

# To Live Freely...

Thursday, March 23, 2006

*People with intellectual disabilities have the right to be equal and active members of the community. Living together with people without disabilities enables them to develop their potential to the fullest, and it allows them to develop friendships and close relationships. These developments eventually lead to tolerance and acceptance of difference in all of society.*

Danijela (37) and Marinko (38) have been a couple for 10 years. Two months ago they started living together in an apartment in block 45, situated in the suburb of Belgrade called New Belgrade. Their best friend, Milica (31), lives with them. Currently, Danijela works only once a week at a McDonald's restaurant, but as soon as she takes care of her medical examination, she will start working full-time at the Jewish Community Center restaurant. Having already successfully completed her training period, she will work in the restaurant's kitchen. Danijela thinks that cooking will not be a problem due to the fact that she and her roommate Milica practice cooking skills on a daily basis. With a smile on her face, though, she admits to learning how to cook just two years ago, at the beginning of her independent living.

Marinko works as a baker's assistant in Sremčica. Every morning he gets up at 4:00 a.m. and uses public transportation to get to work. Although Marinko is skilled in house-painting, he enjoys his current job and would like to work somewhere closer to home, preferably in the center of the town or in New Belgrade.

Danijela, Milica, and Marinko cannot be easily reached at home. In addition to work and everyday obligations, they visit a sports facility at Banjica, where they go to the swimming pool and fitness center three times weekly, from 1:00-5:00 p.m. They also often go to the cinema and theatre or visit friends in the evening. They say that they can't wait for spring to arrive, so they can enjoy all the benefits of their apartment located near the Sava River. Danijela, who is a true sportswoman, especially likes spring. It is hard to put into one sentence all the sport activities she enjoys. She swims and has won seven medals and numerous diplomas at tournaments in the Czech Republic, Germany, and Argentina. She likes to ride her bike, and she has been an active member of a dance group for quite some time. All three of them talk about life in their neat and impeccable apartment with lots of enthusiasm.

At first glance, this is just an ordinary story. Indeed, there is nothing exceptional about the fact that people live together as a couple, that they go to work, practice sports or go

out in the evening. Still, for these people this is a huge step forwards compared to how they used to live. They are part of a pioneer adventure aimed at changing the lives of tens of thousands of people, a segment of society almost completely hidden from the eyes of the public.

**THE UNUSUAL STORY:** Until July 26<sup>th</sup> Danijela lived in the Home for Children and Youth with Mental Disabilities in Sremcica, near Belgrade. Milica and Marinko left the same institution and moved into their apartment two months ago. Danijela was one of five people from that institution who became pioneers in a program implemented by a team of professionals from the Association for Helping People with Down Syndrome.

The basic idea of this program can be summarized thus: People with intellectual disabilities have the right to be equal and active members of the community. Living together with people without disabilities enables them to develop their potential to the fullest, and it allows them to develop friendships and close relationships. These developments eventually lead to tolerance and acceptance of difference in all of society. Two words are vital for this project: inclusion and deinstitutionalization. Inclusion involves the participation of people with intellectual disabilities in all aspects of normal life. This could be, for instance, inclusion of children with intellectual disabilities in the regular system of education together with children without disabilities. Deinstitutionalization involves moving people out of long-stay residential institutions and developing capacity in the community to provide accommodation in apartments shared by up to 5 people. Those people living in the community receive support from trained direct care staff and coordinators/rehabilitators.

In this deinstitutionalization project, the preparations for the transition of the first group into the apartment lasted for about three months. The people who decided to participate in the program were nervous and some of them even scared, says Danijela. The majority of clients at the institution spent almost their entire lives living there, but the wish for change was stronger than the fear of leaving. In the beginning, the direct care staff was with them 24 hours daily. After the first 8 months of life in the apartment they became almost completely independent; they learned how to cook, how to take care of their apartment, how to plan activities and how to work together on solving their problems. In short, they live like any other family. In order to understand the scope of this success it is enough to mention that some of them were never before in the position to hold money in their hands. However, the most important thing is the joy of living that can be felt in their apartment. Today, these people respect themselves and others, and they have a wish to help their friends from the institutions to live in the way that they do in the community. Today, the people living in the first apartment receive 8 hours of support from their direct care staff. This support is mostly just to have someone to talk to and share things with, not because it is necessary in the daily functioning of the

people. Danijela, who expressed her wish to live with her boyfriend and best friend Milica, eventually left this first apartment and is currently living elsewhere. So far, 23 people moved out of the institution and today live in five apartments in Belgrade.

The project is being implemented in cooperation with the institution in Sremčica and the Association for Promoting Inclusion (API) from Zagreb, Croatia . API's experts shared their extensive experience in the field of deinstitutionalization with the professional team of the Association for Helping People with Down Syndrome, led by Dragan Lukić, Ph.D., and Jadranka Novak, the team psychologist. This project is partially financed by Open Society Foundation and Fund for Social Initiatives and receives support from the Ministry of Health and Social Policy. The resources provided by these parties enable a limited timeframe for the implementation of the project, but the issue of future development and sustainability demands a more systematic approach.

**THE PRICE OF QUALITY:** It may seem initially that the overall price of deinstitutionalization is very high, but this assumption is incorrect. If we accept the idea that "the money should be linked to the person," and if the financial resources assigned to people with intellectual disabilities in institutions (around 18,000 Dinar per month) are redirected to support life in apartments in the community, then it can be said that life in the community is more cost-efficient, and the quality of life in the community is incomparably better. Still, this is just one of many issues which need to be regulated by state legislators. The issue of work opportunities for people with intellectual disability also needs to be regulated. Payments for work received by people with intellectual disabilities living and working in institutions are irregular and symbolic. According to the current legislation, if a person with intellectual disabilities works outside of the institution and receives payment for their work, they lose the right to receive any other type of assistance. Finding a job and becoming part of the normal work environment is of great importance for the development of self-confidence and self-esteem, but in order to feel like they are equal members of society, people with intellectual disabilities need to receive fair payment for their work.

We should not conclude that institutions are to blame for all the negative things happening in the lives of the people who live in them. The truth is that in our institutions, Sremcica among them, people do what they can in unfavorable conditions. For example, the Sremcica Institution has 285 clients; one rehabilitator works with 20 clients, making an individualized approach virtually impossible. Many clients share a bedroom, there is almost no privacy, meals are distributed according to a preset regime, and many clients never leave the institution grounds.

**DIFFERENT MODELS:** The idea of large residential institutions where people with intellectual disabilities are isolated from society is part of the so-called *Medical Model in Rehabilitation* developed in the late 19<sup>th</sup> century and prevalent during the 20<sup>th</sup> century. The *Medical Model* sees the atypical person as an anomaly and a medical problem which needs to be *cured* or corrected so that the *patient* can be integrated according to generally accepted standards of *normality*. In this manner, the *patient* is isolated, and all decisions regarding treatment and accommodation are made by experts.

Over time, this model proved to be wrong, and there emerged the idea of providing people with intellectual disabilities with support which will enable them to function in the *outside* world rather than *correcting* them in institutions. Families of people with intellectual disabilities became stronger and started to advocate for their members, and they have been playing an important role in this change of attitudes ever since the second half of 20<sup>th</sup> century. The process was sometimes assisted by influential individuals who had a family member with intellectual disabilities; the first act that regulated and protected the right to education of people with intellectual disabilities was enacted in the U.S.A. during the presidency of John F. Kennedy, whose sister was diagnosed with mental retardation.

From the *Medical Model*, the emphasis was shifted to the *Social Model*, which is based on the idea that people with intellectual disabilities have the same developmental needs as other people and that they are an essential part of every community. For this very reason we need to ensure that people with intellectual disabilities can function as independently and efficiently as possible in their natural environment instead of being isolated. Every treatment, service or accommodation is determined only in conjunction with the individual needs of the person and her/his family with the aim of developing existing potential. Every relevant decision is reached in cooperation with the person and his/her family. Every treatment is focused on developing skills which will enable the person to function as independently as possible. Experience has shown that skills can best be mastered in the natural environment in which they will be applied and that institutionalization either results in the person spending her/his entire life in the institution or in the need for continuous support, once the person leaves the institution, until some of the skills needed for life in the community have been acquired.

Community-based care was implemented intensively in Western Europe, the United States, and Canada during the second half of the 20<sup>th</sup> century. Of the 195,000 persons with intellectual disabilities living in large residential institutions in the U.S.A. in 1967, more than 100,000 individuals were moved out of institutions and placed in small scale, family-like housing in the community, decreasing the number of people still institutionalized to 50,000 people in the year 2000. All institutions in Canada are closed, and in Norway only 3% of people with intellectual disabilities live in residential institutions. In Serbia's neighboring Hungary, a law has been accepted which prescribes the complete termination of institutions by the year 2010.

The staff employed in institutions also often express resistance to changes in the system of social welfare because they are afraid they will lose their jobs if the institutions are closed. This resistance could have a negative impact on the recognition of results of deinstitutionalization projects, since deinstitutionalization makes sense only if the spaces emptied in the institutions are not immediately filled with new clients. The staff should be offered better work conditions with fewer clients in institutions which will be transformed into community-based service providers.

According to recent statistics, there are currently more than 860,000 registered people with disabilities in Serbia, 90,000 of whom are people with intellectual disabilities. In Belgrade alone there are 10,000 registered people with intellectual disabilities. Only 10% of children with intellectual disability are included in some form of professional support (pre-school, primary, and secondary educational facilities and housing facilities for children).

Hidden behind these numbers is an entire army of people who wish to live like everybody else but have little to no opportunity to do so. The Association for Helping People with Down Syndrome deinstitutionalization project gives hope to many of these people. Of course this is a process which will take time, and years will pass before institutions are closed, but the people involved in this project take the words of Edmund Burke as their guideline: *"Nobody made a greater mistake than he who did nothing because he could do only a little."* The worst thing that could happen now would be for the State to remain inactive and not enable the legislative changes necessary in order for the project to become a part of the existing system of social welfare. If that were to happen, then once the donations cease, the people now living in the community would have to return to the institutions. Such a move would be disastrous for them. But this end is not something anyone wants to consider; the experiences of *normal* life, a first-time experience for many of the clients, gives them the strength and optimism to believe that they have started a journey which can only lead them forwards.

*Source: MOMIR TURUDIC, "Vreme" no. 794, March 23<sup>rd</sup> 2006, Belgrade*