

Vreme

Vreme 1169, May 30, 2013./Vreme

The experience of a patient – Dragan Jugovic

I Conquered the Self-stigma

TALKING ABOUT HIS TREATMENT AND THE STIGMA THAT GOES WITH IT, DRAGAN JUGOVIC IS THE FIRST TO COME OUT AND PUBLICLY SPEAK FOUR YEARS AGO IN THE NAME OF PSYCHIATRIC PATIENTS. HE IS THE FOUNDER AND FIRST PRESIDENT OF THE SOCIETY FOR USERS OF PSYCHIATRIC SERVICES “SOUL”.

I am 50 years old and have been treated as a psychiatric patient since my age of 18. Out of those 33 years as a patient I spent 15 years in a hospital on Palmoticeva Street and 18 years in the Laza Lazarevic Hospital. On one hand my experience is one of suffering and torture, but there were pleasant experiences because they also exist together with good people and good doctors. More than 20 times, I stopped counting, I was hospitalized on lock down wards of the psychiatric hospital and on 30 some occasions in day hospitals. All the bad experiences came from the lock down ward and pleasant one from the day hospital. First, on the lock down unit what do my 24 hours consists of. I could either lie in the bed, pace the hallway from end to end or sit in the dining room and inhale the cigarette smokes (although I am a non-smoker), because there are no smoke free areas. And that's the content of my day on the lock down ward. Next comes, the physical and chemical sedation. First the physical: every time I am admitted and I heard it is customary because I weigh over 220 pounds, they restrain me. Regardless of the time of admission I am restrained until the next morning. I heard that patients weighing 130-150 pounds are not tied down, but I who weighs over 220 pounds am always restrained, must be the custom. I must be a treat to myself and to others and the orderlies tie me down, although I never offended a doctor, came in on my free will, didn't break any laws, came to a reputable institution and they tie me down. I am a timid person by nature, never exhibited aggression. I asked “doctor, when will they untie me” and he responds “in an hour”. He lied. I was restrained until the next morning. Twice it happened that I was tied up for 3 days and can you imagine being restrained for 3 days.

There is also the chemical sedation. In our hospital they give massive amounts of medications. May be there is a need for large doses of medication when I am in a rage or really sick, but so much that I don't know who and where I am? I do not understand treatment, chemistry or medicine, but know what it feels being sick, shunned by the society, discriminated, stigmatized

and mistreated. And mistreated by the hospital staff at that. I experienced punishment by injections just like many others did.

Sanitary conditions are deplorable. At the “Laza” everybody is infested with lice. Why would it be any different when they never launder the blankets? They wash the sheets and pillow cases but never the blankets. Lice live on us and cohabit with us at the “Laza”. May I ask something: are we also humans? If we are then we have the right to basic privacy. Then is it acceptable that in both divisions of the hospital “Laza Lazarevic” (in Padinska Skela and in the city) the toilettes are without doors in the lock down and open sections and every by-passer can see and observe you? Is this normal? The explanation is that a patient behind the closed door can flip and do something harmful to himself but this lack of privacy is terribly demeaning. In Gornja Toponica on the ward with most serious cases the patients were hosed down when they soiled themselves. At “Laza” this doesn’t happen but they have group showers. On the lock down ward we are allowed to shower for a few minutes twice a month. And another thing: as a mental patient why do I have to change into hospital pajamas upon admission? I would understand it if I was a surgical patient, had an operation or have a somatic illness or may be in need of infusions. As a mental patient why can’t I wear my own clothes instead of the pajamas to feel like a person? Since 2006 I am almost a regular at the day hospital in a satellite unit of “Laza Lazarevic” in Padinska Skela. Thanks to doctor Milan Davidovic, a man with broad views who treats his patients as humans. He shed the white coat stating that he doesn’t wear it at work. Nurses wear uniforms, the doctor doesn’t.

DAY HOSPITALS: Now a more cheerful subject, the system of day hospitals, a transition toward de-institutionalization. We come here in good mental shape after therapy and the situation here is different. In the hospital I am not a person and they don’t consider me as a human being. They don’t respect my dignity. I go voluntarily to the day hospital, stay the morning and return home in the afternoon, feeling free and human. In the group therapy they teach us social skills and how to live independently. They educate us how to behave and dress, how to live with the mental disease and to accept treatment. It’s easy to recognize psychiatric patients because they appear sometimes neglected. Doctor Davidovic organized classes in cooking, computers, foreign language (English), literature, drama...I can only say the best about the day hospital and had my best experiences there. But to get to the day hospital you have to be significantly improved. If you get sick again, back to the lock down ward, of course me not you.

STIGMA: I shook off first the self-stigmatization. Actually, I stigmatized myself by hiding, afraid to tell anybody about my treatment because of shame. I shed that and then went into public. Many of my friends were unaware of my treatment, I kept it a secret. While a senior in the Mathematical High School I first got sick. I spent a month at Palmotic Street and the psychiatrist advised me to tell my friends that I have a congenital heart condition, rather than mental

disease, as a reason for the hospital stay and treatment. Later I enrolled at the Electro-technical Faculty; major in technical physics, but after completing 19 credits I failed to graduate because of the disease. Diseases affect the will power, the mental disease also intelligence and memory, but the lack of willpower kept me from studying.

I would rather do anything but sit down and study which is sometimes the problem also with healthy but more so with sick people. Although there are mentally ill people who study even get masters degrees, I could not. My will power was cracked, I could not strain and it was hard to prepare for the tests.

If I compare the treatments in Palmotic Street to the one in "Laza" the differences are great. The former is a somewhat elitist hospital. They select easier patients, the ones that are treated the first time and not for long. In Palmotic Street there is no restraining, I didn't experience any major trauma, was well treated and can say it was a classy environment. After 15 years of treatment a severe episode of relapse sent me to "Laza".

I was able to keep my treatment a secret for those 15 years and then one summer I went into the street wearing a fur coat in July. The neighbors called an ambulance and that's the first time they saw me sick. They learned that I had been treated and I stopped hiding this from them. Not all of my friends knew this. My parents protected me when I was sick. When hospitalized I would be traveling or somewhere else, I don't know...Then I would come home but didn't leave the house or socialize until stabilized or in remission. The treatments would last a month or two, not a problem, the month in the hospital is critical and another month I could hide out. How could I talk about it, it is a stigma and I didn't want anybody to know about it. One doesn't talk about it, it is shameful. Much later I was able to break the self-stigmatization. My best friends knew it earlier. I didn't lose any immediate friends because of the disease, may be a single one but only a few. Because of the misperception about us I would advise young people not to reveal immediately their treatment to a girlfriend or boyfriend, but allow them first to recognize the virtues of your soul and character. First establish a friendship or partnership and after three months tell them. Then it is easier to say "I am being treated" because if you revealed this at the beginning you could be rejected.

In my life nobody ever said anything hurtful strait to my face, but I knew they said bad things behind my back. Like "see that building, there on the 4th floor lives a psycho" or walking in the street I overhear "that one there" and that's not paranoia. The mental disease can be concealed for a while but after public fall outs it can't be hidden any more.

THE DISCRIMINATION: By law all employers have to hire a handicapped person per every 20 employees but they don't hire mentally handicapped people. Why? Because we often take sick leaves they employ us part time but even that stopped. Most of us receive disability pensions,

but the ones able to work have a hard time finding a job, very hard. At the job interview they usually ask “have you served in the military?”, “no”, “why?”, “I was excused”, “why?”, “I have a mental illness”-and that interview is over. I supported myself by tutoring students in math and physics. I was paid under the table. After tutoring for 30 years between my age of 17 and 30, I got a family pension. I tutored only when I was well and nobody ever suspected that I am being treated. I graduated from the Math High School and knew my math and physics well and have some didactic talents too. I know how to explain, how to approach a child, I am very patient and never lose my cool. I did it nicely and had success. That is because I worked only when I was well. Had I told a parent that I am a mental patient he would dismiss me immediately. In a heartbeat. Therefore I never revealed to any parent my treatment.

LOVE LIFE: My wife is also treated for a psychosis, we have been married 10 years and we live in our own apartment. Both of us were sick before our relationship began so everything is OK there. We both know this disease. I feel that I could not live without her anymore or how should I say it I can't function without her. It is not an emotional connection only, it is love. We met at a party of normal, healthy people. She recognized me as a patient but I could not read her. At our first date she said “you know I am in treatment” and I said “me too”. She didn't mind being with me because she recognized in me the person she could live with.

THE FIGHT FOR HUMANITY: When you leave the day hospital and arrive at home you realize that you don't have any fulfillment. You coming back to the routine of your sick life which got you to the hospital in the first place and nobody cares about you. There is no more therapy other than the monthly follow up visits that last for 5 minutes just to write the prescriptions. You know what; we lack content in our lives. My life is based on sick foundations and regardless whether it is hereditary or acquired as a result of a trauma I need healthy content to it. And without help I can't get it. Without the help of a psychologist, psychotherapist, social worker, psychiatrist, doctor and medical system I can't live.

The essence of de-institutionalization is to live the life of a respected man, to live like a normal citizen. We are not “the hospital at end of town” and would love to live like any free citizen that didn't break any laws. Why should I be locked up if I am not a criminal? For example, there were at some time 1300 inpatient beds on the territory of Trieste, Italy and now there are 25. The question is, is it necessary to stay in the hospital for a month or two. I only wish a humane approach and acceptance as a man rather than a diagnosis. Humane approach, face to face, man to man and that's why it is not called any more a psychiatric patient but consumer of psychiatric services. The complete de-institutionalization may take 20 years and I don't believe that I'll live long enough to see it, I am 51 now. Doctor Bazalja in Italy fought for a law passed in 1979, but the hospitals closed in 1999. It is a long road.

The Reform of Psychiatry

Far away from contemporary trends

The most successful models of deinstitutionalization included mental health services in the community followed by decrease in psychiatric hospital beds, states for “Vreme” psychologist Aleksandar Dimitrijevic

Presently in Serbia there are five psychiatric hospitals with over 3000 beds that function as asylums far from urban areas, encircled by barbed wire and with demeaning living conditions. However, in only one week many questions were raised on psychiatry moving from closed hospital fortresses to local county centers and the treatment becoming more humane. First, at the Center for Cultural Decontamination by viewing the Italian movie “There Once was a City of Lunatics” that truthfully and emotionally shows the deconstruction of the classical, cruel psychiatric hospital in Trieste. A few days later a law on protection of people with mental derangements was enacted, which deals with humane approach to treatment but still in classical hospital setting and finally the visit of the renown Italian professor Paolo Sere who asserted that the crisis of psychiatric hospital paradigm is apparent worldwide. Instead of the hospitals there is more talk about services in the community based on respect of human rights and deinstitutionalization.

Psychologist Dr. Aleksandar Dimitrijevic, associate professor at the Philosophical Faculty in Belgrade explains for the “Vreme” the essence of these changes. “There are different models of deinstitutionalization. The ones proven to be most successful included the opening of services for mental health in the community followed by the reduction in the number of beds in the psychiatric hospitals. For example if you open 5 beds in protected apartments you close 5 beds in the hospital. The tenants must not be evicted or neglected. The goal of this process is to avoid living for years or decades in places tens of kilometers from the nearest city.

The treatment in the community should enable consumers to integrate into the society, find employment, become members of the library, chess club...This way their capabilities are preserved, they live in families rather than isolation and with time the stigma fades. But for this to happen they need the option to reach for help, the services should be readily available for them to have the feeling of independence...It’s possible that for attain these goals the professionals have to change more than the consumers.”

On the question of is this a global tendency toward this type of treatment, Dimitrijevic answers: “This trend got into the laws and practices of European countries and it is applied in Brazil and some Asian countries. This reform was one of the requirements for Rumania and Bulgaria to enter the European Union. In the last few years Belgrade was visited by many experts and

representatives of user associations from Italy, Holland, England, France because they all want the reform to be implemented as soon as possible in all parts of the world so that a large number of people and children get the chance to live a dignified human life.”

When we talk about the reduction in hospital beds and introduction of psychiatric services in the Health Centers, how far or close are we from such a model? “The professionals in Serbia unfortunately, often are not interested in experiences of the world” says Dimitrijevic. “Some believe that there is nothing new to learn others think that everything should forever stay the same as in the last decades. Witness to this is the recently passed Law, because it contains extremely conservative rules on involuntary hospitalization and offers solutions not yet seen in the world: psychiatric services in the Health Centers that function as ordinary clinics. Staff assigned to work in Health Centers, could not have attended any University classes on preventive mental health in the community and during their entire education was bombarded by the doctrine of prescription writing is the only and most important thing.

To start the reform big changes are needed in thinking and relationships to people including psychiatric patients. Sadly, maybe a change of generation is necessary. How far we are from contemporary trends witness Bosnia where the situation is different and incomparably better for users of psychiatric services. Why is it impossible in Serbia, what’s possible in countries that are less rich, developed or educated, remains a mystery to me.”

Ivana Milanovic Hrasovec

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