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# “Survivor” in Ukraine: Living Disability in a Post-Soviet State

## **Abstract**

[Excerpt] In recent years, new ways of thinking about disability and disability rights have emerged in Ukraine. Most notable is the prevalence of the “social model” of disability that is popular in Western disability rights movements, whose representatives have actively promoted the social model in Ukraine and other post-Soviet countries. The social model, which is based on a minority group model, defines disability as social oppression, and pinpoints disabling political, social, and economic environments that perpetuate and reinforce dependency. Rather than individualizing disability as a personal tragedy, proponents of the social model draw attention to the “obstacles imposed on disabled people which limit their opportunities to participate in society.” These “disabling barriers” may include terminology and classification of disability, as well as a “wide range of social and material factors and conditions, such as family circumstances, income and financial support, education, employment, housing, transport and the build environment and more besides”.

## **Keywords**

disability, Ukraine, discrimination, poverty, stereotypes

## **Comments**

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## **“Survivor” in Ukraine: Living Disability in a Post-Soviet State**

Sarah D. Phillips, Indiana University (sadphill@indiana.edu)

### **Introduction: Disability and Bare Life**

On a warm September evening in 2006, I sat outside with a small group of young and middle-aged wheelchair users at a rustic vacation camp on Ukraine’s Black Sea.<sup>1</sup> We were attendees of a week-long seminar on “Sports and Rehabilitation for the Disabled” sponsored by one of the two major disability advocacy coalitions in Ukraine. The seven people who convened that night for an after-hours chat had come from all over Ukraine (and one man, Arturas, was from Lithuania), but most had similar stories.<sup>2</sup> They had received spinal cord injuries in accidents--car crashes, diving accidents, workplace traumas--or experienced diseases that affected their spinal cord and therefore limited their ability to walk. Although we knew the sea was nearby--less than 200 meters away--we could neither see it nor hear it. The only access point was a yellow brick road of sorts, a steep, winding decline down the side of a cliff that was impassible for all but the most intrepid wheelchair users. (The descent was called “fairytale alley” by locals because it was dotted with wooden cut-outs depicting fairytale scenes. Seminar participants renamed the impassable trail “nightmare alley.”) So we settled ourselves under an awning far from the sea to chat, joke, and get to know one another better.

The group began to reflect on the irony that the week-long seminar they were attending for persons with disabilities was sited at a place so inaccessible to wheelchair users. Arturas and his roommate, Dmitrii (from Kyiv), had taken off one of the doors to their cabin to make a wheelchair ramp over the entranceway steps; they had also removed the doorjamb to the toilet so they could pass through in their wheelchairs. Earlier that day I accompanied Arturas and

Dmitrii down to the sea. Once we reached the sandy beach, the men had to crawl about 20 meters to the water--this had opened a sore on Arturas's leg that was starting to fester.



*A makeshift wheelchair ramp*



*The “nightmare alley” to the Black Sea*

The entire experience--not a new one for him, to be sure--prompted Arturas to assert: “We should organize a ‘Survivor’ (*Ostrov vyzhivaniia* in Russian, or ‘Island of Survival’) TV show for wheelchair users. Talk about ‘challenges’ (Rus. *prep’iatstva*). People haven’t seen challenges until they’ve seen what we face on a daily basis. Getting around the island in a wheelchair in the sand? Building shelters and cooking for ourselves? It would be the most popular show on television. People love to watch how I, a *sheinik* (Rus. tetraplegic) manage to peel potatoes. They’d go crazy for ‘Survivor for Wheelchair Users.’” The others chimed in: “Yeah, Arturas would chop down wood with his teeth!” “The old grannies would watch the show with tears in their eyes: ‘Those poor people.’” “Such a show would be considered

inhumane, and they'd take it off the air." One young man joked: "We'd better be careful--if we show how we can overcome barriers they'll reverse the new accessibility laws; they'll assume they aren't necessary!" 20-year-old Anya, who particularly liked Arturas's idea, put it simply: "There would be no better way for us to announce ourselves (Rus. *ob''iavit'sia*)."



***On the "Island of Survival"***

Arturas's "Survivor" idea prompted Anya, Dmitrii, and others to reflect on the fact that living on the "Island of Survival" would not be very much different from their everyday life as wheelchair users in Ukraine. The proposal and the responses and images it provoked are affecting examples of how persons with mobility disabilities in this post-Soviet state are stripped to "bare life" (Agamben 1988), engaged in a daily struggle for individual survival. This struggle is very real in the context of the economically-strapped Ukrainian state and its inadequate system of emergency medicine, surgery, and rehabilitation services. In Ukraine, 76% of persons who have received a serious spinal trauma die within a few years, often due to complications such as pressure sores and kidney failure (Polozniuk 2005). During interviews that I conducted, some of the seminar participants noted that "only the strong survive." They referred to their life struggles

as “survival of the fittest,” and spoke as if they were engaged in a constant and solitary race against death.

Balancing this awareness of solitary struggle is the sense of community and mutuality that the need for survival (or what some informants called “pulling through” or “scrambling out” (Rus. *vykarabkivat'sia*) engenders. Referring to the importance of information-sharing and networking among persons with SCI in matters of health maintenance and health care, one disability rights activist declared that “only the drowning can save the drowning.” This sense of mutuality was certainly present during the week-long Black Sea seminar. Dmitrii, one of the organizers, told me that although the formal focus of the seminar was the promotion of sports and “active rehabilitation” among the disabled, he was more interested in helping participants develop social networks and friendships among themselves, particularly the teenagers and young adults. Some of the older participants were able to renew contacts with persons they had met earlier at other events and venues. In informal conversations attendees shared advice on matters of health, exercise, medical care, sanatoria trips, finances and employment, activist work, and others.



*A lesson in falling properly from a wheelchair at the Black Sea seminar*

These social acts contrasted with many of the personal narratives I elicited during interviews with attendees, who emphasized feelings of abandonment by the state and sometimes by friends and relatives; highlighted their social isolation as a wheelchair user in their home village, town, or city; and stressed the personal qualities and individual strategies that helped them personally cope with trauma and disability. Put together, these dynamics illustrate how the experience of disability in Ukraine is at once both profoundly individual--as persons are reduced to “bare life,” left to fend for themselves, and their social status is officially defined by their “lack of health”--yet also social and relational, as persons with disabilities seek physical, social, and political empowerment through social ties and advocacy networks. These dynamics also highlight parallels and tensions between individually-focused and socially-focused models of health and illness in the region. These sometimes contradictory ways of understanding and forging the links and divisions between self, society, and the state are ones that are telescoped within the disability community, but they are also being negotiated in many arenas of post-Soviet societies. Amidst market reforms and the concomitant privatization and “de-governmentalization” of many spheres of life, post-Soviet citizens are working out mechanisms for survival, mechanisms that are increasingly personalized and individualized as social safety nets are dismantled and the ailing health care system continues to falter. The experiences of persons with mobility disabilities, and especially those living with traumatic spinal cord injuries, provide an especially vivid window onto these processes.

## **Socialized Subjects and Individual Survivors: The Contradictions of Living Disability in Conditions of Postsocialist Transition**

The Soviet state employed a medical or individual model of disability, one that located disability--a “tragedy”--within the individual (Oliver 1990). The Soviet model has also been called a “functional” model of disability, since the Soviet state focused on the medico-technical aspects of disability, even though surgical and other medical interventions for spinal traumas were never up to par in the Soviet Union. Soviet legislation defined disability in terms of “loss of bodily function” and the extent of “defects” (McCagg 1989, Poloziuk 2004). Disability was defined according to a person’s ability to work, reflecting the primacy given to gainful employment in the workers’ state (Kikkas 2001:113; Madison 1989). Through the compensatory policies of the Soviet Union, persons with disabilities (i.e. those deemed unable to work) were guaranteed social protection in an elaborate system of entitlements and benefits, assistance to individuals that would allow them to live more or less comfortably but usually in social seclusion either in private homes or institutions (Dixon and Macarov 1992, Madison 1989).

In recent years, new ways of thinking about disability and disability rights have emerged in Ukraine. Most notable is the prevalence of the “social model” of disability that is popular in Western disability rights movements, whose representatives have actively promoted the social model in Ukraine and other post-Soviet countries. The social model, which is based on a minority group model, defines disability as social oppression, and pinpoints disabling political, social, and economic environments that perpetuate and reinforce dependency (Gignaca and Cottb 1998). Rather than individualizing disability as a personal tragedy, proponents of the social model draw attention to the “obstacles imposed on disabled people which limit their opportunities to participate in society” (Barnes, Mercer, and Shakespeare 1999:30). These “disabling barriers” may include terminology and classification of disability, as well as a “wide

range of social and material factors and conditions, such as family circumstances, income and financial support, education, employment, housing, transport and the build environment and more besides” (ibid., p. 31).

In independent Ukraine, the social model has been very influential for disability rights activists as they seek to redefine the rights of the disabled. The following formulation by lawyer and disability rights activist Oleg Poloziuk (2005) is representative of how the social model is conceptualized and used by many activists in Ukraine:

Social adaptation, the prevention of maladaptation, and the rehabilitation of the disabled—these are problems of society, and not the individual disabled person, who does not correspond to the ‘norm.’ Here, rehabilitation translates as ‘returning lost functions,’ ‘compensating for lost possibilities,’ and ‘a return to an active life.’ Rehabilitation thus becomes a truly positive outcome: an expansion of adaptive possibilities of a socialized subject, the ability to adjust to new conditions, and to direct one’s own life.

This focus on the “socialized subject” has been taken up in activist circles, and due to the influence of a range of actors, the models of disability and citizenship embodied in Ukrainian legislation are gradually changing. Officially, post-Soviet legislation governing disability moves towards a social or empowerment model of disability that targets sources of oppression such as unequal access to education and work. Major foci of the disability rights movement today include the development of accessible transport and public spaces and buildings, formulation of a comprehensive system of post-trauma rehabilitation, provision of suitable wheelchairs and other equipment, deinstitutionalization of children with disabilities, guaranteeing disabled children and adults equal access to quality education, and equal job opportunities for the disabled. Although many of these provisions are encoded in Ukrainian legislation going back to 1991 (with updates in 2005), due to budget constraints, bureaucratic inertia, political infighting, and a lack of political will, on-the-ground changes are occurring only very slowly.

In many ways this new focus on the “socialized subject” so valued by the international disability rights community and by some Ukrainian rights advocates sits uneasily within the larger picture of the “transition” in Ukraine. As has been noted by other researchers of health and health care in the region (see Rivkin-Fish 2005), market reforms, privatization, and social welfare reform have resulted in an individualization of the population and a focus on individual initiative, resourcefulness, and responsibility as the bases for success (and health maintenance) in the new post-Soviet political economies. Far from removing “disabling barriers” and promoting their “social inclusion,” for many persons with disabilities the transition has meant an overall decline in health services, even fewer employment opportunities as job markets are tightened, and a loss of subsidies and decrease in pensions as the social safety net is dismantled. Removal of architectural barriers moves at a glacial pace if at all, state-funded institutions for education of the disabled have many problems and are widely perceived by potential clients as “Potemkin” institutions (“fronts,” or “just for show”), and serious mechanisms to improve employment prospects for the disabled have not been developed.

In 1992, the Ministry of Health approved the “Provision on the individual program of rehabilitation and adaptation of the invalid (IPRI),” and the “Method of formulating the individual plan of rehabilitation and adaptation of the invalid.” The IPRI plan represents a significant step towards a state system of rehabilitation that would focus not only on medical and technical problems of the disabled, but would integrate economic and social concerns as well. But a mechanism for funding the IPRI process was not approved until 2003 (the program is to be funded through local branches of the Ukrainian Fund for the Social Protection of Invalids (FSPI)), and the program has still not been implemented (Marunych et al. 2004; Polozniuk 2005).

Civil society and official state efforts to empower persons with disabilities and wean them from state assistance therefore entail a number of contradictions. The disabled are encouraged to pursue “independent living” strategies but are not offered the basic prerequisites for doing so, such as adequate housing; accessible dwellings, public spaces, and transport; and opportunities for gainful employment and economic independence. Practices of “active rehabilitation” are promoted by foreign and local disability rights activists, but rehabilitation medicine remains inadequate and some international advocacy groups actively stifle local innovations in the standard “active rehabilitation” program imported into the country. Given these limitations and contradictions, persons with disabilities must negotiate strategies for survival, well-being, and empowerment. Many of my interviewees feel abandoned by the state as services and entitlements are retracted and recalculated, and their citizenship rights are curtailed. Forced into a game of “Survivor,” the seriously disabled must develop individual strategies to maintain health and exercise health agency. It is difficult to talk about “health agency” in this context of structural violence and lack of adequate medical resources and rehabilitation services. The crucial point here is that although disability rights activists and some government officials espouse a “social model” of disability that is supposed to emphasize the social contexts of disability and remove disabling societal barriers, in the context of contemporary Ukraine this discourse at times serves as a smokescreen while the disabled are cut loose from state assistance and left to fend for themselves.

### **Disability, Medicine, and Ukrainian Body Cultures, Or, Becoming a “Judicious Egoist”**

The disabled population with which I am most familiar--wheelchair users with spinal cord injuries (SCI)--paradoxically suffers simultaneously from an overabundance and lack of

medicalized interventions. As mentioned above, disability in Ukraine and other formerly Soviet states historically has been highly medicalized and the disabled have been subjects of a wide range of state medical interventions and medical surveillance. This includes that of the Medico-Social Expert Commission (MSEC) (called the Treatment-Labor Expert Commission in the Soviet Union, and renamed after Ukrainian independence to reflect the new state's supposed focus on issues of social rehabilitation over questions of the labor-readiness of the disabled). The MSEC is the body that assigns individuals disability status, a status that requires citizens to undergo yearly medical evaluations for reapproval. In the Soviet Union, most attempts to "rehabilitate" the spinally-injured were surgical in nature, and this trend continues today. Soviet orthopedists and neurologists commonly refused to reveal to SCI patients that they would never walk again, and repeat surgeries were often employed to sustain patients' hopes. For example, Dmitrii, one of my key informants, endured more than 20 surgeries on his legs; his surgeon finally told him (while slightly drunk) that he had known Dmitrii would never walk--he just performed the surgeries in order to earn some money.

Despite the historically medicalized nature of disability and SCI in particular, today most persons with serious mobility disabilities nevertheless suffer from a lack of medical services, rather than "too much medicine." The Soviet-era practice of providing the mobility disabled with periodic "health trips" to sanatoria is still in place, and two sanatoria in Saki and Slavinsk are designated specifically for this population. At Saki and Slavinsk individuals can receive water and mud treatments, massage, and a range of other therapies, but many of my acquaintances decline these trips because of what they call "the atmosphere of degradation and drunkenness." Widespread ignorance about SCI means that trauma victims are often improperly handled immediately post-trauma (the neck and spine are not immobilized, for example), and

outcomes are thus compromised. Spinal cord injuries usually require initial surgical intervention, and early surgery leads to better outcomes. One legacy of the Soviet system of medicine is that care facilities are very specialized and sparsely scattered throughout the former Soviet Union, which limits access for populations living out of range. The most respected hospitals and specialists in Ukraine offering surgery and treatment for SCI patients are in Kyiv, and some offer services only to registered residents of Kyiv (the *propiska* system is still in force).

This phenomenon of regional specialization continues to affect persons with SCI after the initial trauma and treatment. For example, the only hospital with a known history of treating pressure sores (a common problem for persons with SCI) and ensuing life-threatening complications (often through extensive amputations) is located in the eastern city of Donetsk. The conditions there are quite dire. When I visited the hospital in summer 2005 there was no running water, and the facility experienced frequent power outages, which disrupted surgeries. Unsanitary conditions in hospital wards--even in respected hospitals in the capital city--can make them dangerous sources of possible infection for persons with SCI, rather than sites of treatment and healing. During fall 2006 one friend with SCI who sought treatment in Kyiv for a severe leg burn was turned away by surgeons who feared his condition would become worse if he were exposed to the dangerous micro-organisms they knew were lurking in the hospital. To avoid a nosocomical infection, he was forced to self-treat this serious injury.



*The hospital at Donetsk*

Even when adequate medical facilities and interventions are theoretically available, they are often cost-prohibitive. As anyone familiar with health care in the postsocialist states knows, although the Soviet system of socialized, free medicine is still in place in many areas, truly “free” medicine is a thing of the past. Access to any form of medical care increasingly requires money, and increasingly more of it. This is equally the case for wheelchair users--designated as “Group I Invalids,” or those having the highest disability status--who now (contrary to the law) must pay for their own medicines and medical care, or seek a “sponsor.” Private short-term residential “rehabilitation centers” offering a range of therapy options to persons with SCI have opened across the country--especially in Kyiv--but the high costs involved limit access for most.

Efforts to modernize and reform Ukrainian health care services for the mobility disabled are just getting underway, and reforms are very sluggish. Physical rehabilitation therapy as understood in the West has only recently planted its roots in Ukraine via university exchanges between several higher learning institutions in Lviv and Canada, and Ukraine’s first



*Oleg at a private rehab facility in Kyiv where he was employed*

rehabilitation therapists were graduated from Lviv Polytechnic just a few years ago. Integrating these specialists into the existing Ukrainian health care system has thus far proven very difficult.

These realities raise another important contradiction vis-à-vis the new social model of disability: the dramatic need to improve medical and rehabilitative care for the disabled in Ukraine sits uneasily with the social model, which promotes the demedicalization of disability. While the social model seeks to “socialize” disability by focusing on social contexts rather than discrete disabled bodies and medico-technical interventions, the stark lack of adequate medical options in Ukraine is too acute to accommodate the de-emphasis of physical and medical aspects of disability called for in the social model.

Furthermore, this lack of appropriate medicine actually has an individualizing effect for disabled persons such as those with SCI. Given the poor state of health care available to them, persons with SCI often narrate their “medical adventures” as an epic quest to constantly outwit, overcome, supplement, and survive the official medical options. For this population, controlling well-being means cultivating and refining an intimate knowledge of one’s body to maintain

optimal health and facilitate early detection of problems such as pressure sores and infections of the urinary tract, bladder, kidneys, and bones. This involves constant self-surveillance, self-regulation, and the ability to “read oneself.” My acquaintances with SCI are engaged in a perpetual balancing act between trying to live an active and fulfilling life in a wheelchair and preempting risks to their health and well-being. Many have developed personalized training and exercise regimes that they follow religiously in order to cultivate and maintain good health and physical flexibility and mobility. The need for vigilance and self-surveillance is universal to persons with SCI all over the world, but the need for this highly personalized body culture (Brownell 1995) of “reading oneself” is made more acute by the absence of reliable medical treatments in post-Soviet Ukraine.

I know some persons with SCI in Ukraine who devote 4-6 hours per day to their personal health regimen. Anton, a man in his late forties from Kyiv who received a gunshot wound to the spine nearly 20 years ago, runs on arm crutches for several hours each morning, followed by a lengthy session of weight training in a gym he set up in his apartment. He maintains a strict sleep routine--to bed at 9pm and up by 5am for running. Oleg, a wheelchair user in his late thirties, spends several hours each day doing a series of upper body exercises, and strolls with his wife outside for at least two hours every evening. These men both remarked to me that their regimens sometimes interfere with their friendships and social and work commitments. Having made personal health a top priority, they cannot keep flexible schedules or be as available for their friends as they would like. Indeed, one acquaintance, Pasha, also a wheelchair user in his late thirties, wistfully remarked during one interview that in order to maintain an adequate exercise regime and improve physical well-being after a spinal injury, “one must be a judicious egoist” (Rus. *razumnyi egoist*). Pasha, who lives with his aging parents in a village in Kharkiv

oblast', says that the obligation to help his family with chores such as cooking and light farm work prevent him from becoming a "judicious egoist" who is able to spend more time on self-care. He therefore looks forward to yearly or biyearly stays in a semi-private rehabilitation facility in Kyiv, a sort of working "health vacation" he is able to secure through his connections with disability rights activists in Kyiv and sponsors who pay for his stay. It is only in the atmosphere of this center that Pasha is able to single-mindedly devote himself to a personal exercise regime and rehabilitation therapy, if only for a few weeks each year.

Of course, for some persons with SCI the "luxury" of maintaining a strict personal health regime, or indeed, receiving any physical therapy at all, depends on a range of factors. One's family situation is one of them. Two women in my study, both in their forties, had similar injuries (they were tetraplegics) but exhibit quite different health outcomes. Olga, who lives in Kyiv and has the support of her husband, teenage daughters, and elderly parents, visits private rehabilitation facilities from time to time, goes swimming twice per week (accompanied by her father), and receives physical therapy at home. Maria, on the other hand, is an impoverished single mother of four who lives an hour from Kyiv and has less access to that city's resources.



*Olga swims as her father looks on*

With no family support, and with four children to raise, Maria does not receive any rehabilitation therapy, and her physical condition is noticeably worse than Olga's. Her main social support comes from volunteers from a nearby Baptist church.

These examples show how, in many ways, the experience of serious disability in states such as Ukraine is a profoundly individualized one. Without adequate resources for health care and rehabilitation, persons are obligated to cultivate their own deeply personal body cultures. These time-consuming health regimes sometimes prevent the fulfillment of social obligations, and may be interpreted by friends and family members as "egotistical." The experience of physical disability as a highly personal, individual, and lonely phenomenon also has historical roots. Physical difference was much stigmatized in the Soviet Union, and the visibly disabled were largely confined to their private homes or institutions by a regime that actively sought to keep disabled individuals out of sight and out of mind. Disabled persons possessed few opportunities to develop social networks with one another. For example, between the age of 9 and 21, Oleg left his home only a few times a year, and that usually to seek medical care. Similarly, a woman in her mid-fifties, Svitlana, who had polio as a child and walks with a cane, told me that until she was a teenager she did not realize that there were other "invalids" in the world, because "I never saw anyone like me on the street."

At the same time, in contemporary Ukraine the quest for well-being among individuals with SCI necessarily involves the active utilization of social networks as persons seek out health advice, information, and resources. Non-governmental organizations (NGOs) dealing with issues of disability and health play a crucial role as sites for networking, information-sharing, and the dissemination of medicines, medical materials and equipment, and informational pamphlets on health issues. And as persons with disabilities seek physical empowerment

through advocacy networks (which may lead them to pursue avenues for social and political empowerment as they take up activist discourses), they are often compelled to negotiate new models of health and disability that have been introduced to Ukraine by disability rights activists from European and American countries. My research has shown that, although these empowerment strategies are presented to disabled persons in Ukraine in terms of the social model of disability, with its emphasis on social contexts and disabling social environments, they somewhat ironically encourage persons with SCI to develop individual solutions to the “social” problems of discrimination and marginalization. Although this is by no means a seamless process, and the importance of social networking and social support among disabled persons must also be emphasized and explored, I would argue that these newly popular ways of framing disability rights may actually amplify the processes of individualization and privatization that inform new citizenship regimes in the postsocialist region.

### **NGOs and Strategies for Health**

Given the compromised state of the medical know-how and care available to persons with SCI in Ukraine, they frequently are compelled to seek medical advice and resources outside the official medical system. To learn more about preventative measures or to address specific health concerns, some turn to the scant printed materials that are available. At present the most important printed resource in Russia, Ukraine, and other post-Soviet countries is a book by Russian scientist and journalist Lev Indolev, who received an SCI 30 years ago. In addition to chapters on legal issues, traveling, remodeling living spaces, and others, Indolev’s volume, *To Live in a Wheelchair (Zhit’ v kolisake)* (2001), presents a wealth of information pertaining to prevention and treatment. The book is written in an accessible and lighthearted manner, and

health-related topics include everything from preventing pressure sores to dealing with spasm and problems with thermoregulation, blood pressure, breathing, infections, digestive problems, chronic pain, and others. The print run of To Live in a Wheelchair was very small, however--just 5,000 copies for all of the former Soviet Union--and all copies were distributed long ago. During an interview at his home in Moscow during fall 2006, Indolev told me that he often receives accolades from persons with SCI who say they “ran across his book too late” and wish they had known about it immediately post-trauma when it would have been most useful.

Ukrainian persons with SCI also have access to printed material distributed by a disability rights NGO in Kyiv called “ARIS,” or Active Rehabilitation of Spinally-Injured Persons, a group with whom I have been collaborating since 1999. Most of this material was translated from English-language SCI health literature that I have tracked down for ARIS over the years. Additionally, we are in the process of publishing a Ukrainian-language version of a handbook for persons with SCI published by the New Zealand Spinal Trust, called Back on Track (Verkaaik 2004). ARIS also maintains an extensive internet site that offers information on SCI, medicine, and health.

In addition to providing health-related information to persons with SCI in print form and via internet, ARIS has also initiated a system of providing “first contact people” to visit “fresh” SCI patients in hospital soon after trauma. The “first contact” system was introduced to Ukraine by the Swedish SCI advocacy group Rekryteringsgruppen for Active Rehabilitation (RG), whose representatives began visiting Ukraine, Belarus, and Poland in the 1990s. The RG philosophy of active rehabilitation is embedded in the idea of the “exemplary model;” those people who have already experienced SCI are seen as the best sources of information and support to persons with recent SCI.<sup>3</sup> Inspired by the Swedish model, ARIS began actively recruiting experienced

wheelchair users to visit new trauma victims in hospital. As I learned while acting as a translator between Ukrainian disability rights activists and RG representatives at a meeting in Kyiv in 2002, the Swedes actively discouraged “first contact people” from offering medical advice to SCI patients or intervening in any way in the patient’s medical care. However, the Ukrainian first contact people indicated that oftentimes their visits centered precisely on medical questions and advice, a focus they saw as an absolute necessity in the Ukrainian health care context.

Similarly, the director of ARIS, a woman named Nina in her early sixties whose son received an SCI nearly 20 years ago, was a frequent visitor to Kyiv’s SCI wards, where she acted as a patient advocate, sometimes stepped in to radically change the direction of medical interventions, or simply sought to “force the medical personnel to actually do their jobs.” She educated family members about how to care for their loved ones with SCI at hospital and at home, and asserted that she knew more about the health and medical needs of persons with SCI than any doctor or nurse. Through ARIS, Nina provided persons with SCI with crucial assistance by paying for medical bills, providing medicines, and acquiring wheelchairs and orthopedic mattresses.

Like ARIS, many disability-focused NGOs in Ukraine are sources of health information, medical advice, and concrete assistance in the form of humanitarian aid and sponsorship. They are also sites through which international advocacy groups such as RG have sought to provide material, informational, and moral support to disabled persons in post-Soviet states. In addition to the system of “first contact people,” another focus of RG’s efforts in Sweden and in Eastern Europe has been to conduct “active rehabilitation camps” where wheelchair users are introduced to a strict philosophy of individual independence and receive training in wheelchair sports and overcoming architectural barriers (navigating steps, doorjamb,

and curbs in a wheelchair, for example) and how to independently carry out activities of daily living (dressing, eating, transferring from bed or chair to wheelchair). Instructors are wheelchair users themselves who are certified to conduct the training camps according to the specific parameters set by RG.



***Wheelchair users demonstrate overcoming barriers, techniques many of them learned at RG-sponsored active rehabilitation camps***

Indeed, according to my conversations with some Ukrainian activists, RG eschews any modification of the program they introduced, and have even hired several people in Ukraine to ensure that all camps purporting to represent the RG active rehabilitation techniques adhere to strict requirements. This concerned some local activists, who noted that such standards prevented modifications that might allow Ukrainians to adapt the trainings better to the specific needs of Ukrainian SCIs. They also pointed out that, in order to conduct the camps in the conditions required by the Swedes, NGOs must possess considerable resources; the Swedes no longer provide financing for the camps carried out in Ukraine, only technical advice. This means that only relatively resource-rich groups can hold the camps, where groups are small and participants are hand-picked. This limits the number of persons with SCI in Ukraine who are

able to take advantage of the valuable information and techniques presented at the camps, which are held infrequently due to economic constraints and lack of government support. It is estimated that at least 2,600 persons receive SCIs in Ukraine each year (Polozziuk 2005), and the active rehabilitation camps serve no more than several hundred wheelchair users annually.

These are not the only disconnects. The philosophy of “active rehabilitation” as Ukrainian activists have adopted it promotes personal independence (in a very physical sense) of the disabled in a state that has been perceived to be overly “paternalistic” owing to socialist legacies. It addresses physical independence and training but does little to address the structural violence that prevents most persons with serious disabilities from getting an education, securing employment, and becoming economically self-sufficient, for example. Interventions like this one--while undoubtedly beneficial to individual wheelchair users--are further evidence of the individualizing processes that increasingly define disability experience in postsocialism.

These issues of the “translatability” of empowerment strategies across national borders may not be directly relevant to discussions of health behaviors and health agency, but I have considered them here because such interactions provide further examples of the contradictory frameworks available to persons with SCI for understanding and living disability in contemporary Ukraine. Additionally, such discussions allow us to consider the potential of civil society initiatives such as advocacy NGOs to assist people in their struggles to stay healthy. They also draw our attention to the problems that may limit the effectiveness of NGOs to advance agendas for better health for vulnerable populations.

For more than a decade now, many NGOs have focused their efforts on issues of accessibility, destigmatization, job training and job placement, pension reform, and other social and economic aspects of disability experience. Little work has been done, however, in the area

of health and health care reform. This is true of most local, city-based NGOs as well as the two large coalitions of disability advocacy organizations, the National Assembly of Invalids of Ukraine, and the Confederation of Civic Organizations of Invalids of Ukraine. The only significant health care reform agendas to emerge from the disability rights movement have been centered in the western Ukrainian city of L'viv; these efforts focus on developing a system of Western-style rehabilitation therapy to serve disabled populations. As mentioned earlier, integrating this new area of treatment into the existing Ukrainian health care system has thus far been very difficult, and many newly trained rehabilitation therapists have found work only in private clinics or rehabilitation centers.

In terms of health empowerment, what is needed most is a comprehensive overhaul of the medical system, especially those areas pertaining to spinal cord injury and rehabilitation therapy, as well as the development of a feasible system of financing (i.e. adequate state financing, or viable insurance schemes). Disability-focused NGOs could play a major role in the reform process. It seems, however, that the popularity of the new “social model” of disability--which is favored by many activist groups, government officials, and international donors and granting agencies--has distracted attention from issues of health and medicine and the medical crises many persons with serious disabilities face on a regular basis. History also plays a role: deemphasizing the medico-technical aspects of disability is seen as a modernizing and correcting move in the wake of a socialist regime that treated disability primarily as a medical issue and personal tragedy. The irony is that while the public face of disability is a critique of disabling social environments, few real steps are being taken to address these disabling social contexts. The result is the privatization of these social problems as disabled persons are encouraged to become “self-reliant” and develop strategies for independent living, but without necessary

investments from the state. As they sit down to watch the popular TV reality show aired from the United States, few in Ukraine probably realize that a more authentic game of “Survivor for Wheelchair Users” is playing out right in their own neighborhoods and communities.

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<sup>1</sup> I have been conducting ethnographic research on disability politics and disability experience in Ukraine since 2002. This work stems from my interest in health issues in the post-Soviet region (especially Chernobyl) and previous research on women's roles in NGOs and civil society in Ukraine (Phillips 2008). My disability-related research has focused in issues of mobility disability and the experiences of wheelchair users in particular. In addition to inquiries into questions of health care, health agency, and health behaviors, I have focused on areas such as historical contexts of disability policy and the Soviet disability rights movement; disability and NGO advocacy; disability, personhood, and citizenship; disability, masculinity, and sexuality; and disability in the life course.

<sup>2</sup> Except for my collaborator Oleg Poloziuk, and Nina Syedina, the director of the NGO ARIS, all names are pseudonyms.

<sup>3</sup> See RG's English homepage, <http://www.rekryteringsgruppen.se/php/english.php> (accessed March 9, 2007).