

People with Developmental Disabilities: Living as Everyone Else Does

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An article on community living in Croatia, by Chuck Sudetic

Milica Cicic recalls it raining on the day she and her elder sister stepped from a big blue bus, slogged up a long driveway beside an imposing wire fence, and entered the main gate of the Center for Rehabilitation. On their right, beyond the rim of their dripping umbrella, were a guardhouse of dirty white stucco, a watchman's eyes, and a statue of a woman cradling a child. Cicic was afraid. Her sister was crying and tried to be reassuring: "It's a school, Milica. They'll teach you to read and write."



Milica Cicic lived for twenty-four years at the Center for Rehabilitation

Cicic was 15 years old on that rainy day in 1977. She had never been to school, and the center provided her no schooling she can remember. Even now, Cicic knows little about numbers. She cannot scrawl the letters MILICA CICIC. And, because she cannot gauge the passage of time, from the moment of her sister's farewell, Cicic's days mashed together like lumps of clay in the activities room. Wake-up at six. Breakfast. Crafts. Music, perhaps. Lunch. Maybe a walk around the grounds. Dinner. Arguments and catfights. One of the male residents, Božidar Kobasic, running away. Punishments: head shavings, days of lock up, days of having to wear pajamas instead of clothes. Once an inmate tried to fix an iron without unplugging the cord and died of electrocution. After that it was "Don't touch the irons." "Don't touch the television." "It's nine." "Everyone to bed."

Cicic cannot say exactly how long it has been since she left the Center for Rehabilitation. (It was during 2001.) She did not run away, as Kobasic had run so many times before he was finally released. More than a 100 people like Cicic and Kobasic have built new lives in the world beyond the front gate of the Center for Rehabilitation and other institutions like it across Croatia. They were assisted by the Association for Promoting Inclusion, an organization working to close the Center for

Rehabilitation and similar state institutions and to redirect their public funding into programs that reintegrate former residents into society with full human rights.

A professor at Zagreb University who specializes in rehabilitating people with developmental disabilities, Borka Teodorovic, manages the Association for Promoting Inclusion, which receives support from the Open Society Mental Health Initiative. Teodorovic says that for centuries people like Cicic and Kobasic suffered terribly. Some families rejected them; other families were unable to give them adequate protection and care; some loving caregivers died and left them with no one. And in the world outside the family, the disabled endured mockery, abuse, homelessness, hunger, and castigation as vessels of demons or souls condemned by god. In the late 19th century, social reformers began taking steps to protect people with disabilities by gathering them in institutions where they were fed, kept warm, and clothed. During World War II, Nazi Germany chose another path: extermination in an attempt "to strengthen the nation." After the war, communism came to Eastern Europe. Efforts began to institutionalize and educate the developmentally disabled with a view toward someday allowing them to return to society. In too many instances, however, these institutions failed to educate, train, and return their residents to society. Too often, they cut their residents off from their families and barred them social contacts in the outside world. In many cases, these institutions became expensive life-long warehousing facilities for human beings and disregarded the human rights of the people they were supposed to protect and serve.

Several decades ago, the developed countries of the West began undertaking successful efforts to reintegrate developmentally disabled people into society. Now, the countries of Eastern and South Eastern Europe are following the same course, and the Open Society Institute is assisting their efforts, because the developmentally disabled are among the most marginalized and neglected segment of the population of these regions, says Judith Klein, director of the Open Society Mental Health Initiative. She has carried the idea of inclusion into Romania, Bulgaria, Hungary, Croatia, Serbia, and other countries of Eastern Europe and the former Soviet Union, where tens of thousands of people are locked away. "These people have significantly less ability to advocate on their own behalf," Klein says, "and this, in part, has led to a history of massive institutionalization that is contrary to the principles of an open society and a violation of human rights."

Success requires altering the attitudes of parents, some professionals and members of the government bureaucracy managing these institutions, political leaders, as well as the general public. "We are about 30 years behind," Teodorovic says of Croatia, which has about 4,500 developmentally disabled people in institutions countrywide. "The ministry here has not reached the conclusion that it has to change things. The bureaucrats say they favor inclusion, but they create barriers. They have a plan, for instance, to build five new buildings at the Center for Rehabilitation to house about 125 residents who have the most severe disabilities; the remaining 260 or so residents, they would like to deinstitutionalize. We disagree. We believe it doesn't matter that the institution is great, if it is new and clean. None of these people should be locked away."

"The people living with the worst disabilities will need more assistance in a community setting than the others," Teodorovic says, "but the community can and should bear the costs, because the alternative deprives them of their human rights."

Cicic remembers a team from the Association for Promoting Inclusion asking whether she wanted to leave the Center for Rehabilitation. "They asked if I wanted to go out, to live in Zagreb. They said I would have my own bed, that I would work, that I would earn money and be able to keep it."

"I understood that when I came out I would have to try hard but that I could live as everyone else does," she says. In the center, "they treated us all as if we were children. They used to call us children. But we are not children. I am a grown woman. But there any relationship with a man was considered shameful. The women and men were kept apart. It was unthinkable for a woman and a man to share a room. It was forbidden because it might lead to a pregnancy and abortion. But we should be able to have our own lives."

Cicic's integration proceeded in steps. At first, she shared an apartment with a round-the-clock attendant. Later, she married and moved into an apartment of her own. Today, she holds the keys that unlock the main entrance to the apartment house where she resides. A social worker makes periodic visits. An assistant takes Cicic and other members of the program to shop in groups. Her husband, another former resident of the Center for Rehabilitation, works for a company, placing labels on retail body-care products. Cicic handles the cooking. "I like to make everything, fried chicken, soup, strudel, eggs. And my husband is very satisfied."

Božidar Kobasic knows well the Center for Rehabilitation's front gate. He passed back through it after each of his escape attempts. "They beat me like a horse because I would not obey the rules," Kobasic recalls. "You would run away too if they punished you that way."

Kobasic was born in 1963. He spent most of his childhood in foster homes and institutions before landing in the Center for Rehabilitation in 1979, after a failed attempt to run away. "When you see that wire fence, you know where you stand," he says. "Inside, it was always loud. They yelled at us. The residents would yell and shout."

"I don't know how many times I ran away. I'd climb that wire fence, and on the outside it was quiet, there was fresh air, and I felt fine. Sometimes I'd try to return to my mother. Sometimes I slept with the Roma in a barracks. Sometimes I would stay out for two or three days and return on my own. I had no hope of ever getting out of there forever."



Milica Cicic with husband Božidar Cicic

Finally, Kobasic heard about the Association for Promoting Inclusion and got Borka Teodorovic's home phone number. Day after day, he would sneak into an office at the center and call her on the phone, insisting that he had to get away. "Before we had worked him through the bureaucracy, Božidar made another escape attempt and the police took him to a psychiatric hospital," Teodorovic says. Kobasic was finally placed in a program for supported living in 1999. He took a job with a catering company at first, but now earns about a two euros an hour sticking labels on body-care products. He shares a room in a group home with five other people who enjoy round-the-clock assistance from a social worker.



Božidar Kobasic secured employment and works sticking labels on body-care products.

And, in his free time, Kobasic walks for miles on end. He walks to the city's largest psychiatric hospital to visit his mother. He walks to work. He walks to church and will soon receive his First Communion. He walks to the center of Zagreb, through its open-air market, and up into its old town, and beyond. And on his walks, he has made mistakes. Once, he crossed a street against a red light. A delivery van struck him and injured his leg. "I was in the hospital for a long time," Kobasic says, showing off a scar on his calf. "They put 12 screws in there. But it could have happened to anyone. And I am not afraid to walk on my own. I have no reason to be afraid."

Milica Cicic, Božidar Kobasic, and the other citizens of Croatia with developmental disabilities have an advocate in Zdenka Petrovic. She is president of South Eastern Europe's first nongovernmental organization dedicated to organizing developmentally disabled people so they can themselves express their needs and demand respect for their

human rights. Petrovic knows the loneliness, fear, mistrust of life inside an institution. The 24 years she spent in an institution did not mash together like balls of clay in the activities room.

Petrovic was abandoned at birth in 1965 and placed in a home for children. She eventually lived in a foster family for several years before being institutionalized in 1974. She wanted to go to school, but never got a chance. The institution taught her nothing of letters or numbers except their names. Sometimes she worked outside the institution, but she had to give the money she earned away-until she learned to deposit it in a savings account secretly. The few things she bought or received-a bicycle, a basketball warm-up suit-were either confiscated or stolen. She had no ability to influence the course of her life. "When I was small, I tried to run away, but

I fell into a hole," she says. "There was a big fence all around. Wires. And the gates were closed. When my foster family wrote me, no one would help me write back." She had her hair sheered twice as a punishment for attempting to escape.

In 1998, Borka Teodorovic approached Petrovic, one-on-one, and asked her whether she would like to attempt to live outside the institution. Petrovic credits a program coordinator for encouraging her to adapt to a new life. "He said he would tell me the truth, no matter what," Petrovic said. "Until that moment, I didn't trust anyone. Everything anyone in the institution had ever told me was a lie. I was afraid of everything. I was afraid people on the outside would mock me. I was afraid to cook."

After eight years, Ms. Petrovic has her own apartment. She works. She makes decisions about her life. She has friends and relationships with men. She can read, write, and do arithmetic. At age 41, she is in the fifth grade with four other adults ready to tackle grammar and reading, math, geography, and history. "I buy what I want," she says. "I pay my own rent. I receive some social assistance, but I can work and earn money on my own. They always told me I was incapable of working. They said we were of no use to anyone else."

On July 13, 2005, Petrovic appeared as a witness before the Committee on Human Rights of Croatia's national assembly. She wore a business suit. She enunciated her words clearly, slowly, and with resolve:

"In the institution, they cancelled all of my rights," she testified. "They told me I was unable to go to school. We had no choices. When we complained that things were being stolen, they did not want to listen. We had nowhere to turn."

"My friends who are still in the institution today would also like to come out, they want our help," Petrovic said. "They want to live independently. And I would recommend that a decision be taken to close down all these institutions, and give these people the ability to live independently and work."

Someday-she hopes it is soon-Petrovic will approach the front gates of the Center for Rehabilitation with Cicic and other former residents. They will walk up the driveway alongside an imposing new metal fence and pass the guardhouse of dirty white stucco, the watchman's eyes, and the statue of a woman cradling a child. And once inside the center, Petrovic will approach residents one at a time. She will explain to them the possibilities of life outside. This is exactly how this woman who was told she had nothing to contribute described what she will say:



"I'll ask them whether they want to go outside. If they say no, I'll ask why."

"If they say they don't want to leave, I'll ask them why it is fine in the institution. If they say it is fine because they have something to eat and a place to sleep, I'll ask whether they would like to have a place to sleep and something to eat outside.

"If they say they can't leave, I'll ask them why they can't leave. I'll ask them whether they would like to work and be paid for it. I'll ask them if they want friends, men and women friends.

"If they say the staff won't let them, I'll explain that, once they're outside, they'll have their own friends, they'll decide what to do, what to eat, when to wake up, when to go to bed.

"People are afraid of what they do not know."

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