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 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
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.

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 workforce 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 constituents by offering token help to certain categories of citizens, oftentimes children with visible physical disabilities. At exhibitions of social services and NGOs, would-be sponsors flaunt their “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.