

Living in a “Parallel World”: *Disability in Post-Soviet Ukraine*

By Sarah D. Phillips

Andrei Budnik, who lives in Kyiv, Ukraine, lost the use of his legs in a logging accident in 1989 when he was 22 years old. He lived with his mother until she died last year, and now he lives alone. Because of the stigma and high costs associated with disability, Andrei's brother severed all ties with him when he became a paraplegic. Like most buildings in Ukraine, the building where Andrei lives is not wheelchair accessible. (Although legislation requires that all new buildings be designed to be wheelchair accessible, these laws are not enforced.) To reach his small apartment he must navigate a flight of stairs in his wheelchair. Since public transportation is also inaccessible to wheelchair users, Andrei travels almost everywhere he needs to go in his wheelchair, riding on the busy city streets. On an average day he covers 15-20 miles, which can take as long as 2.5 hours.

In 2000, Andrei, who has competed in national and international sports competitions for the past seven years, set a Ukrainian wheelchair racing record in the 1500 meter, a feat that went unnoticed in Ukraine. He is a professional ballroom dancer, and with his former dance partner took sixth place in the all-around competition at the world championships in Poland in 2001. But Andrei has no official sponsors. He is currently employed as a social worker in a youth organization in Kyiv, a job that offers him personal satisfaction but a very low salary. Andrei survives mostly on a meager government pension of \$30 per month.

These are challenges that are familiar to disabled people all over the world. Challenges such as these make many persons with disabilities in Ukraine feel

The disabled in Ukraine face both hidden and open discrimination in their daily lives, and they are stigmatized through popular stereotypes of disabled persons as inferior, deformed, and even contaminating.



Andrei Budnik, activist for disability rights in Ukraine

as if they live in a “parallel world,” one separate from that enjoyed by “able-bodied” people. The disabled in Ukraine face both hidden and open discrimination in their daily lives, and they are stigmatized through popular stereotypes of disabled persons as inferior, deformed, and even contaminating. These attitudes stem in part from the Soviet-era policies towards the disabled, which perpetuated such harmful stereotypes. Persons with visible disabilities (i.e., spinal injuries, cerebral palsy, multiple sclerosis, mental problems, and others) were isolated in their homes, hidden from the public and thus made seemingly invisible. Since disability was seen as a defect and as a tragedy, the

Soviet regime pursued a policy of compensation. As Andrei put it, “We were given a label [“invalid” in Russian and Ukrainian], a pension, and a license to do nothing.” The invisibility of disabled persons positioned them as a non-problem. Their lives were not discussed, and there was practically no public debate about their needs. When attempts were made to rehabilitate people with disabilities, rehabilitation was primarily medical and vocational in nature, an approach that reflects the ideology that the problem is located within the individual, who needs to be changed/improved (i.e., given maximum physical functioning or gainful employment).

In postsocialism, the greater visibility of people with disabilities—and, especially, the burgeoning disabled rights movement—have stimulated debates about citizens' rights, entitlements, and responsibilities that go to the heart of postsocialist reforms in social policy. People like Andrei, who reject the “tragic” model of disability promoted by the Soviet regime, are taking up new models of disability, models that are influenced by disabled rights movements in Western countries such as Sweden, the Netherlands, Canada, and the United States. Most salient for many Ukrainian activists is the social model, which defines disability as social oppression, rather than a defect located in the individual. Promoters of the social model thus advocate for social policies that would target the source of oppression (i.e., architectural barriers, discrimination in education and employment). Central to these debates is the challenge of balancing fair entitlements for disabled persons with opportunities for physical, psychological, and vocational rehabilitation. A very important concept for many disabled activists is the notion of independent living, a movement that

—continued on page 2, see *Living*

Living—continued

had its origins here in Urbana-Champaign, Illinois and Berkeley, California in the 1960s and 70s. Like the social model, this movement shifts the focus from individual “inadequacies” of the disabled person to environmental barriers, and primary importance is given to facilitating out-of-home activity for people with disabilities.

Some inroads towards these goals are being made in Ukraine. The disability rights movement is one of the most seasoned and respected in the country, and more than 3,000 non-governmental organizations (NGOs) for the disabled and for veterans (many of whom have disabilities) are working to improve the lives of disabled people all over the country. 35 large NGOs for disabled persons recently formed a National Association of Invalids of Ukraine, which is headed by Valery Sushkevich, a Member of Parliament and President of the Ukrainian Paralympic Committee, who himself is mobile impaired. It is hoped that, through the Association, disabled persons will be able to effectively pressure the government to meet their needs. Additionally, the younger generations in Ukraine have become accustomed to seeing and interacting with people with disabilities, and this familiarity has resulted in the weakening of negative stereotypes.

There are several facilities in the country that offer high-quality physical rehabilitation for people with spinal injuries and other motor impairments. Also, a Kyiv factory recently began to produce an “active” wheelchair that is lightweight and easier to maneuver than wider wheelchairs. Such a wheelchair could help people with motor impairments pursue a strategy of active rehabilitation, one of the main goals of the Ukrainian disability rights movement. Unfortunately, these high-quality rehabilitation services and active wheelchairs are cost-prohibitive for many disabled people, who often survive on meager government pensions.

Perhaps recognizing the centrality of economics to the problems of the disabled, the Ukrainian state is currently emphasizing vocational rehabilitation. Unfortunately, these vocational programs have many limitations. Most educational facilities that target the disabled population have not been adapted to accommodate mobile impaired persons, making it impossible for many to attend courses.

Some vocational centers for the disabled are inconveniently located, and users cannot conveniently travel to and from the centers. Some argue that such centers become “reservations” or even “prisons” for disabled people, who are trapped there and effectively segregated from the rest of society. Ukrainian labor laws require that an enterprise’s work-

force include a minimum of 4% disabled people. Paradoxically, such laws often work against people with disabilities. To avoid paying a fine for violating this law, and reluctant to remove architectural barriers to accommodate workers with special needs, many businesses employ “token invalids,” who are paid half their official salary to stay home and conceal the arrangement.

These problems point to more pervasive, yet often hidden, forms of prejudice and discrimination. In political and popular discourse, disability is a theme that is much abused and manipulated. In political campaigns, candidates play on the emotions of certain categories of citizens, oftentimes children with visible physical disabilities. At exhibitions of social services and NGOs, would-be sponsors flaunt their (often fictitious) support of “invalids’ organizations” through enlarged images of disabled people. People with disabilities thus become a commodity to be manipulated by powerful people and groups for their own gain.

In the face of such struggles, disability rights activists like Andrei Budnik are taking matters into their own hands. He is currently studying rehabilitation therapy at a university in Kyiv, which will help him offer rehabilitation to disabled and able-bodied children, teens, and adults through dance, music, and other arts through “Irida,” the civic organization where he is employed. He hopes to help others with disabilities pursue goals of “active rehabilitation” and independent living while challenging negative stereotypes of the disabled.

Sarah D. Phillips is a Visiting Assistant Professor of Cultural Anthropology. She conducted research on the disability rights movement in Ukraine in summer 2002.

A very important concept for many disabled activists is the notion of independent living, a movement that had its origins here in Urbana-Champaign, Illinois and Berkeley, California in the 1960s and 70s.



The Russian and East European Center is especially pleased to welcome **Maria Todorova** to the University and to the REEC community. She joined the History Department this year,

having taught previously at the University of Florida in Gainesville and the University of Sofia, Bulgaria. Professor Todorova is a distinguished scholar of Southeast European history and the history of nationalism. Many students in the humanities and social sciences are familiar with her book *Imagining the Balkans* (Oxford U. Press, 1997), which has been translated into nine languages with Croatian and Albanian translations forthcoming.

Professor Todorova received her PhD in history from the University of Sofia in 1977 for her dissertation on the Tanzimat reforms in the Ottoman Empire. At that time, Ottoman history was considered a safer choice because it was not as politicized as post-Ottoman Bulgarian history. Since then and especially after she came to the US in 1988, her work has focused more on the history of the modern Balkans, but one of the central themes of her work has been the nature of the Ottoman legacy. Her book *Imagining the Balkans* addresses this issue and the fundamental question of how to conceptualize a “region,” especially one that is as complex geographically and historically as the Balkans.

Professor Todorova’s present research continues some of the themes in her earlier work and raises new issues. One theme that her work continues to address is perceptions and representations. She is currently working on the symbology of nationalism by conducting a diachronic study of a Bulgarian national hero Vasil Levski. Another theme of her work is memory. She is particularly interested in how people remember their everyday lives during the communist period and is trying to launch an international project on nostalgia of communism and everyday life.

Professor Todorova has received numerous awards and fellowships for her outstanding work. She held the Guggenheim fellowship in 2001-02 and the National Humanities Center fellowship in 2000. At U of I she teaches courses on the modern Balkans, the Ottoman Empire, theories of nationalism, the history of Eastern Europe as well as an undergraduate course on historical interpretation. She has also been appointed Adjunct Professor of Sabanci University in Istanbul, Turkey.