommodating beneficiaries with “mild” mental disorders is by far better.

Institutional personnel – All the monitored institutions engage various professionals (defectologists, psychologists, teachers, etc.) and medical officers (doctors and nurses). And all the institutions are understaffed, which cannot but affect the quality of professional treatment and healthcare. Bearing in mind large number and structure of beneficiaries, personnel’s inadequate professional capacities pose additional problems. Namely, most of them have not been specifically trained in the skills necessary for treatment of persons such as beneficiaries of the said institutions. Courses of in-service training would surely make them more competent to cope with their everyday tasks. Decades-long neglect of this problem also testifies of the society’s indifference not only for persons with mental disabilities but also for the professionals treating them.

Treatment provided to beneficiaries - Treatment programs are developed on the basis of the assessed degrees of beneficiaries’ mental disabilities rather than on their specific needs and types of support necessary to meet those needs. This is why most of them are deprived of “small pleasures” and of opportunities to develop living habits and gain basic life experiences. Generally speaking, the monitored institutions have developed various occupational therapies and are providing – inasmuch as they can – occupational training to beneficiaries. With the exception of the Kragujevac-based institution, this major segment of socialization is usually available to a small number of persons. The great majority of persons with mental disabilities have no prospects either for

education or employment. Without adequate programs of occupational training, these persons will remain lifelong hostages to institutionalized protection as they will be lacking fundamental living skills.

Contact with families and outside community – Discriminated and stigmatized by the society as a whole, persons with mental disabilities or disorders are practically isolated from the outside world. Despite some progress made in this aspect (e.g. the personnel begun organizing excursions, visits to various cultural and sports events and the like, whereas NGO activists and, occasionally, school children and students pay visits to institutions) quality and frequency of contacts with the outside community are inadequate. Families and representatives of social care centers rarely visit beneficiaries. And yet, families’ attitudes towards their institutionalized members are not indicative only of interpersonal relations. Actually, the way the state treats persons with mental disabilities has been personalized to a large extent. The state has erected huge institutions distanced from urban centers and beneficiaries’ hometowns: thus it has not only isolated them from the society but made it harder for their families to communicate with them face to face. The state has also failed to recognize the need for programs of support to the families of persons with mental disabilities that would encourage quality mutual relationship.

Guarantees for the rights and freedoms of beneficiaries – Speaking of such guarantees almost borders on senseless talk. Once categorized as such, children and juveniles with mental disabilities usually never free themselves from the label. A number of adult beneficiaries have been so categorized since childhood and their diagnoses stay with them as long as they live. In addition a number of institutionalized adults have been deprived of earning ability and no

one has ever appealed to courts of law for revision of those decisions. On the other hand, the personnel themselves take that a considerable number of their beneficiaries are capable of independent living with community support. Given that very categorization leads either to deprivation or limitation

of many human rights (the rights to education, work, participation in public life, etc.) there is not doubt that the beneficiaries of these social care institutions are among the most vulnerable social groups (along with “patients” of specialized psychiatric institutions).

PSYCHIATRIC SECTION

1. General therapeutic environment

All the monitored institutions have been constructed as asylums: they are located away from urban centers, surrounded by fences and composed of big buildings accommodating large numbers of beneficiaries. Regardless of differences in institutions' accommodation capacities and the fact that many beneficiaries are accommodated in smaller rooms rather than in dormitories, the biggest problem is that too many beneficiaries are concentrated in one institution – such concentration cannot but produce deteriorating effects on their physical and mental health and hamper their rehabilitation. All the fact-finding missions were conducted in summer months when many activities could be organized in the open. However, in some institutions this was not possible because of physical limitations. In Tutin, say,

there is hardly any yard at all, while in Veternik a large number of beneficiaries diagnosed with grave retardation sit idly in a small yard in the midst of summer. One cannot but wonder where they spend most of their time in winter months. To all appearances, the two institutions just “accommodate” (keep within four walls) beneficiaries rather than secure them conditions for dignified life and socialization.

The personnel usually wear white uniforms. Their treatment of beneficiaries varies from institution to institution. Many complaints against the personnel were voiced in Tutin – some beneficiaries even claimed they were being beaten. In other institutions, however, doctors, nurses and other officers have developed by far closer relations with their beneficiaries who showed no signs of being afraid of anyone.

2. Medical care provided to beneficiaries of social care institutions

2.1. Medical officers

The number and professional capacities of medical officers vary from institution to institution. The term medical officer here implies the professional on the payroll of the Ministry

of Healthcare. The table below provides information about their professional capacity and number, compared with the number of beneficiaries to whom they provide treatment.

	Veternik	Sremcica	Kragujevac	Tutin
Number of beneficiaries	593	305	921	241
Total number of medical officers	50	21	56	9
Doctors	5 general practitioners (one of them specializing psychiatry) and one stomatologist)	3 (1 stomatologist, 1 general practitioner and 1 psychiatrist)	7 (3 general practitioners, 1 internist, 1 gynecologist and 2 physicians specializing psychiatry)	1 general practitioner presently specializing psychiatry in another institution
Medical technicians/ nurses	44	18	49	8

It seems that the number of medical officers per an institution has been set by the norms that are nowadays totally anachronous. According to the director of the Tutin institution, the “norm” for the number of medical officers in his institutions was 150 beneficiaries, meaning fewer persons by 25 percent. One cannot but wonder about the grounds on which these norms are set, the one laying them down and the

extent to which they are adjusted not only to the number of beneficiaries in each individual institution but also to its actual needs.

Some institutions like the one in Tutin are so understaffed that only three persons work night shifts – a doorman, a male nurse and a medical technician. These three people are looking after as many as 205 beneficiaries.

2.2. Medical equipment and specialized wards in institutions

Speaking of medical equipment, only institutions in Veternik and Kragujevac have proper ones. The situation in Tutin is so bad that it calls for immediate intervention by the Ministry of Healthcare. The institution in Sremcica has a dental ward, which is not licensed by the Ministry of Healthcare, while the dentist himself has been engaged instead of one of the planned physicians. The Veternik institution

has five wards, including a dental ward, but not a gynecological one. The Kragujevac institution has a gynecological ward but not a dental one. The same institution has a ward in each of the pavilions, which makes the work of medical officers easier. In 2008 the Embassy of Japan donated an EEG apparatus to the institution – in the same years 58 beneficiaries with epilepsy were examined.

2.3. Healthcare subsidies

Under the law, medical protection of all beneficiaries of social care institutions should be subsidized by the Ministry of Healthcare and the Republican Bureau for Health Insurance.

However, everyday practice is somewhat different. For instance, the Ministry of Healthcare covers only regular salaries of medical officers but not other expenses such as those related to trans-

portation, night shifts, working holidays, bonuses to specialists and head nurses, uniforms, paid meals, etc. Costs of sanitary supplies and medicaments have to be approved by the Republican Bureau for Health Insurance, which covers them on annual basis and in the amounts (probably) calculated by the number of beneficiaries. Be it as it may, these amounts hardly correspond to actual needs. For instance, the institution in Sremcica is allocated 118,000 RSD per year but spends 900,000 RSD on average on medicaments and sanitary supplies. Subsidies for medical protection should also include transportation of beneficiaries to specialized hospitals

for examination. For instance, the Tutin institution has to transport its beneficiaries to distanced towns, usually to special psychiatric hospitals in Gornja Toponica and Kovin, or to Kraljevo and Belgrade for hospitalization. No one covers these expenses. According to the director of the Tutin institution, they amount to some 550,000 RSD per year. The fact that there is no system solution to the problem cannot be a pretext for inadequate medical protection, he says. To justify his stand, he quotes a case of the women with vision problems (who went blind eventually) who had to be often transported to see specialists in Uzice, Kragujevac and Belgrade.

2.4. Availability of specialist services

Existing medical departments in social care institutions provide only basic services, whereas all other are provided by medical centers in the outside community. Beneficiaries usually have to be transported to hospitals or clinical centers to be examined by specialists. Three out of four monitored institutions are in somewhat better position since they are close to bigger cities (Belgrade, Kragujevac and Novi Sad). In this context, the situation is the worst in Tutin given that all the necessary medical services are not available in the nearest town – Novi Pazar where the hospital has no psychiatric ward. A psychiatrist from Novi Pazar works in the Tutin medical center once a week. Therefore, beneficiaries have to be transported to Kraljevo, Nis or Belgrade for psychiatric treatment.

Specialist examinations of beneficiaries need prior approval from a relevant branch of the Bureau for Health Insurance. The procedure – launched by the personnel that apply for approval – takes time and, as such, delays treatments and control examina-

tions. The Kragujevac institution, therefore, opted for the only possible solution to the problem: it pays all the costs of periodic x-ray scans (presently, 9 beneficiaries are with tuberculosis) from its own pocket. Had it waited for the Bureau to cover the costs, the procedure would have taken months.

Though there are examples of good practice and smooth cooperation, some medical centers seem not to feel duty bound to admit, medically examine and treat the beneficiaries of social care institutions. So it happens that the Psychiatric Hospital in Kragujevac would not admit the beneficiaries of the local social care institution and sends them on to Gornja Toponica and Belgrade. Treatment and hospitalization of beneficiaries with somatic diseases is also problematic. The Ministry of Healthcare should urgently react at such practice to prevent further discrimination of beneficiaries instead of leaving social care institutions at their own devices.

Further, there is the problem of how to engage consultants, i.e. various specialists all the institutions need from time to time. The amendment to the Law

on Healthcare dealing with additional work and enacted in December 2008 made engagement of specialists working full-time in public medical centers problematic for social care institutions. The amendment provides that only university professors shall be entitled to work as consultants but, as the personnel said, “professors would not come.” Directors have been trying to solve the problem this way or another. So, for instance, whenever he needs physiatrists and psychiatrists as consultants, the director of the Veternik institution engages retired specialists. However, this cannot completely solve the problem: retired specialists are not authorized to put their seals on the forms for hospitalization. The director of the Kragujevac institution required explanation from the Ministry of Healthcare but received no answer whatsoever – so she continued paying consultants. Her institution engages a specialist in internal medicine, who is trained in ultrasound and conducts ultrasound examinations four times a month, a psychiatrist who works on EEG readouts and provides neurological therapies (two-three times a week),

an EEG technician and another specialist in internal medicine, who only conducts medical examinations. The Tutin institution engages a specialist in general medicine, who comes three times a week, and a retired psychiatrist for monthly visits. Whenever necessary the psychiatrist is consulted by phone. In the Sremcica institution, neurological therapies have been provided for years now by a physician working for the Institute for Mental Health. Consultant services are sometimes paid under specific projects.

By the book, all the institutions would have to transport beneficiaries to medical centers with adequate specialist services upon approval from relevant social insurance funds. Considering the number of beneficiaries who need continued treatment by a variety of specialists, distances (especially the Tutin institution) and bureaucratic procedures (waiting lists, verified forms issued by funds, etc.), strict respect for the Law on Healthcare would obviously jeopardize beneficiaries’ health. This is yet another absurdity stemming from a bad or non-existent cooperation between various governmental institutions.

2.5. Availability of medicaments

Participatory payments and financial participation in medical supplies are notably problematic. Whereas participatory payments can be afforded somehow (40 RSD per a box of medicaments) participation in medical supplies sometimes amounts to 50 percent of actual price (e.g. tranquilizers that are abundantly used in institutions). Institutions have to cover these expenses from their budgets. Though directors and doctors seem to do their best to provide most adequate therapies for beneficiaries, this is about a grave system problem threatening to result in inadequate medical care. Namely, since the Republican Bureau for Health

Insurance provides insufficient funds on one hand, and insists on cuts in expenses on the other (e.g. insists on the use of old and cheaper drugs instead of new generation drugs with fewer side effects), social care institutions are forced to make choices that can be adverse to beneficiaries’ health. For instance, the institution in Kragujevac spent 2 million RSD on ampoule therapies in 2008. The Bureau had approved only 7 million RSD for tablet therapies, whereas the institution had to pay 23 million for medicaments on prescription. The director says that the Bureau keeps warning her that she spends too much money. Never-

theless, she prioritizes new and quality drugs for her beneficiaries.

Regular inoculation against flu is directly connected with the issue of adequate treatment and availability of medicaments. Inoculation is not regular. Asked about the reasons for lower mortality rate in the Kragujevac institution (52 beneficiaries died in 2008,

and only 9 in the first six months of 2009), physicians said that was mostly to be ascribed to vaccination against flu, which is not systematic but “surplus vaccines” had been distributed to the institution. One can only conclude that a regulation on regular vaccination in social care institution would considerably reduce mortality rates.

3. Treatment of mental disorders

3.1. Persons with mental disorders accommodated in social care institutions

All the four monitored institutions also cater for persons with mental disorders classified other than “mental retardation.” Most of these persons are accommodated in the Kragujevac institution: out of 921 beneficiaries, 534 suffer from mental illnesses. The institution is one of the five social care institutions in Serbia catering for persons with mental disorders with the exception of mental retardation. According to its director, some 2,000 persons are accommodated in these five institutions (apart from the one in Kragujevac, institutions in Stari Lec, Novi Becej and gerontological centers in Aleksinac and Curug fall under this category) and there are no criteria for their institutionalization. This is a significant piece of information. It indicates that 2,000 persons, once institutionalized in social care institutions, are not only totally isolated but also “wiped out” from ongoing analyses of and plans for transformation of psychiatric services. However, persons with mental disorders are also accommodated in other institutions such as the one in Tutin that caters for 106 beneficiaries with mental retardation (out of 241 persons accommodated in it). Some are diagnosed with Parkinsonism (3), alcoholism (2), depression (1), schizophrenia (26), epilepsy (29), internal diseases (14) and diabetes (8). These are obviously their “primary”

diagnoses for which they should not be institutionalized at all.

A considerable number of beneficiaries are with “combined” pathologies. The term, used in institutions, indicates a beneficiary suffering from at least from one type of mental disorder except for retardation. However, his/her mental disorder needs not be chronic and of psychotic character. The interviews conducted with beneficiaries indicated that many of them suffer from behavioral disorders but show no symptoms of psychoses whatsoever. Out of the total number of beneficiaries in the Sremcica institution, “about 50 percent” are either on psychiatric or neurological treatments, while some 40 suffer from epilepsy. Other disorders include personality disorders, schizoaffective disorders, depressions and schizophrenia. As for the Veternik institution, out of 593 beneficiaries 405 are either on psychiatric or neurological therapies and 169 of these beneficiaries are with epilepsy.

What are the criteria for accommodation of persons with mental disorders in social care institutions? Even should we perceive the situation as a relic of “the old system” when the very label “social case” opened the door to institutionalization, why is it that nothing is done nowadays for all those people’s social reintegration? This best exemplifies the absence of coordination between two systems (ministries) –

healthcare and social. Whereas specialist psychiatric hospitals are reducing their accommodation capacities (which is not followed by development of adequate community service for protection of mental health), social care institutions are constantly pressurized to admit persons with chronic mental illnesses.

It should be noted that no difference is being made between such persons who are accommodated in social care institutions and those in specialist psychiatric hospitals – they are all institutionalized because “there is no other place for them” and because they need additional support and psychosocial treatments. Accommodation of these persons in social care institutions cannot solve the problem, which can be properly tackled only through community-based living and development of community-based mental health protection systems. Such programs would surely make it possible for most of these persons to return to their hometowns or families. As things stand, the problem is “moved” from healthcare domain to social domain

and results in less appropriate treatment and deprivation of many rights of persons with mental disorders.

As of lately – and probably under the pressure from general public and negative reports by international organizations – the state has been trying to foster community-based models of protection and, for this purpose, requiring social care institutions to systematize beneficiaries’ documentation. This requirement causes many problems in institutions. For instance, a beneficiary of the Tutin institution has been admitted because she had no place to live in and she has been institutionalized by her own free will – however, according to her documentation she has been admitted as a psychiatric patient diagnosed with schizophrenia. The institution even tried to replace this diagnosis with mental retardation but a relevant social care center contested it. The problems in categorization and re-categorization best exemplify the poor cooperation between institutions and social care centers, which cannot but negatively affect beneficiaries’ position and rights.

3.2. Psychiatric (and neurological) therapies and control

The inspection of psychiatric and neurological therapies for beneficiaries was done by random choice of medical files.¹ Since it was impossible to go through all files of the beneficiaries on therapies, the conclusions drawn about pharmacotherapies (quality or possible misuse) can only be generalized. Except for those in the Sremcica institution, doctors and medical officers elsewhere were most cooperative and helped us to inspect medical files, lists of therapies, special protocols, etc. A psychiatrist in Sremcica refused in a roundabout way to let us look into the

files of some beneficiaries. When we asked to see at least one single file, she reluctantly produced one. And she is the only psychiatrist engaged on full-time basis in all the four monitored institutions (the one in Kragujevac will have two psychiatrists on its staff in a couple of months when two physicians are due to finish their specialization).

And yet, it was in the Sremcica institution that we had the opportunity to talk to a young man of 24 categorized as a case of slight mental retardation but also diagnosed with bipolar affective disorder for which he has been treated in “Dr. Laza Lazarevic” hospital. Two years ago he was put on Moditen Depo and has been getting it since despite the

¹ The term „neurological therapy“ is used as a synonym for anti-epileptic therapy.

fact that he shows no symptoms whatsoever. The case itself exemplifies several problems in the use of psychopharmacotherapy – however, to draw a definite conclusion one needs to carefully examine all medical records. It can be said for sure that psychopharmacotherapy is applied in these

institutions more frequently and in bigger doses than it would have been under the programs of psycho-social support in the community-based system. As things stand now, therapies are used to pacify and, probably, discipline beneficiaries.

Selection of drugs: We take that younger persons should not be administered older generation drugs such a phenothiazine neuroleptics and particularly not depot products. This also relates to phenobarbitone for persons with epilepsy. The Kragujevac institution can be singled out as an example of good practice – according to physicians, only 5 or 6 beneficiaries are on phenobarbitone therapy out of 60 suffering from epilepsy.

Regular control and modification of therapy: There are serious indicators that therapies are not modified (doses reduced) when acute crises are over. Patients are put on neuroleptics even when they are agitated or manifest aggressiveness and kept on them even after such states are over. We have information that a beneficiary was put on neuroleptics as a child because of acute agitation (or “behavioral disorder”) with no symptoms of psychotic disorder – he has been on this therapy for years. The Veternik institution can be singled out as an example of good practice – the institution sends beneficiaries to the Clinic for Neurology in Novi Sad for EEG at least once a year or at two-three-month intervals if necessary; it also tries its best to replace old generation drugs with new generation ones.

Monotherapy: Judging by some medical files and lists of therapies we inspected, drugs are combined unnecessarily (e.g. two neuroleptics). Therapies should include as few as possible drugs particularly when administered to children.

3.3. Hospitalization in psychiatric institutions and clinics

A beneficiary whose mental health starts deteriorating is transported to a psychiatric hospital or clinic. A social care institution fills the necessary form for admission to hospital, which has to be approved by the branch of the Republican Bureau for Social Insurance in the beneficiary’s hometown or the place where he/she has been treated before. Presently, hospitalization in psychiatrist institutions lasts 21 days at most.

An analysis about the number of such hospitalizations per year and their actual outcomes would be most

welcome. Bearing in mind the overall situation of psychiatrist hospitals in Serbia, one can hardly assume that beneficiaries are getting some better treatments in them than in the institutions they are coming from. Asked, “What is it they are doing better in hospitals than you do here?” the personnel mostly referred to bigger doses of drugs. Such an answer indicates that the cuts in healthcare expenses and the number of personnel have impaired social care institutions’ capabilities to provide more adequate psychiatric (and psycho-social) support to their beneficiaries.

3.4. Crisis intervention programs

None of the interviewed members of the staffs denied occasional incidents, violence and conflicts among beneficiaries and against them. And yet, procedures for such situations vary from institution to institution. The Sremcica institution has not developed any procedure whatsoever for physical restraint. In Veternik, agitated beneficiaries are restrained with sheets or strapped shirts. The physicians showed us a simple protocol but the one planned to the point – it just provides the name of the person who ordered restraint and the time when restraint was ended. As for the Kragujevac institution, it has a more detailed protocol that includes procedures for physical restraint in force since June 2008 and named “the protocol for intensified supervision.” Accordingly, when under “intensified supervision” a beneficiary is only occasionally fixated, but the beginning and end of the fixation are not registered. The institution in Tutin has a room for isolation but has not developed procedure for fixation as it still waits for the Ministry of Healthcare’s guidelines. The collegium of directors of social care institutions, meeting twice a year, submitted a draft protocol to the Ministry a couple of months ago. The collegium still waits for a feedback.

Pharmacotherapies for agitated or aggressive beneficiaries are notably problematic. They are administered intramuscularly and usually consist of

10-mg ampoules of Bensedine or 10mg ampoules of Haldol, often combined. While inspecting medical records in Tutin, we often saw the note “if necessary, injection of Haldol 10 mg plus Bensedine 10 mg.” For instance, such therapy is prescribed to 12 beneficiaries on the list of 15, while the rest receive just ampoules of Bensedine “because they are with epilepsy” (phenothiazine neuroleptics are contraindicated with epileptic patients). Nurses are administering ampoules “for 5-7 days until a beneficiary calms down.” The director confirmed that injections were given frequently. These facts may leave the impression that therapies are used for punishment. Example: A beneficiary described as excessively aggressive often breaks everything around him. He has been diagnosed with code F21, meaning mild mental retardation, and G40 indicating epilepsy. It was hard to obtain answer from the personnel about the reasons for his aggressiveness. As we insisted on the answer, a nurse said, “He turns aggressive when left without cigarettes.”

All the institutions should develop more detailed procedures for crisis intervention and introduce them step by step: adjust their procedures for physical restraint with pharmacotherapies so as to avoid “chemical restraint” first, then adopt protocols that would be available to analyses and finally start implementing the procedures for conflict resolution without methods of restraint.

3.5. Understanding of beneficiaries’ behaviors and mental states

We observed a phenomenon that might seem banal but is potentially most threatening to beneficiaries. Medical officers (doctors and nurses alike) were often incapable of explaining sudden changes in beneficiaries’ behavior – outbursts of aggressiveness or agitation. It seems that the personnel

are either not trained or motivated enough to recognize and understand psychological processes or, even worse, that they do not expect beneficiaries at all to have understandable and meaningful emotional reactions. In other words, medical services are either not properly organized (shorthanded, untrained, etc.)

or dehumanized. Example from the Sremcica institution: According to the personnel, a ten-year-old boy with visible cuts on his head turned aggressive and crushed his head on a billboard. The psychiatrist only said he had been expelled from a special school and refused to answer other questions. However, it turned out over the interviews with nurses and other medical officers that the boy's feelings were badly hurt after expulsion because "he no longer rode the bus with

other children." Another (positive) example from the Kragujevac institution: The personnel were describing a sudden change in a beneficiary's behavior (she became aggressive and was destroying plants in the garden) but also speaking about the methods by which they were trying to determine the cause of such change (it turned out to be "a broken heart" case) and the methods they were using over individual and group therapies.

4. Deinstitutionalization

All the four monitored institutions are doing their best to reduce the number of beneficiaries and gradually release those capable of living in the outside community. However, several problems hinder the process: 1) the existing programs (ranging from "Halfway House" to actual deinstitutionalization) are either at the very beginning of implementation or misinterpreted; 2) non-existent "exit doors"

(institutions can prepare beneficiaries for release but cannot ensure their living outside the institution; social care centers and non-existent system of community-based living are the biggest stumbling blocks); 3) non-existent system solutions (e.g. re-classification, restitution of the right to support oneself, education, employment programs, etc.).

Existing programs: All the four institutions have just begun developing the programs for community-based living. Out of 305 beneficiaries of the institution in Sremcica, 26 are included in the program and live in five apartments in Belgrade (one apartment houses 5-6 persons). They have been accommodated in these apartments under the project realized by NGO "SAPI." We could not obtain the information about the criteria by which these beneficiaries have been selected or prepared for community-based living. Therefore, we can only assume that they have been selected by their respective levels of independence. We did not have the opportunity to see the apartments. According to the director, NGO "SAPI" submits reports to the Ministry but not to the institution. She herself has inspected all the apartments and is pleased with living conditions, furnishing and equipment, as well as with the support the new tenants are getting. However, financial sustainability of this form of community-based living has not been legally solved yet and, therefore, the doors to the apartments could be closed to beneficiaries at some point. All the beneficiaries accommodated in the apartments earn their living with the assistance of another non-governmental organization. However, their employment has not been regulated so as to last.

Institutions in Kragujevac and Veternik are implementing "Halfway House" projects, and Veternik managed to organize community-based living for 10 beneficiaries. Their concepts of the project, however, seem to differ. The Kragujevac institution has perceived it (properly) as a part of a larger program and temporarily stopped sending beneficiaries to the outside community when social care centers proved incapable of providing support to them. On the other hand, the director of the Veternik

institution, the same as his counterpart in Tutin, has different plans: they both intend to continue constructing “halfway houses” (actually, this is about securing additional accommodation capacities rather than deinstitutionalization). Thirty-six beneficiaries of the Tutin institution have already been accommodated in the facilities located in “farmland” without any certain prospects for leaving them.

Non-existent “exit doors:” Many members of institutional personnel expressed complaints about cooperation with social care centers. Representatives of these centers do not inquire about beneficiaries regularly, rarely visit institutions and are incapable of ensuring community-based support to beneficiaries able of independent living, they said. The last statement is most indicative since it is obvious that many beneficiaries could return to communities. It goes without saying that social reintegration would significantly foster their mental health but also have a positive effect on the beneficiaries remaining in institutions. The whole system is so planned that institutions can in no possible way reduce the number of beneficiaries (unless they die) and are, at the same time, under constant pressure to admit more and more people (159 persons are on the waiting list for the Kragujevac institution). Should community-based living be ensured for at least a greater part of beneficiaries capable of independent living, those who stay in institutions would be getting better care and protection until they turn fit for community-based living.

Non-existent system solutions: Many problems facing beneficiaries that are crucial for their successful social rehabilitation are explained within the aspects under the scrutiny in all the four institutions. True, institutions should show more initiative for solving all these problems. However, lasting solutions can only be found through cooperation between various governmental institutions.

HOME FOR CHILDREN AND YOUTH WITH MENTAL DISABILITIES “SREMČICA” IN BELGRADE

1. Introductory remarks

The Home for Children and Youth with Mental Disabilities Sremčica exists since 1969. With the development and urbanization of Sremčica suburb, the Home is today connected to the city by modern roads. Located at the entrance to this suburb, it occupies a 10 hectare property and it is surrounded with vegetation. The capacity of this institution hasn't changed and it is 300 places for housing chil-

dren and youth with medium, moderately severe and severe mental disabilities, from the minimum age of 10.

At the time of the visit by the Helsinki Committee, there were 305 beneficiaries in the institution. Out of this number, 28 were part of the living with support program (26 were housed in 5 rented apartments in Belgrade, two in a village household in Knić).

2. Living conditions

The institution is composed of a total of 13 buildings, three of them dedicated to the housing of beneficiaries (children's, men's and women's pavilion), seven serving technical purposes, and the three remaining being the management building, the ambulance and the accounting department building.

For decades no funds were invested in this institution; however, changes that significantly improved housing conditions are now visible in all buildings. The electrical network was reconstructed, most of the funds needed for installing a water heating system were secured, both the interior and the exterior of the buildings were renovated, the furniture was partly renewed... It goes without saying that further investments are necessary in order to finalize the reconstruction task and improve the general living conditions, but the current condition of rooms beneficiaries use is, for the most part, satisfactory. A lot of furniture and technical equipment is still lacking, and especially bedding, blankets etc.

However, the available space is insufficient for the housing of so many beneficiaries, and we believe this to be a significant problem. Rooms accommodating as much as 14 children are absolutely not an acceptable form of housing, regardless of how nice they look. Overcrowded rooms with too little space have many negative implications – from the inability to equip the rooms with necessary furniture, lack of privacy, to the possibility of provoking a psychological problem such as feeling claustrophobic, nervous, endangered, etc. Institutions of this type should devote special attention to providing conditions which will protect beneficiaries' right to privacy, as well as to developing habits which will prepare them to better adapt to life in the community.

The staff obviously put some effort into making the rooms as pleasant as possible – many rooms have flowers, paintings, nice curtains... However, many areas within the facility still appear cold, and need to be improved in cooperation with the beneficiaries. Furthermore, it is unacceptable that the

Sremčica suburb still has no sanitation system, forcing the institution to use septic tanks. Regardless of the fact that this area is far from the city, we believe that the city administration should immediately give it priority in connecting to the city network, primarily because of the existence of such a big institution.

The children's pavilion houses children from the age of 5 to the age of 15. Out of 82 beneficiaries, accommodated in 8 rooms on the ground floor and first floor, 59 are boys and 23 are girls. There are a total of 9 bathrooms with toilets, 8 classrooms – common rooms, and one room for the educators on each floor (ground and first). The offices of the speech therapist, social worker, psychologist and habilitation service chief are located on the second floor, as well as the sensory and parent room. This floor was added in the previous year and the building was renovated. A large room for meetings, performances and the like with 250 seats was also built.

The so-called women's pavilion houses female beneficiaries over the age of 15. We were told that the oldest beneficiary is 50. Around 80 beneficiaries are accommodated in 16 rooms on the ground floor and first floor of the building. There are a total of 4 bathrooms with toilets, which means that there are 20 beneficiaries to one bathroom, i.e. toilet. There are 4 living rooms, 4 kitchenettes and a laundry room.

At the time of our visit, there were 120 beneficiaries in the men's pavilion, between the age of 15 and 50, accommodated in 25 rooms with 3 to 7 beds. Four bathrooms per pavilion (both men's and women's) are insufficient to maintain adequate hygiene of such a large number of persons. Last

year a second floor was added to this building, but according to the staff, construction work was faulty and now there are certain problems with the roof. At the time of our visit, the work on replacing doors and windows was underway. Along with recent renovations, this certainly improves the quality of accommodation and living conditions of beneficiaries. Despite this, we believe that space and equipment needed for a larger number of living rooms is still lacking, since only three rooms are currently adapted for this purpose.

Technical buildings house numerous workshops (cardboard production, toilet paper production, handmade folk artifacts production, tailor's workshop, print shop and carpenter's workshop), which have also been renovated; the physiotherapist's room is also in good shape, but the gym is in poor condition and needs total renovation and purchase of appropriate equipment. The kitchen and dining room are sufficiently large and luminous, and there are separate rooms for hairdressers, bakery, storage, laundry and boiler room. Additional funds are needed for replacement of old furniture, broken or missing equipment for preparing food and in the laundry, some machines and technical equipment...

The institution has an agricultural property, with buildings for breeding pigs, chicken, egg laying hens and compost refining, which are far from the housing area and do not jeopardize hygiene and activities in that area.

There are large, well-kept green areas between the buildings, sitting benches, a sports playground and equipment designed for playing and activities of younger beneficiaries. The functionality of the exterior could be even better with a little investment and initiative.

Recommendations

- In cooperation with local and state bodies provide funds to connect the institution to a proper sanitation network; the city of Belgrade must make investments into the development of Sremčica its priority, in order to establish the necessary level of hygiene and health safety of the Home beneficiaries;
- Carry out necessary reconstruction of buildings in order to reduce the current overpopulation to a level which is bearable and more humane;
- Finalize the renovation of buildings making them better equipped and thus creating an atmosphere and living conditions similar to a family way of life;
- Provide funds necessary for purchasing equipment and arranging the interior, in order to enrich activities and contents of the work with children and create conditions for quality expert work, which are currently lacking.

3. Institutional personnel

The structure of the staff according to their job position is the following: management, counselors, and caregivers, medical, administrative and technical employees, making for a total of 142 employees. Out of this number, 42 are expert employees: social worker, psychologist and speech therapist (one each), defectologists (20), work therapists (7) and work instructors (12) for different skills. Work instructors have the 4th level degree in vocational education; work therapists have the 4th, 6th or 7th level degree in vocational education, while all other employees have university degrees. The majority of employees have more than 10 years of employment, but there are some younger employees as well. As to their gender, the female employees are the large majority.

All beneficiaries have a master educator, that is, one educator has between 15 and 20 beneficiaries in a group. This number is somewhat smaller in the children's pavilion (between 6 and 12 children). According to the staff, the main problem pertains precisely to the large number of beneficiaries per group. They believe that they have no time for individual work, while group work with this number of beneficiaries does not yield maximum effect. This opinion is not acceptable, since it is well known that the optimal number of participants for group work

is between 18 and 22. Apart from the general opinion of the staff that more expert employees need to be hired, some of them believe that administrative obligations are too numerous, which sometimes contributes to the lack of time necessary for high-quality and direct work with the beneficiaries. Similar comments were voiced in the majority of institutions of this type, and they point more towards the inertia of the staff and their refusal to accept personal responsibility for the low-level quality of the beneficiaries' overall living conditions within the institution.

As the work is organized in shifts and the number of educators (20) is relative to the number of educational groups, it practically means that caregivers and work instructors are those who take care and work with beneficiaries in opposite shifts. However, overtime is very rarely needed, while at duty times two educational groups are joined together. This is done during holidays, weekends, etc. Medical staff and caregivers are working night shifts.

The staff expresses interest in additional education since they realize that the knowledge and skills they apply are based on obsolete orientations and methods of work. In addition to this, the employees point out that the structure of beneficiaries is leaning gradually towards those with psychiatric and behavioral problems. Beneficiaries are aggres-

sive and destructive, and the staff has a hard time dealing with these problems and situations. The staff uses the knowledge learned on seminars they attended (Maria Montessori program, Sensory room, Reeducation of psychomotrics...) in their work, but also points out that much more work should be done and invested in programs and education aimed at preparing beneficiaries to become more independent in local communities (daily sojourns, foster families for children, living with support), since this yields good results in practice.

It is certainly very difficult to organize the life of such a large number of beneficiaries in accordance with their needs. However, we believe that the employees do not have the same perception of their role and responsibility for the actions and behavior of the beneficiaries. When talking with the staff, we heard different comments which corroborate this belief: “When the Roma children first arrive, they find it interesting to have their own

beds and other things they did not have before, but as time passes they become bored and start running away”... “Sometimes we are faced with the problem of overeating. We don’t know what to do with that excessive energy which is channeled the wrong way”... “One girl breaks things, screams. I can’t work with people like that. My hands are weak, and she can hit you, spit on you. What to do in a situation like that? We heard about the isolation room, that we have the right to use it. This punitive measure yields results, the news would spread, especially amongst the older ones. However, only the psychiatrist can order isolation. Maybe at least some sort of restraint, so they can’t hurt themselves”. The dominant impression is that the staff does not have the appropriate knowledge and skills to deal with delicate situations. Furthermore, the attitude towards the beneficiaries is more passive and observing, and less active in terms of joint work towards a higher quality of life and a pleasant atmosphere within the Home.

Recommendations

- Encourage the staff to improve their professional education in the fields pertaining to the problems they face in their everyday work and for which they need additional knowledge;
- Increase professional competence of the employees and improve the monitoring and evaluation of the institution’s work by providing expert advisory support;
- Encourage communication and experience sharing among people who work in practice, as well as between these people and relevant institutions, regarding issues and dilemmas related to reform processes.

4. Activities and organization of work with beneficiaries

As we have already mentioned, the Home in Sremčica is meant for housing children and youth aged ten or older, with medium, moderately severe and severe mental disabilities. However, there are currently more adults with mental disabilities in the House than children and youth. Roughly, the ratio is 2:1. Out of the total number of beneficiaries, 29 have minor mental

disabilities, and most of them were accepted in the Home at the recommendation of the competent ministry since a more adequate accommodation could not be found. The majority of beneficiaries, 218 of them, have medium mental disabilities, 23 have moderately severe mental disabilities, while 34 beneficiaries have combined intellectual and physical disabilities.

This structure partially explains both the organization and the method of work in this institution. Namely, after a child is admitted, the expert team (social worker, defectologist, psychologist, doctor, and other experts, if necessary) makes a decision as to the group the child will be placed in, based on the documentation from the originating Center for Social Care, the age and the physical and intellectual capabilities of the child, as well as the period of adaptation and monitoring (3 to 6 months). The newly arrived beneficiary is placed in the chosen group (children's pavilion, or men's or women's pavilion for adults). The most common problems during the period of adaptation, according to the staff, are fear of separation, emotional problems, behavioral problems and regression. Most often, the staff helps children integrate in the group and the way of life within the Home through group meetings where they include older members, the so-called "group protectors", or they evaluate which member of the group would be the most adequate "pillar of support" for the newly arrived beneficiary. As we have already mentioned, the groups of children are heterogeneous, age between 5 and 15, of both genders. There are 8 educational groups and the same number of educators in the children's pavilion. Each group has between 6 and 12 beneficiaries. Defectologists work with these children according to the educational plan for children with moderate mental disabilities. In addition to these types and methods of work that have been in use for many years, the staff who were trained also apply a modified Maria Montessori program. The Sensory room is also used, and according to the staff, it yields good results. The degree to which the employees point out the aggressive and destructive behavior of beneficiaries is a little unusual, bearing in mind that the basic purpose of the

Sensory room is relaxation and relief of tension; thus, it might be a good idea to review the possibilities for a more functional usage of this room. Beneficiaries under the age of 15 who do not attend school, spend their time mostly in carrying out basic daily activities. There is a "Montessori room" equipped with various didactic equipment and toys. The staff explained that "it is a room where better children come, the ones who do not break things and who can learn not to take the toys out of the room". We did not find out how many children this meant, or how many beneficiaries use the "Sensory room". These two representative rooms are certainly not sufficient to meet the needs of the large number of beneficiaries; furthermore, they are obviously used selectively and are not available to all children. This also points to insufficient professionalism of the staff who should be trying to meet the needs of the children, regardless of the manner they express those needs, and use their expertise to help children express their needs in a socially articulated way. Caring for material goods must not be placed before the needs and interests of the children.

When they turn 15, children are placed, according to their skills and abilities, in appropriate groups in the women's or men's pavilion. In the women's pavilion, the beneficiaries are divided into 4 groups and work in workshops within the institution. Four educators have around 20 beneficiaries per group. Out of the four groups, only one (around 20 beneficiaries) is below the physical and psychological level necessary for job assignments within workshops, but they have certain activities organized in the living room. The choice of work activities is made by the expert team based on the assessed abilities, but also the wishes and preferences of the beneficiaries. In the men's pavilion, the beneficiaries are divided into 8 groups where the number of beneficiaries varies

from 14 to 20. One educator-defectologist works in every shift. He or she conducts workshops for development of motor abilities, while a certain number of beneficiaries also work at the institution's agricultural property. In the second shift, beneficiaries work in workshops. According to the staff, out of the eight groups, only one (around 14 beneficiaries), due to lower abilities, does not have job assignments in workshops.

It should be pointed out that the expert team, together with the originating CSC, makes a joint protection plan for each beneficiary, while individual treatment plans are created by the expert team in cooperation with educators and other experts in the institution. The educators told us that the most valuable source (of information) when getting to know a child is the data and diagnostics from the Institute for mental health. However, they are not available in every case. Work orientation means activating the abilities of the beneficiary which will promote his or her independence. The contents of the work, through regular activities which the educators conduct, include self-servicing, development of speech and language skills, development of psychomotorics, work education, free activities, musical and painting activities. Both individual and group work are applied. Special attention is given to organized free-time activities, which are realized through different sports and cultural activities (swimming pool, karate club, games without boundaries, shows, parties...). Specific problems that the staff face in the course of their daily work and which make them feel powerless are the issue of large groups, as we have already pointed out, the lack of appropriate equipment and workspace, as well as the aggressive behavior of beneficiaries (both towards inventory and objects, as well as amongst each other and towards the

staff), auto-aggression and escapes. They point out that the emphasis in their work with children is on positive behavior, that is, awards, and not punishments and prohibitions. Some of the data presented to us were contradictory, and we got the impression that the activities are either not carried out, or are carried out in an incompetent manner.

In accordance with the conditions and funds, certain workshops are operating where beneficiaries carry out job assignments under the supervision of instructors: tailoring shop, cardboard production, post-processing, screen printing, offset printing, homemade arts and crafts and carpenter's shop. The staff told us that the final products of the beneficiaries' work are sold on sales exhibitions and that the money is used to purchase the necessary work materials, namely that the beneficiaries have no remuneration for their work since it is part of their work-occupational therapy (vocational skill learning, carrying out job activities).

The education of beneficiaries is conducted in a special primary school "Anton Skala" in Belgrade, which 32 students attend. Since the school is far from the Home, special bus transport is organized for them. In addition to that, due to the lack of space in the school, as we were told, two classes have been opened where tutoring is held within the Home. They include 15 beneficiaries, and the classes are taught by two teachers-defectologists who come from the school. We were not able to see the rooms where the classes are held. From the data that we reviewed, we concluded that the majority of students in the school are also children from Sremčica, which greatly impoverishes their educational environment and social life.

Two beneficiaries attend the secondary school for the education of children with developmental difficulties (special school). Since all beneficiaries are classified in one of the categories of

mental retardation, it is impossible for those who in reality have no difficulties in intellectual functioning or have very mild difficulties to attend regular schools. Out of the total of 117 beneficiaries aged between 7 and 18, about 50 attend school (but only special), which accounts for 43% of the number of those for whom schooling should be obligatory.

These data show that the majority of beneficiaries are deprived of any type of education, and those who are included in the educational system, acquire education in conditions of double segregation: they are segregated by attending a special school and, at the same time, by the fact that in classes they attend the majority of children come from the Home. Isolated in this way, they have no contact with children and young people who possess diverse knowledge, have various interests and experiences and different social skills, or with children of their age who live with families. The organization and practice of providing care for children and youth in this Home deprives them of the basic and critical encouragements for emotional, social and cognitive development, as well as of the appropriate conditions necessary for preparing them for a life in the community.

On basis of the outlined structure, it can be concluded that this institution in fact has a capacity of around 100 beneficiaries (children and youth over the age of 10) according to the norms, while the large number of adult beneficiaries is, amongst other things, a consequence of poor functioning, that is, an extremely low capacity of non-institutional alternative types of care available to mentally challenged individuals. This is primarily corroborated by the fact that only about 40 adult beneficiaries have no work engagements, while all others (in addition to those with mild mental disabili-

ties) have developed both skills and capabilities, through expert and pertinent educational activities, as well as through instruction on work tasks in accordance with their needs and psychological and physical capabilities. In the majority of cases these skills and capabilities are sufficient to enable them to return to their local communities and to function almost independently through protected housing and accommodation in smaller housing units with support. Therefore, the majority of adult beneficiaries are ready for Living with support, Halfway housing and other forms of less restrictive environment or protected non-institutional living. The documentation of the institution reveals that during 2008 only one beneficiary was returned to his biological family, while foster families were found also for only three children. Living with support in Belgrade was organized for 26 beneficiaries in five apartments located in different parts of the city. The entire project is led by the SAPI NGO, with funding obtained through projects and from the Ministry of Work and Social Policy. All those living with support are registered as beneficiaries of the Home, but for the last 5 years, namely, in the period this project has been developing, employees of this institution were not part of this program and have no feedback information about their beneficiaries. This is not a good example of partner relations, and we believe that the institution, for many reasons, should be an active participant in providing help to their beneficiaries in becoming independent. In addition to this group in Belgrade, one married couple also participates in the Living with support program, in a village household in Knić. They are also on the list of the Home in Sremčica, while the local CSC is looking after them. The institution has somewhat better information about this couple through their colleagues from the CSC.

It would be irresponsible to leave Living with support on the level of a pilot project, that is, not to include it in the new Law on Social Care as an equal form of care provided for children and youth, but also for adults. If not, every attempt of the staff in this or

similar institution becomes pointless and useless, reform process and the concept of deinstitutionalization nothing but words on paper, and integration and inclusion of beneficiaries merely a theoretical ideal and well conceived model.

Recommendations

- Encourage the staff to implement different programs and activities in their work with the beneficiaries, and to assess the situation and needs of every beneficiary more frequently;
- Investigate, in cooperation with competent institutions at all levels, the possibilities and alternatives for gradual re-socialization of beneficiaries through special programs and activities that will precede their discharge and be realized within the Home or through efficient social support;
- Encourage all competent bodies to undertake necessary measures to ensure the best interest of beneficiaries who, in view of the type of social care needed, are not appropriately housed in the institution.

5. Contact with families and the outside community

Having reviewed the documentation of the Home, we learned that representatives of only 42 CSCs out of the total of 102 originating CSCs paid visits to the beneficiaries in 2008. Moreover, it should be pointed out that these CSCs have a number of beneficiaries housed in the Home. The question is whether all CSCs participate at all in drafting and realization of beneficiary care plans and in the preparation of their discharge? The staff pointed that the CSCs are intolerably slow when discharge of beneficiaries is concerned, and that they often refuse to come for the drafting of discharge plans or to take charge over the beneficiaries. When invited by the Home staff to come, visit their beneficiaries, and work on finding solutions that are in the best interest of beneficiaries in cooperation with the Home expert team, they often respond that they have no funds, no vehicles or no available experts. In some cases the joint care plan is sent for synchronization by mail! On the other hand, the staff believes that the situation has somewhat

improved recently, namely, that visits are more frequent after the ordinance of the competent Ministry to reassess the needs for further housing. Also, contacts are more frequent when beneficiaries are minors, while there is almost no interest for adults. There are Centers which believe that Home housing is a final and permanent solution, which is why they are insufficiently engaged in finding alternative forms of care within local communities. CSCs especially lag in delivering Decisions on Guardianship, which some of them fail to deliver even after several written requests and pressure by the staff. CRCs also fail to provide personal documents of beneficiaries on time, as well as data on changes in socio-economical, material, legal and family status of beneficiaries.

Within the overall structure of beneficiaries, only four of them have no family and relatives. If we consider this number negligible, than the fact that over 100 beneficiaries have no contact with close relatives, while around 50 have contact rarely and only over the phone, point out to serious flaws in the

work of both the CSCs, and the Home staff. It is very hard to accept that in the case of more than a half of beneficiaries it is really impossible to establish a better cooperation with parents or close relatives. The question arises whether everything has been done to improve this cooperation and contacts? Realizing that a child's intellectual development is slowed down causes stress, disbelief, confusion and crises in many families. However, this is exactly why it is being pointed out that stronger cooperation and support of CSCs is needed in the work with families which, for different reasons, are not interested in cooperation, both while the child is housed in the Home and upon his/her discharge. The staff emphasizes the fact that when the family is preserved and interested in active participation in the process of developing capacities and skills of a child, or alleviating the aggravating consequences to his/her development, the best results are reached in practice. The experience with adults also shows that intellectually underdeveloped persons who are deprived of the support of their families have the biggest problems. The Home staff also has to be active in this regard, since their more intensive engagement in establishing more frequent and better contacts with families is also needed. When asked more specific question on this issue, the staff failed to offer specific answers, but some agreed that the role of the staff in this cooperation could and should be more important.

However, it is very indicative that a large number of beneficiaries often run away from the institution. Some of the staff explained these escapes in the following way: "We can't stop those who want to run away... more than a third of the beneficiaries are Roma children, and they can't stay in one place"... "I believe that they run away because they do not want to live

here, they simply don't!". The impression is that certain employees believed escape to be an innate proclivity of the beneficiaries, rather than an act of reaction to numerous unmet needs, but also to conditions, organization and content of life within the Home. The psychologist told us that the staff knew where the majority of beneficiaries went on their run, while other staff members pointed out that those with mild developmental problems, who are housed in the Home due to the fact that the parental rights of their parents were revoked, are the ones who escape most frequently. As an example, they told us about a girl who was abused by her stepfather and mother, but since being housed in the Home, she keeps escaping and returning to her abusers. The staff portrays escapes as a state of affairs and a confirmation of problems and inadequate behavior of beneficiaries. Organization and content of the life within the Home, as well as their attitude towards beneficiaries, are not perceived as reasons for escapes. Children that we spoke to told us they run away because they were bored, or because they wanted to see their parents, relatives or friends, while some were adamant in their claims that they felt much better in the places they run to. We believe that the staff, at least in these cases, obviously fails to find an adequate approach, since they are unable to grasp the complexity of the living conditions of the beneficiaries. Instead of being offered expert help, a feeling of warmth, safety and the much needed sense of belonging, the beneficiaries are left without understanding and remain isolated with their problems, which is why they cope better in their old environments.

The next important element in cooperation is most certainly the school, that is, the education of beneficiaries. Besides the aforementioned flaws, the impression is that the staff is also failing to do everything in their power to support the beneficiaries, as well as encour-

age and help them to overcome their learning problems. We were told that the adults “who show interest” are given the opportunity to acquire basic literacy in cooperation with the people’s university “Đuro Salaj”. However, the motivation is primarily left to the beneficiaries, and thus additional engagement and a more active approach of the staff is needed.

As to the other types of contact between beneficiaries and the environment, the staff points out good

ment, the staff points out good cooperation with sports clubs (Crvena Zvezda and Partizan, archery club, sports associations...), theaters, and popular singers. In general, the level of cooperation with the local community is assessed as very high. The beneficiaries who we spoke to confirmed that these activities are taking place, but not sufficiently enough.

Recommendations

- Create different forms of cooperation with the environment, the local community, as well as with NGOs and associations, cultural institutions, etc., and include the largest possible number of beneficiaries in these activities;
- Focus on the assessment of strengths and needs of a child and his or her family, in order to reinforce the capability of the family to take care of the child, and work in particular on maintaining and improving their mutual relationship;
- Take a more active approach to supporting the relations between each beneficiary and other individuals and organizations which are of importance to him/her;
- Improve the quality of relations between relevant institutions (ministry, other similar institutions, CSCs), in order to provide better and higher quality care for beneficiaries, protect their interests and improve their general position in the institution and in the society;
- Work on combating prejudices about children and youth with developmental disabilities through media and campaigns, raise the awareness of citizens about the importance of the presence of people with developmental disabilities in the life of a community, and promote methods for providing help and support to these individuals;
- Set clear criteria for ensuring the rights of parents and children with developmental disabilities to participate in decision-making process regarding issues important to beneficiaries (housing conditions, rules of conduct, education, right to cultural and spiritual development, etc.).

6. Guarantees of rights and liberties of beneficiaries

Although the House in Srem-čica is meant for housing children and youth, as we have already pointed out, the majority of the beneficiaries at this time are adults. This situation is a consequence of decades-long marginalization and isolation of individuals with mental disabilities. The no less discriminatory attitude of medical experts, which is, unfortunately, still present, contributed additionally to the stigmatization of these individuals. Parents are often encouraged to place children

in institutions, while those who refuse to do so face enormous problems, and receive almost no support in solving them. If we add dysfunctional families to this, as well as other situations that influence the decision to place a child in institutional care, it is clear why individuals with mental disabilities often spend their whole lives in institutions of social care. In order to change this practice and the attitude towards individuals with mental disabilities, new and more adequate sys-

temic solutions in all areas of social life are required.

The Home in Sremčica is only one in a series of institutions where all the flaws of the current treatment of these individuals can be observed. We were told in the institution that the beneficiaries are, for the most part, categorized prior to arrival or at the beginning of their stay in the institution. The realization of this process is within the competence of CSCs, which should also perform regular re-categorizations of beneficiaries upon the initiative of the institution where a child is housed. The experience of this institution is that re-categorizations are performed very rarely, even though the institution requests them. Bearing in mind that, according to current regulations, re-categorization is performed until the age of 18, the majority of beneficiaries remain permanently marked and, in reality, “imprisoned” by the category which they were placed in based on a single screening, and which took place in early childhood. This is by all means only one of the forms of serious violation of beneficiaries’ rights and inhumane behavior. In this way, the development of a child is impeded from the very beginning, since without appropriate expert assessment and a continuous monitoring, it is impossible to grasp the needs of a child, develop an appropriate approach and plan methods of support necessary for attaining the best emotional, social and cognitive level, especially in institutional living conditions. Timely and accurate diagnosis, regular monitoring and adaptation of the approach to the developmental needs of children and individuals with mental disabilities belong to their basic rights.

A decision upon which an individual is placed into the category of people with mental disabilities further leads to numerous restrictive measures,

primarily in the field of education and employment. In the best case scenario, the right to education is limited to special schools, or as it is more often the case in practice, it is completely denied. In the Home they offered us the example of a boy who was expelled from school, since according to school management, he was unable to fit in! After that, the boy became more aggressive and he keeps asking every morning to climb the school bus with other children. Expelling students, and from a special school at that, constitutes discrimination and denial of the right to education, and inhumane and degrading treatment, which is unacceptable. We believe that the institution should have reacted in this case, the same way it should have a resolute and clear attitude regarding the issue of re-categorization requests. Education is of critical importance to these children in acquiring social skills, in the absence of which integration in the society is impossible.

The right to employment is also either very limited, or completely denied. The concept of human rights neither recognizes nor accepts a hierarchy among human rights, nor does it allow for any right to be excluded. Another aggravating circumstance is the possibility of divesting a person of his/her legal capacity in a later period of life, which has, so far, almost never been questioned in practice.

In addition to these, systemic problems, which significantly determine the rights of beneficiaries, many other aspects in the Home also fail to offer sufficient guarantees that the best interest and basic human rights of beneficiaries will be respected. We believe that the unacceptably poor cooperation with CSCs results in denial of numerous beneficiaries’ rights, from drafting inadequate programs which fail to provide for good and comprehensive treatment, to the lack of possibility of continuous and high-quality contacts with families,

and the extremely rigid solution to keep the beneficiaries in institutions since the state and its institutions offer no other alternative. Within the institution itself, much more attention should be dedicated to the participation of beneficiaries in all activities, as well as in reaching decision that are important to them. Motivation and support should become more prominent in the contents of work, since this has a strong influence on preserving and developing abilities, and thus also on improving self-respect and development of dignity necessary in the protection of personal integrity.

The institution should also formulate a broader specter of activities (workshops, games, movies, etc.) through which the beneficiaries could be educated, in an appropriate and eas-

ily understandable way, about their rights and mutual relationships, and how to recognize threatening behavior and react in these situations, etc. We have not seen any notice boards or messages regarding this subject in the buildings where the beneficiaries are housed. Furthermore, there is no information on display about names and numbers of the members of the Internal team for the prevention of abuse and neglect.

Beneficiaries who are able and rational enough have full control over their allowance, while others spend allowance through educators. Those working at the Home's agricultural property, as well as in workshops which earn money from the sale of their services and products, do not receive remuneration for their work. Several other institutions offer better solutions.

Recommendations

- The Ministry of Social Policy must initiate systemic changes within its own jurisdiction, but in other state institutions as well, primarily regarding education, healthcare, culture, sport, etc;
- The institution must take responsibility for the protection of beneficiaries' rights and interests in the segments that are in the competence of the CSCs; in regard to this, it is necessary to insist on all initiatives coming from the institution;
- Every employed expert should be serving the needs of beneficiaries; social workers, legal and other experts should have direct contact with beneficiaries in order to adequately monitor their needs and be able to react to them;
- Pay more attention to informing and educating beneficiaries on their rights;
- Increase the overall participation of beneficiaries in activities and programs, and encourage them to get involved in different forms of social bonding;
- Improve the system of awarding and establish a sustainable remuneration mechanism for services and work performed by the beneficiaries;
- Improve cooperation with other institutions and maintain continuous communication in order to share experiences.

HOME FOR CHILDREN AND YOUTH WITH MENTAL DISABILITIES “VETERNIK” IN NOVI SAD

1. Introductory remarks

The Home in Veternik is part of Novi Sad suburb with the same name, located about 15 kilometers from the city. It consists of 17 buildings with a total area of 11500 square meters, located on a 18,5 hectare property. This makes Veternik one of the largest social institutions for housing beneficiaries in Serbia. It was founded in 1971.

The capacity of the Home was reduced slightly (from 550 people to 500), but at the time of our visit there was a total of 593 beneficiaries in the Home. Although it is meant for housing children and youth over the age of 10, with moderate, moderately severe and severe mental disabilities, almost a half of the beneficiaries (256) are indi-

viduals over the age of 27. Incidentally, this is the only institution where the term “profound mental disability” is used for individuals with severe mental disabilities.

In addition to its primary activity, the institution has been providing the services in the Day Care Center in Novi Sad for 25 years, while the construction of a 101 square meter facility meant for the Center for Short-Term Accommodation (up to six months) is underway. This Center will also be financed by the City administration for social care. As it was explained to us briefly, this facility will be in the service of overcoming crisis situations in families whose children are housed in the Day Care Center, as well as for specialized foster families.

2. Living conditions

The accommodation of beneficiaries is organized following the pavilion model, but also within smaller housing units.

Beneficiaries showing the highest level of independence are housed in four housing units (houses) on the property. The houses are equipped and function following the model of living with support. Three of them are old, and have been renovated for this purpose and modestly equipped, while the fourth is new, with significantly better living conditions. It currently houses 3 girls and 7 boys, with the support of personal assistants. Although the houses are not of the same structure and quality, housing within them is far more adequate than

the oversized pavilion housing the remaining beneficiaries.

The housing of the majority of beneficiaries is organized in several buildings which form four units-pavilions (A, A1, A2 and B): for children with moderately severe, “profound” and multiple disabilities; for youth and adults with moderately severe, “profound” and multiple disabilities (separate pavilions for men and women); a pavilion where children with moderate disabilities, youth and adults with moderately severe disabilities and individuals with physical disabilities are housed in separate units; this pavilion houses 119 bedridden beneficiaries. The so-called C pavilion consists of small housing communities.

In closed-type pavilions, A1 and A2, there are total of 159 beneficiaries (82 women and 77 men), all adults with moderately severe, “profound” and multiple disabilities. Both buildings have flat roofs, which results in rain water leaking. Thus, certain areas within these two buildings appear derelict. Each pavilion has one living room with no furniture, except for the mats on the floor and benches against the wall; most of the rooms have six beds, and doors of metal construction, which can be opened only from the outside; there are no personal features nor items, clothing and underwear are shared; in general, as the staff points out, everything is focused on “maximum security” and “better control” of beneficiaries. The entire interior is dark and without enough fresh air. Bathrooms and toilets in the women’s pavilion are in a somewhat better state, but in general, the interior appears dehumanized and does not offer a possibility for any kind of decent living of the beneficiaries. Between the buildings, that is, between the men’s and women’s pavilion, there is a garden with lots of trees, several benches and swings, but beneficiaries mostly wander around aimlessly, sit or lie in the garden. The life of beneficiaries housed in this section, with restricted movement and activities reduced to eating, sleeping and maintaining hygiene, constitutes a severe form of inhumane and degrading treatment and discrimination of these individuals.

The pavilion housing children with moderately severe, severe or multiple disabilities (around 80) appears more humane and warm only at first glance. Boys and girls are housed together, although in separate rooms with 3 to 10 beds. Only beds exist in sleeping rooms, many of them of metal construction and rusty. Some rooms are painted in warm colors, some have curtains, but are nevertheless imper-

sonal, some even derelict. The staff in this wing also claims that the “security reasons” dictate the living conditions. There is one common room with toys and didactic equipment where children, who are able to, paint and color. The area is organized in such a way that children can create smaller groups, in order to establish direct contact, and learn communication skills and cooperation through joint activities. Children assessed by the employees as incapable of participating in these activities spend time in another room, sitting on mats and benches, rocking backwards and forwards. They are very agitated, but the staff in attendance only takes care that they don’t hurt themselves; there are no other activities. Regardless of the large park, the animals at the agricultural property, the pool, the sensory rooms and Montessori rooms, most of these children remain closed in the building in which they live, deprived of all audio, visual, tactile, motoric, social and emotional experiences necessary for their development.

The B pavilion is the largest, and has several units, where around 250 beneficiaries are placed depending on the type and level of their disability and age. The children’s rooms have between 4 and 8 beds; they are better equipped and warmer, with enough light and inflow of fresh air. The rooms dedicated to educational work and other activities are also better equipped. The areas for adults are in a worse condition, lacking furniture and equipment. Individuals with physical disabilities are housed in the unit which has an exit to the yard, with enough parasols and a sitting area with a sunshade. The most distressing conditions, however, are in the unit housing children and youth with “profound” and multiple disabilities, who are also bedridden. There are 48 of them, between the age of 5 and 30, housed in twelve four-bed rooms. These children and youth spend all their time in infant

beds with side bars; they can only see the ceiling, the walls, and the beds and children opposite of them. Some of them are occasionally seated in a wheelchair next to their beds, in the same room. Rooms are located on the first floor and have no balconies. Children are never taken outside. They never see other children who walk or play. They never see colors or any other sight apart from the white walls and the faces of those who feed, change and bath them. They do not hear people talking; no one addresses them personally, nor expects anything of them. Even in these circumstances, the living conditions of these children and youth could be made more humane without significant material investments. Circumstances in which they live are inhumane and represent a form of torture.

The C wing, with small housing communities, is the preparatory step towards living with support. Younger beneficiaries (young men and women) who are capacitated to a great

extent, are housed in several rooms with adjoining living room, small kitchen and bathrooms, equipped as to provide for the highest possible degree of independence of members of the housing community. In compliance with available funds, these rooms are appropriately equipped and maintained by beneficiaries themselves. The institution invested a certain amount of money into renovation and equipment, while beneficiaries themselves add personal touches, which makes this pavilion appear much more humane despite some shortcomings.

In addition to well maintained green areas, beneficiaries have at their disposal a gym (which is in a poor condition), a hairdresser, a small club with a library which has around 3000 books, and a rather large open pool.

Additional funds should also be invested in the renovation of the kitchen and dining rooms in the pavilions, the laundry and other technical/supporting buildings, as well as in the necessary technical equipment, machines and appliances.

Recommendations

- Urgently provide funds for the repair and reconstruction of all pavilions, namely, of the areas that were not invested in or that are subject to rapid dilapidation;
- Humanize the conditions in rooms used by individuals with severe disabilities and multiple disabilities, as well as bedridden individuals; special attention should be devoted to children's pavilions which should be redecorated and adequately equipped with appliances for visual, audio and other stimulation;
- Aim towards forming a larger number of housing units with adequate living conditions and best treatment of smaller groups of beneficiaries.

3. Institutional personnel

The institution has 281 employees who are divided into three sectors: the health and hygiene sector with 160 employees, the special education and rehabilitation sector with 60 employees, and the general and technical services with 61 employees. The sector for special education and rehabilitation is organized in two services: educational work and professional and voca-

tional skill-learning. The experts within the service for educational work are two social workers, a psychologist and a speech therapist, while the educators (28) are mostly defectologists, pedagogues or teachers (Serbian, physical education). The service for professional skill-learning employs three defectologists, one work therapist and 10 instructors with third or fourth degree of voca-

tional education. The medical staff consists of five doctors and 44 medical technicians. Most employees have been working for many years, but there are some younger employees, as well. Gender-wise, there are more women than men.

Educators have groups with over 20 beneficiaries which, according to them, is the main problem. They believe that quality work with children and youth with moderate and moderately severe mental disabilities demands individual approach and dedication, which is very difficult to achieve with such a large number of beneficiaries. The staff points out that group work is possible, but in small groups with 5-6 beneficiaries. On the other hand, although the majority of employees already have the education necessary for working with this population, they are all motivated for further education. According to them, theoretical knowledge, literature and handbooks, which are the basis for drafting work plans and programs, are outdated (from the eighties), and are no longer applicable from the view point of contemporary orientation and approach in the work with children and youth with different levels of mental disabilities. To corroborate this, the staff points out that they started to attend workshops and courses for working with the beneficiaries only recently. Thus some of them have attended the Maria Montessori program (24), Enigmatic world of senses (21), Guide for practical work with autistic individuals (20) and Course for therapeutic horseback riding.

One should bear in mind that although significantly more beneficiaries are housed in units and wings, the appropriate educational and vocational skill-learning activities are restricted to beneficiaries for whom this could have an effect, according to the assessment of the staff. Sometimes that does in-

clude more than 20 beneficiaries, but due to the abovementioned staff deficit, it is impossible to realize the planned activities with a larger group. As there are 14 educational groups, this means that there are 14 educators in each shift having primary groups of about 20 beneficiaries. Caregivers and medical staff mostly work with the remaining beneficiaries (almost 300). The caregivers, however, have no medical education and are not sufficiently trained to work with such severe and complex disorders. During weekends and holidays the work regime is different, and there are only two educators in each shift with 14 educational groups. At these times, the activities of beneficiaries are freely directed. It is obvious that the institution does not have enough employees, both medical and expert, engaged in education and rehabilitation. We believe that a significant problem is that the non-medical staff (caregivers) is not fully trained for adequate work with beneficiaries, which further complicates the position of the expert staff: "The only thing bedridden beneficiaries get is nursing. They are neglected. There are great women, nurses and caregivers, but the policy is such that it neglects"... "They move from their rooms only if their parents take them somewhere". These facts have serious consequences for the treatment of beneficiaries, but also have a negative impact on the employees themselves: "We are constantly under stress; we are simply unable to monitor each child at every moment. It happens, for example, that while we work with agitated children, another child jumps out of a window. This is something you can't recover from, ever... Being on duty is especially trying. Weekends and vacations are the weak points".

As overtime work, the staff mentions activities which include taking children into the city, to shows or manifestations outside the institution... Remuneration for overtime work is not

clearly defined, but sometimes the staff receive days off. In addition to the common viewpoint that stress situations and job difficulty require reduced service years for retirement, during our talks with several expert employees of different vocation we noticed their pronounced sensibility towards beneficiaries and genuine concern about the inadequate conditions for their treatment. One young educator described it like this: “The number of us here is not sufficient and we need education and expert support, but personal traits: emotional stability, love for children, humanity and creativity are the necessary conditions for working with this population. All of us who directly work with children become very attached, we get to know them well and we are aware that much more could be done. Yet, we are helpless... we are dispirited and it’s hard for us to bear it”.

Some of the employees pointed out that seminars were not available to all, namely, that the same people are always sent to attend. It is our impres-

sion that additional expert training is necessary for all employees, at this moment probably most urgently for caregivers and medical staff, but also for others employed in the Home. This is corroborated by the statements we heard from the staff not in charge of direct expert work: “We are very lonely. We would like to visit other institutions, see how they work. We really need some type of cooperation and supervision.”

Finally, we want to point out that certain employees felt the need to talk about poor relationships amongst the staff, claiming that “serious oversights and very unpleasant things are taking place” in the institution. Bearing in mind that the visit by the Helsinki Committee unfortunately coincided with the already initiated formal inquiry regarding these claims, we focused on the position and treatment of beneficiaries. However, a certain level of tension amongst the staff is noticeable. We believe that significant attention should be devoted to this issue, in particular since the institution already has enough problems functioning as it is.

Recommendations

- Find an adequate solution for hiring a larger number of employees in order to meet the needs of all beneficiaries and treat those with severe disabilities in a more humane way;
- Provide necessary seminars for all employees, in order to increase the level of professional competency, which would in turn enable better and high-quality engagement of those who are currently not employed in the most functional manner;
- Enable the sharing of experiences and good practice amongst the institutions with similar categories of beneficiaries;
- Investigate possibilities for a different organization of work with beneficiaries, in order to create smaller groups offering better chances for rehabilitation and education, and at the same time, making the employees’ job simpler and more efficient;
- Establish a volunteer service, both expert (students from appropriate faculties as well as professionals) and humanitarian, engaging youth and citizens with different educational background, but with a developed sensibility and desire to help the weak;
- A strong volunteer service is necessary and extremely useful especially for institutions which have a huge number of beneficiaries and a staff deficit.

4. Activities and organization of work with beneficiaries

As we have already mentioned, the Home currently houses 593 benefi-

ciaries. Out of this number, as much as 421 are over the age of 18, while the

number of children and youth with different degrees and types of difficulties is 172. There are 32 beneficiaries with mild mental disabilities; some of them were re-categorized and placed in the group with mild mental disabilities after a certain period, some others were admitted to the Home upon a request of the competent ministry because a more adequate accommodation could not be found. Another 144 beneficiaries have moderate mental disabilities, 200 have moderately severe, 160 have severe (profound) disabilities, while 57 have multiple disabilities with primary mental disability. Both genders are equally present.

A large number of adult beneficiaries were placed in the institution when they were younger. Some of them have learned how to take care of themselves with appropriate assistance, and they can leave the institution and function in a local community. Obviously, there are some adult beneficiaries who require round the clock care and help, primarily medical nursing and care. For this reason, a very important issue is how adequate accommodation and care can be provided for such a large number of beneficiaries (both children and adults) with combined and complex disabilities, moderately severe and severe mental disabilities, as well as those entirely dependant – bedridden. As we have already pointed, the treatment of these beneficiaries is entirely unacceptable. Having in mind their number, it is even hard to provide adequate palliative care, not to mention other forms. It is hard to imagine that in Serbia, at least for a significant period of time, conditions necessary for these people to live in a family surrounding (either biological, adoptive or foster) will be created. For this reason, it is necessary to find an acceptable institutional model of care in parallel with the development of services of non-institutional housing.

This certainly entails smaller institutions, which would be fully prepared to provide, in the first place, the best quality of life accompanied by medical, as well as all other dimensions of social rehabilitation.

As to the beneficiaries for whom educational process is organized, including vocational skill-learning, they are in better position. Naturally, we are talking about the realistic situation they are in, although we believe that they do not belong in this institution at all. During admission, based on the documentation of the originating CSC, the expert team (head of the service, psychologist, social worker, legal expert, doctor) assesses the physical and psychological capabilities, maturity and intellectual capacity of the beneficiary and decides on the most adequate group, and the work plan and program. The staff claims that the problem occurs when the documentation is not detailed or when it quickly (during the period of observation) becomes obvious that the beneficiary (either child or adult) demonstrates an intellectual potential different from the one specified in the documentation. However, considering the degrees of disability this institution is registered for, no type of mental disability should come as a surprise to the staff. This is especially true since they know that one screening cannot offer a reliable assessment of a person's condition, and that this is reached through continuous monitoring in everyday situations, which they are capable of doing. During the period of adaptation, the staff faces the usual problems, fear of separation and difficulties accepting the house rules. According to the staff, they are able to handle these problems with success. The staff helps a child to settle into a group and the institutional way of life through more frequent individual conversations, both with the child and with the parents, by improvising a family environment with the help of toys and personal items. The staff does not

insist on including the child in group activities if he/she refuses, and allows the child to be only an observer during the adaptation period.

The psychologist who has been working in the Home for 10 years tests every child after the period of adaptation. She gives recommendations for re-categorization and for enrollment in school. Incidentally, 24 out of all the beneficiaries under the age of 18 attend the special school "Milan Petrović" in Novi Sad. "Children really like going to school, and according to the data we have received, they are successful", the psychologist explained. Educators help children with their homework. However, this school only enrolls children with moderate disabilities. Thus, because of categories which are often unreliable, many children can't even enroll in the special school. We have to point out that, in accordance with our current legal provisions, the refusal of an educational institution to enroll a child represents an act of discrimination and a violation of the right to education. Due to the very large number of beneficiaries, the psychologist had to prioritize in her work and focus on younger children, amongst whom many have behavioral problems. In addition to individual work, she started group workshops with them as well. A decrease of aggression amongst the children has been noticed since the groups became smaller.

The general framework, that is, the work plan and program in the Home is realized at four educational levels, which last for periods between one and two years. Every level includes development of specific abilities and skills in accordance with assessed and actual physical and psychological abilities of every individual beneficiary. Individual and group work programs are created by the principal educator. According to the educators, the most valuable sources of informa-

tion when getting to know a child are the parents (if a child has them), and the opinions of the defectologist and psychologist. The effects of a program depend on the methods used by specific educators. Thus, some children show progress, while others stagnate. Ever since the institution hired a group of young educators the approach to children has improved. There are positive advancements thanks to the method of work which puts children into action, and is directed more towards their interests and needs.

The content of work, that is, regular activities the educators carry out include self-service, development of speech and language, development of psychomotorics, work education, free activities, musical activities and painting. Each further, higher level implies and includes more complex operations. In addition to these forms and methods of work that have been used for years, alternative methods of work are applied lately, through the Montessori program, therapeutic horseback riding and the use of the sensory room. The institution has two sensory rooms and two rooms equipped for the Montessori program. However, we were unable to find out how many beneficiaries actually used these rooms. Between April and September last year, 50 beneficiaries were included in the therapeutic horseback riding program. The institution owns two horses, and professionals from the Hipotens Association work with the beneficiaries. The physiatrist decides who will participate in the program, while consent has to be given by parents or the CSC.

A beneficiary who masters the fourth level, is placed in the professional and vocational skill-learning program, which is realized through numerous workshops, depending on capabilities and proclivities. Funds and conditions permitting, the following workshops where beneficiaries work under the su-

pervision of instructors operate: tailoring, embroidery, knitting, weaving, and polyvalent workshops. The staff told us that the final products of beneficiaries' work are sold and that the money is used to purchase the necessary working material, or organize fieldtrips, which positively influences their motivation. This type of activity is very important, and should be additionally encouraged. We got the impression that some instructors perceived their work and the participation of the beneficiaries as an occupational activity; they are insufficiently aware of how important every, even the smallest work activity can be for the continued existence of these beneficiaries outside of the institution.

When asked what awards and punishments they used, the staff answered that the most usual award and commendation was candy, whereas denying candy was the most usual punishment. Furthermore, additional punishments used are criticism, warning or prohibiting beneficiaries from using computers, going out, etc. The majority of staff uses the system of awards and punishments bearing in mind a specific child, namely, taking into account what is motivating that child. Furthermore, they point out that the emphasis in their work with the children is on positive behavior, namely, the awarding part, rather than prohibitions and punishments. However, the fact remains that the beneficiaries are punished by being deprived of the basic pleasures, which are already below the minimum.

The staff explained that the beneficiaries who master the existing programs in the institution in a period which lasts in practice between 6 and 8 years become capable of taking care of themselves with minimal help. At that moment, beneficiaries move from the pavilions to the housing units. Beneficiaries who live in housing units within

the institution are satisfied with their accommodation, but they told us that they would nevertheless like to live outside of the Home. Although this form of care has proved to be extremely useful in view of the integration of these children and youth, the capacity is not even close to sufficient compared to the effective number of children and youth who acquired skills necessary for this form of care, which serves the ultimate goal of making beneficiaries independent and integrating them into the society. This results is a situation where beneficiaries spend longer periods of time than planned in the housing units within the Home, because the next link in the chain leading to independence is missing. The housing units do not offer opulent capacity, merely about 60 places. Specialized foster care, halfway houses, and living with support have still not materialized in practice, in the real sense of the word. The projects in question exist while there are funds to finance them. The road towards de-institutionalization is a process where all participants (and not only housing institutions) have to do their part of the work and provide the conditions necessary for the life of beneficiaries in an open community. It is of critical importance to assess the objective possibilities and effective capacities, as in the contrary, the worst damage is suffered exactly by those for whose benefit the reform is carried out, namely, the final recipients. Preparing beneficiaries for discharge from this and similar institutions and their monitoring must be carried out in a better and more efficient way, which entails cooperation of competent CSCs, as well as the engagement on all levels in developing a support network.

The problem of oversized groups is reflected on the quality of work with each child, as well as on the possibility of organizing other activities (walks, fieldtrips, visits to the city...). Under these circumstances, it is impossible to

meet the needs of every beneficiary. This inevitably leads towards neglecting them. The lack of support on the part of caregivers and other supporting staff is evident, as well as the lack of adequate working space and material. The responsibility of the state is to pro-

vide adequate living conditions as well as the conditions necessary for the development of potentials of individuals with mental disabilities, and in particular, to ensure their humane treatment. However, the institution itself has to put more effort into this.

Recommendations

- Provide funds necessary for equipping and redecorating the facility in order to enrich the activities and contents of work with children and to create conditions for quality expert work, which are currently lacking;
- Encourage the staff to implement programs and activities based on the principles of best practice and inclusion in their work with beneficiaries;
- In cooperation with competent institutions at all levels, develop possibilities and alternatives for gradual re-socialization of beneficiaries;
- Through special programs and activities within the Home, develop the model of “small housing communities” and living with support; make certain that the models do not overlap, but that they enable an increasing level of independence of beneficiaries;
- Put more effort into expert training and raise the level of workshops’ functionality;
- Create activities and contents for beneficiaries with severe (“profound”) mental disabilities.

5. Mutual cooperation and contact with the outside community

According to the staff, cooperation with CSCs should be better. They believe that to that end CSCs should participate more actively in promoting specialized foster care, that is, increase its help and support to these families. During the time a beneficiary spends in the Home, contact and exchange of information with the originating CSC is done mostly over the phone, while regular contact and joint action take place only during admission, that is, when the general care plan is being drafted. The cooperation is least efficient in the discharge preparation phase. From our brief conversation with the children, we found out that the originating CSC rarely gets in touch and visits, although they “keep on promising”. The children are often told that the reason for this is the distance between the originating CSC and the Home, etc. However, upon reviewing

the documentation, we found out that as much as 501 Home beneficiaries were from the province of Vojvodina (121 from Novi Sad, 101 from neighboring municipalities and 279 from other municipalities in Vojvodina); 86 beneficiaries came from other Serbian municipalities, while three came from Bosnia and Herzegovina and another three from Montenegro. This is, without any doubt, an institution where almost all beneficiaries are at the closest possible distance from the places they came from, and consequently from the originating CSCs. This situation is truly unique, which is another reason why we cannot find a reasonable justification for the originating CSCs, especially if we have in mind that around 200 beneficiaries have parents and relatives as immediate guardians, while all the others are in the custody of the CSCs.

All in all, the staff assesses the cooperation with CSCs and the competent Ministry as the poorest. Some believe that people from the field have to be part of the team when drafting and implementing new programs and projects, and that more frequent analyses of situation in institutions are necessary before systemic solutions are adopted by the competent Ministry. The atmosphere and relations amongst the staff were, for the most part, assessed as satisfactory, which is somewhat contradictory to the tensions that many mentioned. It is our opinion that we are dealing here with different perceptions of professional and personal relationships on one side, and behavior provoked by some other motives on the other.

A large number of employees perceive working with families as the most important role of CSCs. Although the employees clearly understand the importance of maintaining a relationship between a beneficiary and his family, it appears that they can't recognize their own role as clearly, especially in regard to encouraging and including parents in the treatment of their children. We believe that the staff must also assume an active role, by offering parents the possibility of participating in decisions pertaining to life in the institution, and that parents should be included in appropriate programs and activities in order to establish relations with their children and overcome the feeling of helplessness, shame and fear. According to the educators, it is not rare to have one parent visit the child regularly, while the other refuses to come, or comes seldom. There are also children who are most often visited by close relatives. In these and similar cases, supporting the family becomes extremely important, since if it is adequate, it might result in the child being taken over from the institution. At the same time, we are aware of

the fact that many parents and relatives are incapable of taking over the children, but in these cases, a clear distinction should be made as to the reasons. Where the reasons are only socio-economic (and not the inadequacy of parents), a system of adequate support should be developed, rather than looking for the alternative in a foster family or an institution.

As to other forms of contact between the beneficiaries and the outside world, they are realized through sporadic visits by children and students, NGOs and associations, or beneficiaries from similar institutions. For the past four years a successful cooperation with colleagues from Prague is taking place. Two years ago, beneficiaries and staff from Poland visited the Home, while 23 beneficiaries and 4 educators returned the visit last year. Although these forms of socialization are valuable, the contact of beneficiaries with the outside world is much more frequently realized through organized visits to different manifestations, shows, exhibitions, concerts, and through regular visits to the town. However, these activities are available only to beneficiaries with mild and moderate mental disabilities. We were told that "all those who are allowed to" travel to the seaside. Thus in June this year, 43 beneficiaries spent their summer vacation at the seaside, while another group of similar size was planned for August. When we asked about the criteria that are critical for the assessment of who "is allowed to go", we were told that they were medical. Respecting this argument as truly important, we nevertheless remain somewhat skeptical as we are aware of the generally negative attitude of medical staff towards individuals with mental disabilities and the decade-long "categorization" which deprived many of them of their basic human rights.

We should point out that, since recently, the staff and beneficiaries are engaged in preparing theatre perform-

ances and shows. On the occasion of the 35th anniversary of the Home, a performance took place, with the participation of 46 beneficiaries. Another performance was prepared, where in addition to 15 beneficiaries and 2 educators, another two boys from regular school participated. This performance took place last year during the International Day of People with Disability, and it was also given in kindergartens in Novi Sad and its surroundings (Futog, Veternik). These examples are en-

couraging, since they indicate that a process of integration of people with mental disabilities is possible. Unfortunately, the fact that this is not continuous practice is not encouraging. Even if the financial conditions are met, it is still impossible, due to previously described problems, to organize these activities for a larger number of beneficiaries at the same time. Thus, from the point of view of individual beneficiary, contacts with the outside world happen quite seldom.

Recommendations

- Enable families and other interested individuals who are close to beneficiaries to participate more actively in issues concerning living conditions, expert work and the future of beneficiaries;
- Formulate education and support programs for parents and relatives;
- Cancel the limitations regarding visits to beneficiaries, bearing in mind their interest only; visitation hours can be only limited for health and therapeutic reason, and that only for certain beneficiaries;
- Open the institution, as much as possible, to the outside world and intensify cooperation with educational, sports, cultural, business and other actors;
- Improve the quality of relationships between relevant institutions (Ministry, CSCs, faculties, medical institutions, etc.);
- In cooperation with competent institutions and media, work on combating prejudices and forming a sensitized attitude of the broader public towards individuals with mental disabilities.

6. Guarantees of rights and liberties of beneficiaries

The way this institution was conceived is the cause of most of the shortcomings and violations of beneficiaries' rights, which is a subject already discussed at length. Although a social institution, the Home in Veternik closely resembles special psychiatric hospitals meant for long-term hospitalization. Given the fact that a large number of people spend their whole lives in such institutions, under similar conditions and with the same treatment and activities, it is clear that we are facing a systemic, deeply rooted negative approach to people with mental disabilities. Regrettably, it is the medical profession that plays the crucial role in this. We believe that this

attitude of medical professionals is precisely the key factor which slows down and aggravates the process of de-institutionalization and a different approach and social integration of these individuals. Naturally, this discriminatory attitude, which is still largely present, provoked a similar attitude of other institutions, and the society as a whole. In this context, the Home in Veternik is no exception. In addition to problems which are a consequence of systemic flaws, some oversights are the result of insufficient professionalism and a lack of readiness to change that. This is an obligation and responsibility of the management and all employees. In addition to all said, another shortcoming we ob-

served is the common practice that the legal expert and social workers (there are two of them) are not in contact with the beneficiaries and do not participate in their care. All three of them are part of the expert admission and discharge team, but this is, however, a formal procedure. Administrative procedures between the institution and CSCs have nothing to do with the beneficiaries, nor do employees understand what other role they could have. The legal expert has no contact with the beneficiaries, nor does the institution initiate any proposal or procedure pertaining to their rights. Social workers told us that they know some “ambulatory, better patients”, who often come and ask when they will be visited by the CSC, when they will be able to leave the Home, etc. We concluded that these were beneficiaries with mild and moderate mental disabilities, mostly those who are largely independent and whom we ourselves met several times within the institution. However, bedridden, as well as beneficiaries with moderately severe and severe disabilities, who are housed in protected pavilions, are not familiar to the social workers, nor do they ever meet them. During our conversation, one parent called to announce that he would be taking his child out tomorrow. The social workers explained to us that this was the usual procedure. In accordance with the procedure, they then make a phone call to the pavilion and inform the educator and the medical worker, who prepare the child and the therapy for his/her day out. Everything is recorded in various notebooks, books, files... but our impression is that, in the whole system, those who “record” the real human being are a minority.

In regard to the abovementioned visit, we want to point out another bad solution that is being used. Namely, the rules of the institution

which allow visits to beneficiaries every Wednesday from 9 a.m. to 5 p.m., and every second Sunday in the month from 8 a.m. to 12 noon, are very rigid and hard to understand. At that, families are allowed to come and take beneficiaries home at any time, which gives the impression that unannounced and unplanned visits present an “inconvenience” to the staff. We perceive this as a serious problem, not only because this is an open-type care institution, but also because this practice limits the rights of both the beneficiaries and their visitors. Negative consequences of this additional isolation need not be explained. Professionals should be aware of that.

Nowhere in the institution, not even in the buildings where independent beneficiaries are housed, did we see signs indicating any type of education of beneficiaries regarding basic human rights or the rights of individuals with mental disabilities. Apart from the rules pertaining to the organization of life and distribution of responsibilities within the small housing communities, there are no pictures, signs or text on this subject in rooms, living rooms or notice boards in the pavilions. As informing this population about their rights is of existential importance, the expert staff should devote significant attention to this issue. In our conversation with the beneficiaries, their identification with the category they were placed in was prominent, as well as the acceptance of segregation and some types of discrimination as completely normal. This is detrimental to the development of their identity, self-respect and dignity, which are very important aspects of the work with people with mental disabilities.

We also had the impression that the beneficiaries are not sufficiently (some not at all) included in the decision-making process regarding issues important to their life, not even regarding less important, everyday activities. Some younger beneficiaries told us that

they do not trust the institution management, the state and the system of social care, because “everyone lies to them and they only make promises”, while no one wants to see them and talk to them.

Many beneficiaries objected to the quality of food and hygiene, as well as to the lack of personal items: “Children don’t have their own towels, slippers”... “There are children who do not know what a banana is. I can’t remember a cake”... “It is not right to threaten a child: you will get to eat if you help”. We assume that the institution has high expenditure, which prevents the staff from fulfilling every wish of such a large number of beneficiaries. However, taking their needs into account and their more active participation in making different decisions is their right, which this institution is obliged to respect and improve, the same way it is under the obligation to provide for the use of person items, wardrobe and other items of importance to beneficiaries.

The staff was noticeably reserved concerning questions about the existence of any type of abuse. Most of them claimed that such things never happen, neither by the staff and the people from the outside, nor amongst the beneficiaries themselves. Considering the huge number and structure of

beneficiaries, and the small number of employees (especially overnight and during weekends), this claim does not appear too realistic. Doctors told us that, in crisis situation, they use straightjackets, drugs, and that there is also an isolation room. We believe that it is necessary to develop rules of conduct in such situations, train the staff in non-violent self-protection skills as well as skills needed to protect other beneficiaries, instead of hiding problems that are unavoidably an integral part of life in such an environment.

Finally, we want to point out that the Home in Veternik is one of the institutions which need urgent help on many issues. Dedication and effort, which numerous employees evidently invest in their work with very demanding beneficiaries, cannot yield any significant results without additional help of the state and the entire society. Thus, we consider, mildly put, as unusual, the orientation of the Home and the city authorities towards expanding the Home’s activities, in a situation where the institution already takes care of an insurmountable number of beneficiaries, for the majority of whom models of quality life and care have not been established. Dispersal of already insufficient funds and employees will not only worsen the position of beneficiaries, but will also additionally violate their human dignity.

Recommendations

- Establish functional cooperation with the CSCs in the field of protection of beneficiaries’ rights and interests as well, which means that the institution should also initiate and more actively participate in these proceedings;
- All employees should have appropriate contact with the beneficiaries and, as part of their work, be dedicated to creating the best possible conditions for their development;
- Develop suitable programs and activities through which the beneficiaries could learn about their rights in a way acceptable to them;
- Increase the participation of beneficiaries in all activities and programs;
- Design detailed rules of conduct in crisis situations and train staff for this type of interventions;
- Maximally “open” the institution and enable free communication of beneficiaries with people close to them.

HOME FOR ADULTS WITH MENTAL DISABILITIES IN TUTIN

1. Introductory remarks

According to the Decision on the network of social care institutions, the Home in Tutin is dedicated to housing adults with moderate and moderately severe mental disabilities. The capacity of the Home is 220 places, but at the time of the visit by the Helsinki Committee, there were 241 beneficiaries in this institution.

The Home consists of one building housing the beneficiaries and one management building. Both are located in the city proper, amongst other buildings and residents. There

are 205 beneficiaries housed at this location. In addition to this, the Home owns an agricultural property which is located outside of the city, where 36 beneficiaries currently live. There are two buildings on this property; one is a house where the living with support program for 14 beneficiaries is implemented, while another building, which is currently being expanded, has a varying structure of beneficiaries, and at the time of our visit, we found there 22 beneficiaries.

2. Living conditions

The main building was constructed in 1957. At that time, the building was, most certainly, located far from the city. For decades, no funds were invested into this building; only in 1992 it was partially renovated, while the building was expanded in 2000. The one-story building, which has the capacity for 200 people, houses moderately severe and dependant (bedridden, semi-ambulatory) beneficiaries in 22 rooms on the ground floor, and beneficiaries with moderate mental disabilities in 24 rooms on the first floor. A smaller number of four-bed rooms have their own bathrooms, and these rooms are decently equipped (TV, table, closet). However, most of the rooms accommodate between 5 and 6 persons, who share bathrooms with four showers and a bathtub for bedridden beneficiaries. Most of the rooms have only old beds and a few pieces of furniture with a TV; everything is worn out and in poor condition. The building was constructed in such a way

that the majority of halls, rooms and living rooms do not have sufficient light, while certain areas lack sufficient fresh air. Woodwork is also worn out, which certainly has consequences on the quality of heating during the winter period. Ground-floor halls have wooden handrails for easier movement, but they are also dented and old. The general atmosphere is very depressing and gloomy, and is in no way appropriate for housing such a large number of beneficiaries, especially bearing in mind the degree to which they are dependant on support from others.

The kitchen and dining room are on the ground floor and are in a very poor condition. Adequate equipment for preparing and serving food is lacking, worn out tables and chairs have recently been replaced from the institution's own funds, humidity is extremely high... The kitchen is small, has two gas burners and two electric plates. There are no auxiliary appliances, and the three cooks and two food servers do all the work manu-

ally (cleaning, peeling, cutting) for 240 beneficiaries. Three beneficiaries passed sanitary screenings and help with dishwashing. Such poor working conditions must have consequences on the quality of food, as well as on sanitary probity of food preparation and dishware hygiene maintenance. The long tables in a row in the dining room do not offer the possibility of making contact during the meals. Eating is dehumanized and devoid of a social dimension.

The ground floor also houses the barber shop, a social club and offices of the social worker and technician. In addition to the rooms for accommodating beneficiaries, the first floor has modestly equipped rooms intended for vocational occupational therapy, as well as a living room where beneficiaries watch TV, play chess, dominoes... The general impression is that the living conditions are poor, which is why significant investments are necessary for resolving the existing problems, as well as for purchasing the necessary equipment and embellishing the entire interior. As things are now, despite the efforts of the institution, it is very hard to maintain even the basic level of hygiene. It should be added that the conditions under which the staff works are not much better.

There is a narrow green area in front of the building, not big enough to be used by over 200 beneficiaries housed in this building. There is also a small inner courtyard between the two buildings. The area in front of the building is maintained, there are flow-

ers and several benches. However, there are neither parasols nor awnings to create a larger shaded area outside, so the beneficiaries are forced to spend the majority of their time indoors during summer, rather than staying outside.

Living conditions on the property outside the city appear much better at the first glance. Namely, as these buildings are new, all furniture and equipment is also new, rooms have a smaller number of beds, the quantity of fresh air and light is satisfying, and so is the general level of hygiene. However, the surroundings, which are not inhabited, give more of an impression of isolation than integration of beneficiaries into the social environment. Both buildings outside the city are heated with electrical radiators and a wood stove. Since winters in this area are very long and cold in this part of the country (Pester Plateau), such a heating method cannot provide temperatures sufficient for comfortable living during winter periods. Another problem is food delivery to the agricultural property, since the number of vehicles is insufficient. As we have already mentioned, one building is still under construction, which means it may be more functional once it is finalized. The exterior around the buildings also needs to be reconfigured, as at the time of our visit it was disorganized and served no purpose. Investments which could contribute to a more pleasant and humane environment do not entail large funds. However, the location of the buildings is also a big problem, and the institution has to find an adequate solution to at least alleviate this problem.

Recommendations

- Provide funds for improving the quality of housing, that is, for resolving existing problems, renovating the interior and purchasing adequate equipment;
- Engage in solving the problem of remoteness of buildings on the agricultural property, so that the beneficiaries do not remain isolated and deprived of activities and care the institution is under the obligation to provide.

3. Institutional personnel

The institution employs 15 expert workers: one legal expert, two special pedagogues (occupying the positions of social worker and defectologist), six work therapists (only one with university degree, all others with high school degrees) and seven work instructors with high school degrees. According to the prescribed norms, the number of work therapists and instructors should be lower, and thus two work therapists and two instructors are financed from the institution's own funds. The staff points out that the number of expert workers prescribed by the norms is not in accordance to what is needed in reality. As an example, the Home does not have a psychologist, because the norms prescribe that only institutions with over 250 beneficiaries can have one. Considering the structure of beneficiaries, the lack of medical staff is even more important. The Home has only 8 nurses, 1 head nurse and 20 caregivers with no medical education. The neuropsychiatrist currently specializing within the institution is the only doctor. During the nightshift, one nurse and one caregiver look after the beneficiaries, along with one doorman who secures the building. The agricultural property hires two agricultural workers, one work instructor and the head of agricultural property, who is an agricultural engineer. During the night, only one caregiver and a worker who provides security for the property look after the beneficiaries. In any case, the current number of employees is insufficient to realize all aspects of expert work with quality, that is, satisfy the everyday needs of beneficiaries. Most certainly, the reasons for this situation lie within the competent institutions, but also within the internal organization of the Home itself.

The professional incompetence of the staff causes the most serious concerns. When asked about additional education and problems in the work of the expert service, the staff offered no specific answers. The argumentation was reduced to the lack of funds. Also, it was conspicuous how much the staff was uninformed on this issue ("we have not been informed that such educations exist"... "No one is inviting us"). In a small and undeveloped community, such as Tutin, it is practically impossible to find appropriate professionals. The Home is in a most unenviable position to house a very delicate population, and at the same time, have no chance to select suitable experts. If we add additional aggravating circumstances (remoteness from the city, poor financial situation, professional isolation from current trends, etc), it would be truly unfair to place the entire responsibility for the poor state of affairs on the institution only. We believe that it is primarily the state that is responsible for providing adequate living and working conditions in the institution, as well as expert training for the staff. It is absolutely unacceptable to leave this institution to its own resources, more so because almost every unfavorable circumstance is present in the Home in Tutin. The state has the obligation to provide continuous training for the staff, as well as to invest additional effort to overcome the current state of affairs (for example, to offer higher salaries to professionals from other parts of the country, who would work in Tutin in continuity for a year or two, and during time could significantly help the institution).

The entire staff is united in the belief that their job is very difficult and stressful, and that it is not appreciated enough by the society. There is also a strong feeling of marginalization in comparison to other similar institutions,

in terms of insufficient, that is, lesser help and support from the higher authorities. The staff often goes on sick leave and it is obviously hard for them to cope with their everyday work duties. The social worker told us that “everyone who is working here over five years is on sedatives”.

Upon reviewing the documentation, we were assured that the form was very detailed, but whether it was adequately applied remained a question.

Considering the elementary education of the employees, which does not offer even the minimum of

knowledge necessary for working with people who need comprehensive and constant support in order to reach even the lowest level of achievement and pleasure in life, and considering that it is impossible to find persons with appropriate education in Tutin and its surroundings, it is necessary that the state provides carefully selected training programs for the staff and continuous advisory monitoring of the institution’s work. The current state of affairs points towards neglect of both the beneficiaries and the employees.

Recommendations

- Ensure expert training and seminars for the staff in order for the planning of activities to be in accordance with methods and techniques of best practice;
- Simplify administrative obligations in order to ensure more time for quality and direct work with beneficiaries, especially considering the insufficient number of employees compared to the number and structure of beneficiaries;
- Provide computers and other equipment which will improve the work efficiency of the staff and enable communication with colleagues from other institutions, as well as “distance learning”;
- Encourage expert counseling and experience sharing among people who work in practice, as well as between these people and relevant institutions, on the issue of social sector reform;
- Discuss the possibility and necessity of hiring a psychologist and other needed experts with the competent institutions.

4. Activities and organization of work with beneficiaries

The reason for placing the majority of beneficiaries in the institution is the absence of close relatives (around 160), but there is also a significant number of beneficiaries whose families are not ready to take care of them (about 70). Although the institution is dedicated to housing individuals with moderate and moderately severe mental disabilities, the total number of these individuals is around 150, while the others are categorized as having mental health problems (around 40), combined disorders (around 20), hearing impairment (around 10) and the

like. Both genders are equally represented.

Regrettably, the social worker and defectologist (both special pedagogues by education) were not in the institution at the time of our visit (both were on vacation). As we were told, no one except them is competent to give us more specific information about the contents and organization of work with beneficiaries, that is, information about the admission procedure and assessment of newly arrived beneficiaries, as well as about the drafting of the care plan. Since this is the duty of the expert team, which consists of the abovementioned absent

employees, we are forced to describe this aspect only on the basis of observation and conversations with beneficiaries and work instructors.

Work instructors and caregivers are in charge of direct work with beneficiaries, and their work is coordinated by a work therapist. They are organized in six groups, which means that groups have about 40 beneficiaries, and that every group is the responsibility of one work therapist and one work instructor. For the time being, caregivers are not attached to particular groups, although this is planned for the future. However, when the groups are this big, it is impossible to develop an individualized approach in accordance with the needs and capacities of every beneficiary. An inevitable consequence is that the individual becomes invisible and his needs neglected. Life follows rigid, impersonal rules, which are in the service of maintaining the minimum necessary functioning of the institution, but not of fulfilling the needs and interests of the beneficiaries.

Capacities of workshops (agriculture, handmade folk artifacts production, mechanics) offer the possibility of employing only a small number of beneficiaries (around 40 in total). In the tailor's workshops, only 4 to 5 beneficiaries are being trained on one sewing machine. According to the documentation, almost half of the beneficiaries have work engagements. However, activities in the social club or, for example, creative workshops are also considered as work engagements. In any case, larger capacities for vocational and professional skill-learning are lacking, since the current structure of beneficiaries has the potential and need for more diverse contents of work engagement. Adequate space and equipment for a higher quality realization of vocational and professional activities is also lacking. The situation with workshops is similar. Around 17

beneficiaries participate in the creative workshop: they mostly draw, color, write and read. Work with beneficiaries that we were shown includes a small number of individuals, and the activities are stereotyped and not individualized. The atmosphere is very bleak, and lacks dynamics. We were told that the conditions were not met for the beneficiaries to use a gym for sport and recreational activities. The idea is to renovate the existing atrium to serve this purpose, but there is currently no money even for this.

The contents of work, that is, regular activities that the expert staff carries out, are reduced to morning activities. After lunch, beneficiaries have time to rest and carry out free activities, which are very rarely organized by the staff. We were told that one-day field-trips, barbecues in the open, holiday celebrations and shows are sometimes organized.

There are no organized activities for beneficiaries housed in facilities outside the city. "They decide themselves what to do". Living with support offers a higher degree of independence and initiative and reduces the feeling of total submersion in the masses. However, in Tutin, many beneficiaries still share a small common area, which violates the privacy of each one of them. In addition to this, residents have no contact with other people, the city infrastructure is unavailable to them, and they are unable to participate in the life of the community, although the competent institution staff had assessed them as capable of independent living. In practice, they do not have the conditions necessary to reach this goal. Living with support should enable the integration of beneficiaries into all segments of the open community, and each household should function as an independent economic unit; thus, the number of beneficiaries living with support in one housing unit should not exceed five persons. Current

conditions and contents do not allow such an approach. It is therefore necessary that the state, in this domain as well, increases the knowledge and skills of the staff through training programs, thus enabling them to improve living with support. It is important that this type of social protection is not left to improvisation and that erroneous models are not established.

When asked about unsolvable situations or those that made them feel powerless, the staff explained that they are related to beneficiaries that are either aggressive or overly reserved (showing no interest in any type of activity or event taking place in their surroundings), or to those who don't accept accommodation, refuse food, etc. The staff noticed that these were bene-

ficiaries who came from families, who have more difficulties adapting than those with experience of institutional life. The staff was astonished by the question as to what is their reaction to these situations, and they obviously fail to realize that they could have a role in solving these problems.

Our general impression is that the lack of educational seminars and professional training has a clear impact on the views and orientation of the staff in their work. The staff points out that specific trainings have only recently become available, but that there are insufficient funds for different types of training, or more precisely, not every employee who works with beneficiaries has the opportunity to attend trainings.

Recommendations

- Set clear criteria for providing help and support to institutions, in order to prevent favoritism, that is, discrimination of both beneficiaries and staff;
- Provide funds necessary for purchasing equipment and arranging the interior, in order to enrich activities and contents of the work with the beneficiaries;
- Encourage the staff to implement programs and activities based on principles of best practice and inclusive approach in their work with beneficiaries;
- State institutions must intensify their effort to provide non-institutional support for beneficiaries who are able to function outside the Home;
- Improve the conditions of living with support and harmonize them with the original concept and purpose of the program.

5. Contact with families and the outside community

By the end of our visit, we had a brief meeting with the social worker who gave us some information regarding this aspect. As in other institutions, the greatest problems in cooperation are with the Centers for Social Care. Documentation is often delivered late or is incomplete. There were even cases where documentation was falsified, in order to house beneficiaries who in reality did not belong in this type of institution. Such cases are not rare and create additional problems. Thus, in some situations the social worker insists on meeting and talking

with the beneficiary whose admission documentation was sent. An additional problem is the fact that only a small number of Centers visits or asks about their beneficiaries. The main argument is the remoteness of the originating Center, that is, the institution, and the lack of funds, etc. The situation pertaining to contacts between beneficiaries and their families and relatives is similar.

As we have pointed out several times, we believe that the institution also has the obligation to encourage and look for ways to establish communication, both with Centers and with families, and

to do it permanently, during the whole year. Although the documentation states that almost all beneficiaries who have families (about 70) are having regular contacts with them, the staff told us that only a small number of families visited regularly, more precisely, about 15. Others maintain only occasional contacts.

As to other forms of contact, we have already mentioned that activities such as fieldtrips are organized occasionally, while a smaller number of beneficiaries (50) visited the seaside last summer in the organization of a humanitarian organization from Niš. Furthermore, every year the same group of 14 beneficiaries goes on a summer vacation. Its members are persons who are living with support in the house outside the city. Although this is a logical decision, it is not acceptable to segregate and discriminate amongst beneficiaries. The institution must devise several possible activities and recreational contents, and they must be available to all beneficiaries. The only justifiable restrictions when selecting beneficiaries are those of a medical nature. Since it is impossible to ensure

such activities for all beneficiaries, similar activities should be provided for others. Unfortunately, it is discouraging that these activities are not more frequent, so that more beneficiaries could participate. Although these activities are extremely useful and efficient, they are more the exception than the rule, since they depend on material and financial means. If we add to this that visits to the institution are very rare, we have to conclude that the institution itself did not develop enough activities directed towards including beneficiaries into the life of the community, or towards connecting them in any way to the outside world. This serious shortcoming is also felt by the beneficiaries. Most often they approached us and asked when they would be able to go home.

These, as well as many other problems related to integration of people with mental disabilities, can only be solved in cooperation with the broader social community, by combating prejudices and creating a positive attitude of the general public towards these individuals.

Recommendations

- Encourage the staff to offer continuous care and support to beneficiaries in maintaining and improving their relationships with families, relatives and other individuals;
- Improve the quality of relations among relevant institutions (Ministry, Centers for Social Care, Homes), in order to find more efficient and sustainable solutions that improve the position and care for people with mental disabilities;
- Work on combating prejudices about people with mental disabilities through media and campaigns, and promote methods for providing help and support to this population;
- Invest effort in establishing different forms of contact between beneficiaries and the local community and environment (business subjects, educational institutions, NGOs and humanitarian organizations, etc.);
- Enrich the selection of activities and contents and make sure they are available to all beneficiaries, in accordance with their medical condition and capabilities.

6. Guarantees of rights and liberties of beneficiaries

Apart from the usual secretarial tasks related to legal operation of the institution, the legal expert participates in the work of the Expert team and the Committee for admission and discharge of beneficiaries. Akin to the majority of other institutions, the Home in Tutin does not have the practice of offering legal advice to beneficiaries, since this is in the competence of the originating Centers for Social Care.

Considering the poor living conditions and the small number of insufficiently professional staff, we believe that the beneficiaries are highly exposed to neglect and degrading treatment. Some of them complained that certain employees “harass them”, and “push them around”, and there were even complaints that “some employees beat them”. Although the staff denies such claims, inhumane behavior, even abuse, is quite possible in institutions with large numbers of individuals with mental disabilities, and the abusers could be different people (supporting staff, visitors, citizens...). The management must devote appropriate attention to this problem, by monitoring for illegal behavior towards beneficiaries, as well as by taking necessary measures even if there is the slightest suspicion that these claims might be true. Beneficiaries we talked to do not know whom they would turn for help, and many of them think that no one would believe them, and consequently no one would protect them.

Incidentally, the Home has a Rulebook on the prohibition of abuse, as well as a Rulebook on nightshift work and emergency procedures for staff (in case of escapes, injuries inflicted on beneficiaries or employees, death of a beneficiary, fire or other natural disasters). They are also expecting the opinion of the competent

Ministry on the Rulebook which regulates the measures of restriction and restraint, submitted as a proposal by the Collegium of Social Institutions Directors. We did not receive precise answers regarding the reactions in emergency situations, but it is entirely realistic to assume that an agitated or aggressive beneficiary is secluded in the isolation room to receive sedation therapy. Naturally, the staff is not trained with non-physical and manual techniques for overcoming resistance.

The staff claims that they have problems with frequent escapes, self-inflicted injuries, epileptic beneficiaries and those who have “hysteric fits”. Since the majority of beneficiaries come from other institutions and not by their own volition, an approach is needed that understands anxiety, respects resistance, develops trust and recognizes the fact that a longer period of time is necessary for adjustment. Great discontent, anxiety and aggressiveness of beneficiaries are often consequences of the fact that they are not accepted by the environment, that their needs are ignored or unnoticed, and their living conditions degrading and depriving. As we have already mentioned, the staff did not attend the necessary educational training and has difficulty dealing with delicate situations. This leads to increased stress amongst the employees, and there are also cases of injuries inflicted by the beneficiaries.

Disposition of allowances is regulated in such a manner that beneficiaries who are able to, have full control over their allowance, while others spend their allowance through authorized caregivers. About half of the beneficiaries have full control over their allowance. Furthermore, a meticulous record is kept of gifts, packages and money sent to particular beneficiaries, although the number of such cases is small.

In the newly built facility outside the city we talked to a female beneficiary who has been in the Home for full 26 years. She is still very rational and her faculties have been preserved, although she has been housed in different institutions of social protection since her youth. She told us through tears that she hadn't seen her two sons since she arrived to this Home. After being transferred to Tutin, she gave birth to two more sons, who she also never saw again. According to the unreliable and outdated information she has, two of her children have been placed in foster families, and the two others in different social institutions. The Home contacted her originating Center for Social Care asking for information about the fate of these children and, if possible, to get in contact with them. However, they received no answer. The beneficiary told us that they sent their appeal to the wrong address, because her documentation was in another Center! To make the whole story even more tragic, she claims that she was sexually abused by an employee at the time, and that the birth of two children while she was in Tutin was a consequence of this abuse. One employee who has been working in the Home at the time said that no one ever investigated her claims.

This case is one of the most drastic examples of everything bad,

inhumane and degrading in the social treatment of people with mental disabilities, as well as in a system of social care we hope does not exist anymore. We want to believe that this is a case of negligence and a rare event where one girl, with minor mental disabilities, was continuously placed in social institutions, left there to live her whole life without even one revision of her categorization, a girl whose children were taken away and placed under different types of social care, without having any contact with her (and maybe without having contact amongst themselves), while competent expert services and professionals did not even attempt to alleviate and rectify the unacceptable oversights of their predecessors. Her stigmatization and discrimination prevented even the investigation of the possibility that a severe criminal act was committed...

Unfortunately, even today, in different social institutions all around Serbia, there are people who were terribly wronged. However, to many others, social institutions provided basic conditions for survival. We decided to publish this story so that it will never happen again, and so that employees in social and state institutions understand the necessity of undertaking immediate and thorough changes, not only in the area of social policy.

Recommendations

- Raise the level of employees' responsibility in terms of guaranteeing the rights of beneficiaries and their overall protection, both within the institution and beyond;
- Insist on expert education of staff both in regard to the attitude towards beneficiaries, and in regard to appropriate models of behavior in emergency situations;
- Provide adequate methods of informing beneficiaries of their rights, and inform them also, in an appropriate manner and through acceptable contents, about ways to protect themselves from individuals and situations that threaten them.

HOME FOR ADULTS WITH MENTAL DISABILITIES AND INDIVIDUALS WITH MENTAL DISORDERS “MALE PČELICE” IN KRAGUJEVAC

1. Introductory remarks

The Home was founded in 1972 and is located in the suburb “Male pčelice”, ten kilometers from the center of Kragujevac. It occupies a 17 hectare property, and owns another 5 hectares of agricultural land outside of the city.

The Home is intended for housing adults with moderately severe and severe mental disabilities and individuals with mental disorders. The capacity of the Home is 850 places and it hasn't been changed, although the Home always accepted a greater num-

ber of beneficiaries. At the time of the visit by the Helsinki Committee, which took place at the end of June, there were 921 beneficiaries in the Home, while admission requests were submitted for another 159 individuals. The institution houses only adults, 506 women and 415 men. There are 534 individuals with mental disorders and 387 individuals with mental disabilities. Out of this number 263 have moderate mental disabilities, while 124 have moderately severe and severe mental disabilities.

2. Living conditions

The beneficiaries are housed in five pavilions. The first, second and third pavilion were renovated, and have a heterogeneous structure of beneficiaries (in proportion with the total number, there are more beneficiaries with mental disorders than those with mental disabilities). The fourth pavilion houses only beneficiaries with moderately severe and severe mental disabilities, while the fifth pavilion is psychogeriatrics, which houses mostly older people and bedridden beneficiaries.

The three renovated pavilions are completely equipped with new furniture and technical equipment, they are large enough and have sufficient lighting, they have balconies, kitchenettes, rooms meant for work-occupational therapy, living rooms on every floor and offices for expert staff. Each building has two floors with two separate wings, while rooms have four

to five beds. Male and female beneficiaries are separated, and every room has a TV and a closet for personal belongings. Since the buildings were not renovated at the same time, additional investments are already needed in certain places, but the very important thing is that a high standard of accommodation was set, which should be maintained in the future. It is noticeable how much attention was devoted to the arrangement of the interior: attention was paid to the choice of colors, matching curtains, bedcovers and mats, pictures and furniture... Unfortunately, the fourth and fifth pavilions were not renovated, and the housing conditions in these pavilions are significantly worse. This specially pertains to the fourth pavilion, which needs serious reconstruction. We were told that these buildings required much larger investments, due to the necessary roof repairs, drainage, etc., which are a precondition for the renovation of the interior. Due to

a lack of funds, money was so far invested only in improving hygiene and safety conditions. Bathrooms in the fifth pavilion have been adjusted to fit the needs of old and bedridden beneficiaries (although the number of toilets and showers is insufficient), while halls have handrails installed for safer movement. There is video surveillance in the hall and the stairway, as well as in the room for intensive care. Furniture and equipment in both buildings are worn out or lacking, some rooms are damp, while living rooms are small and inadequate. An important detail we observed was that closets were bought for the first time for beneficiaries in the fifth pavilion, and every beneficiary has his/her own reserved area. The closets are locked, and the nurse keeps the keys. We presume that this solution was compulsory, because the closets are shared, but also because of the danger that these beneficiaries may have with them small items that they could swallow. Although the staff resisted this innovation, we believe it to be very good and necessary both from a humane and a therapeutic view, since it respects and promotes the preservation of the sense of privacy and personal integrity. It is thus advisable, funds-permitting, to purchase, within the room renovation process, more closets, nightstands and other pieces of furniture which remind of, or are part of every beneficiary's privacy. This attitude shows that the institution respects individuals with mental disabilities and mental disorders, and that their capacity and emotional needs are not ignored. Incidentally, during the summer, beneficiaries spend most of their time outside, in a nicely arranged summer-garden.

In order to reduce the demolition of the inventory as well as self-inflicted injuries and, at the same time, provide conditions for a decent life of beneficiaries, plastic mirrors were in-

stalled in bathrooms, visible parts of equipment and pipes are behind a wall and in a special room which is kept locked, while instead of regular faucets, taps are sensor-activated. Working out such solutions, which are motivated by the care for the quality of beneficiaries' life and the protection of their dignity, testifies to high professional goals set in this institution.

A smaller number of beneficiaries are housed in a separate, new facility, which is meant to serve as a "halfway house" for accommodating a total of 12 beneficiaries who are preparing to leave the Home and live in the open community. This facility has two wings, with three two-bed rooms with bathrooms, a living room and a kitchen in every wing. They are fully equipped to function in accordance with the model of independent housing community.

The House has a total of three dining rooms for beneficiaries. One is used by the beneficiaries of the fifth pavilion, while the first and second pavilions have a shared dining room, and the same goes for the third and fourth pavilions. Considerable attention was devoted to the renovation of the main kitchen, storage and warehouse, where the sanitary and hygienic conditions are excellent. The Home has its own gas station and the appropriate equipment, which provides for normal functioning of the kitchen in case of a power shortage. Considering the large number of beneficiaries, funds should be secured for replacing the old equipment and purchase of missing electrical appliances. It would also be very useful if the institution had its own bakery, especially because it could provide vocational training for the beneficiaries. In the kitchen and some pavilions insect repellent appliances have been installed on a trial basis, and they are very efficient, so the institution intends to install them in all the buildings.

In addition to the management building and the aforementioned six housing buildings, there are separate buildings that house workshops, the boiler-room, the laundry, various warehouses... The institution owns a large agricultural property with fertile land, greenhouses and a large number of cattle. Funds need to be invested into these buildings in order to improve the conditions, as well as to purchase new equipment and machinery.

Beneficiaries also have at their disposal a very pretty exterior; the

large area between and around the facilities is neat and carefully maintained, covered with greenery and flowers, with plenty of trees, benches, gardens with awnings, etc. There are also open sports fields meant for recreation, as well as different competition events (basketball, volleyball, football, bocce...). Funds-permitting, the institution should work on further arrangement of the exterior, since the available space offers possibilities for an even better use by beneficiaries.

Recommendations

- Invest effort into renovating all buildings and providing similar living conditions for all beneficiaries;
- Maintain acquired standards of accommodation, and strive towards forming smaller entities, where beneficiaries could function akin to a family community;
- Based on a long-term plan, define realistic possibilities and tasks with the aim of reducing the number of beneficiaries and transforming parts of the institution towards social rehabilitation.

3. Institutional personnel

The institution operates through the following services: legal and employment service, economic-financial service, maintenance service and the service for social work, medical care and protection, and rehabilitation. The service for social work employs seven expert workers with appropriate university or higher education degrees. One social worker is in charge of each pavilion. The rehabilitation service employs a staff of 25: five defectologists, nine work therapists, and eleven work instructors. Apart from the work instructors who have middle school degrees, other expert workers have university degrees. Work therapists are pedagogues, andragogues, chemists, music teachers, physical education teachers... Work instructors for different vocations are in charge of work engagements of the beneficiaries, and expert workers for workshops and work-occupational activities, therapeutic

communities. The medical service employs seven doctors and 49 medical technicians. The staff with more years of service mostly work in pavilions IV and V, while the younger employees work in pavilions I, II and III. However, a system of rotation exists. Generally, amongst the expert staff, women are more represented than men (instructors are men).

According to the staff, obstacles and problems impeding improvement and more efficient work with beneficiaries are related primarily to the number of employees compared to the number of beneficiaries. One social worker for about 150 beneficiaries is in reality unable to meet the needs of every beneficiary at any moment. Some beneficiaries told us that they have to wait several days for a chance to talk to the social worker. The situation with other expert workers is the same. Furthermore, in this institution there is also a significantly

larger number of beneficiaries who have the capacity to be included in different types of vocational skill-learning. However, considering the number of beneficiaries and employees, it is obvious that expert workers can hardly meet greater demands, especially considering that all categories of employees work in both shifts (medical technicians, caregivers and cleaning staff work in the third shift).

On the other hand, there are differences among the employees themselves regarding the approach and orientation in expert work. Although the majority of staff has appropriate education, not everyone is motivated for further education. They told us that they attended expert seminars, congresses and meetings to gain additional expert skills, but, when asked what part of this knowledge they used in their work with beneficiaries, some of them failed to offer specific answers. Certain employees explained that the work with “such a population” did not offer possibilities for any kind of “more purposeful” expert work, but the viewpoints and approach of most of them was highly professional and in accordance with current trends in the treatment of individuals with mental disabilities. We were told that a certain number of employees attended the education for the application of the Maria Montessori program, and that there is a plan to start using this method in the work with the beneficiaries in the fourth pavilion (moderately severe and severe mental disabilities) in the near future. We were also told that the educational program School of life skills is currently underway. Since this is a program for training professionals to assess and prepare individuals with developmental problems for the greatest possible degree of independent living, the institution included

26 employees in this training, coming from all professions (defectologists, caregivers, medical technicians, doctors, and cleaning staff), who work directly with beneficiaries. The general impression is that the younger staff shows more interest in education, as well as in following and applying modern orientations and approaches in their work with beneficiaries, which is only logical. In addition to pointing out that highly specialized trainings have been organized only recently, the staff told us that, due to insufficient funds, not everyone has the opportunity to attend these trainings.

Finally, we want to point out another important fact. This is one of the few institutions amongst all those we visited, where we were given clear, comprehensible, precise and complete data on all issues important for the life of beneficiaries from the director herself. Even more important is the observation that she knows every beneficiary, and that she obviously has daily contact with them. We had the opportunity to witness this every step of the way. The beneficiaries themselves think of her in a particularly warm and intimate way, which happens very rarely. The fact that she worked for seven years as a councilor (psychiatrist) before being named director of this institution, is now an experience of great value and help. This, and several other good examples, should serve as an orientation to the Ministry and Executive boards of institutions when electing directors. As we have pointed out several times, a specific sensibility (in addition to expert qualification) is necessary for working in social care, with appropriate professional experience being another requirement necessary for executive positions. These preconditions have been met in all the institutions that we marked as examples of good practice.

Recommendations

- Encourage all employees to attend professional trainings in areas pertaining to problems they face in everyday work, and for which they need additional knowledge;
- Find an adequate solution for hiring a larger number of staff in order to meet all the beneficiaries' needs; a possible solution is taking on a larger number of volunteers who could be of great help to the staff, under expert supervision;
- Improve cooperation and sharing of experiences among people working in the field, and look for good examples of work in other countries as well.

4. Activities and organization of work with beneficiaries

The staff told us that the documentation of a newly arrived beneficiary often is not of great help in drafting the care and work organization plan. In these situations, much more important are the assessments of the expert team and consultants during the observation period. Based on physical and psychological capabilities of the beneficiary, as well as his/her intellectual capacity, a decision is made on the selection of the most adequate group (and pavilion), followed by a work plan and program. According to the staff, problems in the adaptation period are uncommon, since this population spent most of their lives in similar institutions, and are used to the institutional regime of life (more than 600 beneficiaries have been only in this institution for over six years, while as much as 406 over ten years). However, the staff notices that there is a big difference among the beneficiaries depending on the institution they came from: "for example, all beneficiaries from Višegrad come work-capable... those with minor, moderate or even moderately severe disabilities... they really work with them in Višegrad ... the ones coming from families are the same, but they are very few". There are beneficiaries who never attended school, yet they have the potential; the staff noticed that certain beneficiaries felt uncomfortable when they had to sign their name "with a finger". This gave the staff the idea to organize a literacy course, which was carried out with

success. The fact that the institution and the employees recognized this, as well as many other needs of beneficiaries, and reacted adequately to them, speaks about a high level of competence and adaptability to the realistic state of affairs. According to the documentation, as much as 480 beneficiaries have different work engagements, which are classified in four groups, depending on their complexity. The first group consists of jobs in workshops (cardboard production, handmade folk artifacts production, carpenter's and tailor's workshops), in the central warehouse and on the agricultural property, and it includes 116 beneficiaries; the second group consists of jobs in the dining room, barber shop, laundry, library, management building, doorman's post, etc. and it includes 240 beneficiaries; jobs in the third group (transporting the laundry, making coffee) are performed by about 40 beneficiaries, while the fourth group consist of different occupational activities where 84 beneficiaries participate. It is very important that all beneficiaries who have work engagements are "paid" for their work, namely, they receive allowances between 500 and 1200 dinars. Both the work groups, as well the amount of money for each job are clearly defined. The employees of the Home have evidently invested a lot of effort in designing different possibilities, and what is more important, in supporting and awarding every effort of each beneficiary – from the simple jobs such as making the beds or transporting the

laundry, to those much more skill-demanding, such as jobs in workshops. The situation with creative workshops is similar. The number of beneficiaries who regularly participate in specific creative workshops (music, folklore, literary, journalism, drama, painting, computer, sport...) is about 200, where some of the beneficiaries participate in several of them. Such an approach is very useful and encouraging for beneficiaries, and is certainly a positive example of professional and respectful attitude. The staff also uses these activities to develop socially desirable models of behavior.

Beneficiaries who do not fulfill their work and other obligations set out by the house rules regularly are transferred to work positions with less remuneration, while the beneficiaries who show positive social behavior and work hard are awarded with the possibility of work engagement on better paid jobs, or receive the maximum sum within the set allowance. In addition to this, further contribution to their motivation comes from presentations of their work at different exhibitions beyond the institution (but in the institution as well), as well as when their work is sold, or interest for it is expressed by third parties and the wider community, and from similar social acknowledgments. Furthermore, beneficiaries are awarded with additional independent visits to the city, organized dinners in the city, parties...

Our impression is that serious educational and vocational skill-learning systems could be established pretty easily in this institution, provided there were more employees and additional space and equipment. This would be very important in making beneficiaries more independent, as well as for their reintegration. The institution has similar ideas, and a project for the construction of a small factory, that is, a business center, has also

been made. This business center would unite and expand the existing workshops and put them in the service of vocational skill-learning for a larger number of individuals with mental disabilities, and not only those from the institution. Considering the fact that the process of inclusion hasn't yet started in Serbia, and that it will primarily include children, we believe that the development of this and similar centers would be extremely important for the education and vocational skill-learning of a large number of adults who are housed in different social institutions.

Incidentally, other work contents, that is, regular activities that the expert workers carry out include the group morning meeting (all beneficiaries from the pavilion), and after that, occupational and work activities, which are carried out until lunch. After lunch it is time for a siesta, and the afternoon is reserved for recreational and free activities (creative workshops, sports activities, movies, social games...). In nicely equipped rooms for different creative activities located in renovated pavilions, beneficiaries spend longer periods of time transforming their ideas into final products, with extremely good support of work therapists. In the fourth pavilion, beneficiaries with severe intellectual problems have regular occupational therapy. They make pictures using grains by themselves and enjoy music, while a lot of their equipment is produced by beneficiaries working in the tailor's shop. This encourages useful cooperation and communication between beneficiaries with different capabilities. During our visit to this pavilion we were able to notice that, regardless of the degree of problems these beneficiaries had, the atmosphere was fairly calm and there was a good, albeit reduced communication between beneficiaries and employees. We also noticed that the behavior of beneficiaries was in accordance with some general rules. About 30 beneficiar-

ies in the fifth pavilion are taking part in occupational therapy, and 20 other in lower intensity work therapy. Despite poorer conditions, activities in these two pavilions contribute to a feeling of meaning and maintenance of vitality of the beneficiaries.

Another example of positive approach to individuals with mental disabilities is the initiative organized last year by the institution, aimed at eliminating the deeply-rooted term “pavilions” and replacing it with nicer and symbolic names; beneficiaries themselves chose the names of the pavilions they live in (Rainbow, Pearl, Heart, Sunnygirl, Sunflower), while the management placed signs with new names on all buildings and printed t-shirts with appropriate signs for internal competitions.

The staff explained that the only case where they are powerless in carrying out activities is with old beneficiaries suffering from dementia, who, as a rule, do not accept housing, refuse food, and show no interest in any type of activity or event taking place in their surroundings. When asked what they do in these situations, and what they believed was the cause of such behavior, we received a reasonable explanation that the beneficiaries were moved from their environments involuntarily, and that their behavior and mood are a natural reaction to specific circumstances. One of the employees added in

a low voice: “you know, these beneficiaries die very quickly in the institution”. After a brief discussion on this issue, the staff concluded that the most adequate accommodation for these beneficiaries would be in daycare centers, where they would have adequate care and organized activities during the day, while returning in the afternoon to their families; in such a way, they would not feel isolated from the local community, while their families would be able to carry out their everyday work and other engagements. Unfortunately, when we asked them whether they have shared their views with someone, whether they contacted the Center or the family and discussed with them this idea or some other more adequate solutions for beneficiaries, the answer was negative. As we have mentioned before, some employees believe that these beneficiaries can’t be helped (but apparently also others with severe mental disabilities or dependant-bedridden) because they “suffer from dementia”, “they are bedridden”, “show no interest”, “do not cooperate”, etc. Although diverse activities and contents are available within the Home, a small part of the staff “knows from experience” that they cannot be carried out with certain beneficiaries due to their poor psychical and psychological condition or lack of motivation. Our impression is that they lack the knowledge and skills pertaining to methods they could use to animate these beneficiaries.

Recommendations

- Provide funds necessary for additional equipment and arranging of a larger number of workshops and creative workshops in order to enrich the activities and contents of work, and make them available to an even larger number of beneficiaries;
- Attend trainings for instigating interest and activities among beneficiaries with more serious disabilities as well;
- Develop programs in cooperation with competent institutions on all levels, aimed at improving the chances for gradual return of beneficiaries to social life;
- Launch initiatives for overcoming the current weak spots in mutual relations and functioning of certain parts of the system, especially regarding certain Centers for Social Care;

- Work on realizing the idea related to procurement of certificates for beneficiaries who demonstrate a satisfactory level of work and professional competency;
- Develop the idea to establish a business center for education and vocational training of individuals with mental disabilities on the basis of existing needs and realistic possibilities, in order for this project to be sustainable.

5. Contact with families and the outside community

Cooperation with Centers for Social Care is assessed as poor in this institution also: “a very, very small number of Centers makes inquiries about their beneficiaries, and the number of those who visit them is even smaller”, “when they bring them here, they forget about them”. The institution has the practice of organizing an annual “family meeting” (on that day, all Centers and families of beneficiaries are invited to visit). The Director told us that last year, out of 542 family members only 140 came, and only 21 out of 129 Centers responded. The institution is now considering the possibility of canceling this “special day”, since it was determined that the hope and expectation of beneficiaries that those most dear to them will come to visit have very detrimental consequences for beneficiaries who end up having no visitors. As to the dynamics of family visits, the staff points out that “no one is interested in beneficiaries”. However, we believe that this statement, at the same time, underlines the fact that this issue needs to be approached in a different and more serious manner. According to the documentation on the structure of beneficiaries in terms of the manner personal contacts with close relatives and other close individuals are maintained, only 110 beneficiaries have no relatives, 280 have relatives, but no contacts, 80 have relatives who make inquiries only over the phone, 201 have rare contacts – without predictable dynamics, and 92 beneficiaries are contacted less than once a month, but there is a continuity of contacts. The information that about

150 beneficiaries have regular contacts with their families, but only 80 of them spend weekends and holidays in families is shocking. All in all, we were not surprised by the statement of one of the employees that beneficiaries “are much calmer when they come back from a weekend out”, because everybody agrees that these contacts are highly important for the stability and wellbeing of beneficiaries. However, we believe that one public phone booth is not enough for such a big institution, although the staff told us that beneficiaries are allowed to use office phones to call their families. Also, except in cases where beneficiaries are prevented due to medical reasons, it is not good to contact their families instead of them. Since this problem is characteristic for all social institutions, we will repeat once more our opinion that these institutions are also under the obligation to encourage and investigate permanently, during the entire year, ways to improve contacts of beneficiaries both with their families and with originating Centers.

Concerning other types of contacts between beneficiaries and the outside world, our assessment is that under current circumstances (small number of staff, lack of technical and material means, and other actual problems), the staff is doing their best to include the largest possible number of beneficiaries in activities such as visits to exhibitions, theatre shows, movies, fieldtrips, sports manifestations, different competitions, etc. Until 2008, there were as much as 550 people who never left the Home property; at the end of June 2009 the number of such beneficiaries was re-

duced to 110 (those with most severe disabilities, who get very agitated if they need to leave their pavilion). This is, without a doubt, an excellent result.

Another very commendable issue is the engagement of staff on regular contacts with youth from the local community, the Red Cross, different associations, embassies and NGOs, with the goal of improving the housing conditions through different donations, but also of including beneficiaries in activities of the local community. Cooperation with some vocational schools exists, and students from these schools come to the Home where skilled beneficiaries train them for certain operations. Talks with the Medical

Faculty have also been initiated for the purpose of establishing better cooperation, since some students are already coming to the institution. Together with the Home for Children without Parental Care and the Geriatric Center from Kragujevac, a project was drafted on opening a joint space, where products made in these social institutions would be sold, and a certain number of beneficiaries employed. The fact that families and children of the employees participate in celebrations, fieldtrips, etc. together with the beneficiaries, and often visit the institution, perhaps speaks best about the attitude towards the beneficiaries. This also contributes to the destigmatization of both the beneficiaries and the Home.

Recommendations

- Continue the good practice and keep maintaining the cooperation with the local community, NGO sector, domestic and foreign foundations, agencies and other organizations;
- Insist on raising the quality of mutual relations between relevant institutions in charge of ensuring the best interest of beneficiaries;
- Intensify the engagement of the institution in establishing and improving the quality of contacts between beneficiaries and their relatives and other persons close to them;
- Work on combating prejudices about people with mental disabilities and mental disorders through media and campaigns, and promote methods for providing help and support to these individuals.

6. Guarantees of rights and liberties of beneficiaries

As we have mentioned before, the Home has a significantly larger number of beneficiaries with mental disorders than those with mental disabilities. Furthermore, although this institution is meant for housing individuals with moderately severe and severe mental disabilities, in addition to individuals with moderate mental disabilities, we also noticed some individuals with mild mental disabilities, which was subsequently confirmed by the staff. The practice of categorizing people with mild mental disabilities as having moderate disabilities (in order to place them in institutions) is unac-

ceptable. This is not only a legal problem, as such practice also leads to further discrimination and broad violations of human rights. This widespread practice is the best indicator of how bad and outdated the system of social care is, but also how inefficient and unsustainable it is, even with manipulations.

This is also supported by the data on work and professional engagement of beneficiaries. Namely, it is paradoxical that about 500 beneficiaries demonstrated through their work engagement in workshops that they are able to perform certain jobs (for example, in the carpentry, tailoring and upholstery

workshops, in cardboard production or in maintenance and kitchen jobs...). The idea of the Director that the possibility of issuing diplomas, that is, valid certificates for these beneficiaries should be investigated is very sound, and demands an appropriate solution, if the intention to help this people to become independent and return to the open community is genuine. However, in order for this intention to be truly realized, it is necessary to reconsider and restore the legal capacity of hundreds of people living in institutions all around Serbia. Given the length and costs of the appropriate court proceedings, the competent bodies should look for an alternative solution. This is a very complex and serious issue, which should be tackled by several Ministries.

A related example is the issue of protected housing, namely, "The halfway house", which presents a problem for all institutions. The explanation we were offered in the Home was that, in cooperation with originating Centers, the staff selected and prepared for discharge only 14 beneficiaries, although the initial plan was to prepare 12 beneficiaries, which is the capacity of the halfway house, every six months. Unfortunately, seven beneficiaries have been living in the halfway house from 2004 until today, as the Centers still have not provided housing and other support needed for living in the local community. From the point of view of the institutions, this situation reflects a sequence of problems related to several issues: should the purpose of the halfway house be changed since the Centers are unable to provide further housing; how to return these seven beneficiaries back to the pavilion, that is, how to explain their years-long privileged position compared to other beneficiaries; should new beneficiaries be placed in the halfway house after such an ex-

perience; how to solve the problem of required engagement of employees (five in accordance with the project) for only seven beneficiaries, in the situation where the institution faces big problems due to the lack of staff, etc... In general, it appears to be overambitious to expect Centers, especially in poor and underdeveloped communities, to be able to provide funds and conditions for non-institutional housing of all beneficiaries who could integrate into their local communities. However, the issue here is not an imposed obligation, but rather the consent of certain Centers to secure the admission of specific beneficiaries. The final impression is more than troublesome: in order to create an illusion that everything is in compliance with the law, and in order for everyone "to cover" their personal responsibility and protect their job position, the rights of beneficiaries are being severely violated.

Besides these problems, which we believe to be systemic, and which jeopardize the rights of beneficiaries, the Home has invested maximum effort into improving the overall living conditions and providing full protection and humane treatment of beneficiaries. Special attention is paid to informing beneficiaries, and all the pavilions have notice boards displaying numerous information on various events, opportunities for work and occupational engagement or entertainment, as well as other contents of interest for their everyday life. A Council of Beneficiaries has also been formed, and their viewpoints and demands are very seriously considered and accepted as much as possible. The institution has a good Rulebook on organization and work with beneficiaries, very detailed rules on disposition of money belonging to beneficiaries who are not able to do that independently, etc. In court and police proceedings, either the legal expert or the social worker represents the beneficiary, and they always try to avoid any sanctions for the benefi-

ciary. Instead, they propose that monitoring by the institution be increased and additional measures in regard to expert work be taken. Although we were told in this institution once again that originating Centers are responsible for taking care of property and other rights of beneficiaries, we believe that the legal service of the Home should be far more active in this regard. Considering that social workers in pavilions carefully monitor all information of interest to beneficiaries, it is necessary to create better mutual communication in order to raise the protection of beneficiaries' interests to a higher level.

Considering possible cases of abuse, the House staff does not hide the fact that fights occur from time to time, but they claim there is no abuse of beneficiaries neither by the staff, nor by other beneficiaries. Beneficiaries whom we spoke to confirmed this account, and it is interesting that they mentioned several persons whom they can turn to in case of problems (starting with the Director, then the social workers, doctors, work therapists, etc). This points to a good relationship with the staff, and the existence of trust, which is an important guarantee of good end efficient legal protection.

Recommendations

- Through appropriate content of expert work and different activities, raise the awareness of beneficiaries regarding their rights and possibilities they have to protect these rights;
- Dedicate more attention to the exchange of data about beneficiaries amongst different experts and services, and establish mechanisms for acting when a beneficiary's rights are violated or jeopardized.

PHOTO-GALLERY

Home for Children and Youth With Mental Disabilities „Sremčica“ in Belgrade



Home for Children and Youth With Mental Disabilities „Veternik“ in Novi Sad



Home for Adults With Mental Disabilities in Tutin



Home for Adults With Mental Disabilities and Individuals With Mental Disorders
„Male pčelice“ in Kragujevac

