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Abstract

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Keywords

disability, disability rights, human rights, discrimination, public policy. Americans with Disabilities Act, ADA

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Disability and Citizenship in Post-Soviet Ukraine: An Anthropological Critique

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Introduction

In this paper I examine Ukraine's burgeoning disability rights movement through the lens of citizenship to illustrate the complex processes through which certain categories of people (here, persons with disabilities) are transforming themselves—and being transformed—into particular types of citizens in a changing welfare state. I take an institutional and relational approach to understanding “citizenship,” a tack that has recently been suggested by scholars such as Margaret Somers (1994, 1995) and Allison Carey (2003), to suggest approaches to understanding citizen-state relations that shed light on the complex intersections of agency, power, and personhood that post-socialist social justice struggles entail.

The paper is based on ethnographic research I have conducted since 2002 (most recently during spring/summer 2005) throughout Ukraine. This research centers primarily on mobility disability (i.e. persons in wheelchairs and others with limited mobility). As a relatively visible group with (seemingly) definable “needs” (i.e. lifts, accessible transport, specially designed living spaces, access to places of employment), during the last decade persons with mobility impairments have been primary targets of intervention by government agencies, medical and rehabilitation professionals, human rights advocates, and others. Persons and groups with mobility disabilities thus form a locus where diverse disability discourses, models, and practices intersect (Frank 2000, Hockenberry 1995, Kohrman 2005, Langan 2001). While societies for the deaf and blind were established and active in the Soviet Union, mobility disability has come under public scrutiny only recently, and mobility impaired persons are at the forefront of the disability rights move-

ment in Ukraine today. In step with this research focus, most respondents involved in this study are persons who have experienced traumatic spinal cord injuries (primary causes included diving accidents, falls from heights, automobile accidents, and gunshot wounds). Other participants included persons with cerebral palsy, muscular dystrophy, multiple sclerosis, spinal tumors, Bekhterev's disease (a chronic and progressive autoimmune disease resulting in immobility of the spine), under-developed limbs, and those who had contracted childhood polio.¹

Theorizing Citizenship

In recent years there has been a revival in studies of "citizenship," especially among scholars interested in the social justice struggles of disempowered groups. These inquiries have built on the work of T.H. Marshall, whose seminal volume *Citizenship and Social Class* (1992, originally published in 1950) moved notions of citizenship beyond the narrow scope of individual liberties to include considerations of economic and social rights. Recently, scholars of citizenship have focused on a range of marginalized groups to challenge the liberal abstract notion of "rights:" the poor (Lister 1990), ethnic minorities (Smith 1989), and women (Jones 1990), for example. A small but growing body of critical literature has begun to take up questions of citizenship in relation to disability in a variety of societies: (Barton 1993, Beckett 2005, Bérubé 2003, Carey 2003, Danermark and Gellerstedt 2004, Das and Addlakaha 2002, Jayasooria 1999, Kjellberg 2002). This new work on citizenship and disability builds on Marshall's framework to treat citizenship as a fluid concept that is dependent on a range of institutional, societal, and personal variables. Citizenship is thus examined as a "contested truth" whose meaning is historically and politically constructed (Somers 1994:65).

In recent years several scholars of disability have explored how trajectories of citizenship are contingent and fluid (Bérubé 2003). A relational approach has also been articulated by those who emphasize the links between the self and society that struggles for citizenship inevitably entail. Citing Quicke (1992), Barton (1993:241) notes that, "The question of citizenship raises the issue of the nature and relationship between the subjective experience of self and self-development and the public aspect of self as an agent of community relations." Drawing on similar themes, Kjellberg (2002) has explored how citizenship for persons with mental disabilities in Sweden entails living and interpreting one's own personal environment (home, work, family), and the general environment (services, structures, social networks, attitudes). In this article, I employ this kind of relational approach to explore debates about disability and citizenship in post-Soviet Ukraine.

1. Over the last decade, persons with these disorders have come to be identified (and to self-identify) with the general category of *koliasochnyki* (wheelchair users) or *spinal'niki* (persons with spinal and spinal cord injuries or diseases). Amputees, and people with tuberculosis of the spine, spinal meningitis, hernias, spinal hemorrhaging, and rheumatoid arthritis are often also included (Indolev 2001:11-25).

In Ukraine, stakeholders in the disability rights movement draw on a range of discourses to make certain claims to full citizenship for the disabled and to forward political and social agendas. Several of these understandings have developed out of interventions that international disability rights groups (especially from Scandinavia and the United States and Canada) have introduced in Ukraine, and the interactions and discussions between local activists and international partners that these interventions have produced. Other discourses have developed more out of the historical, economic, and social contexts unique to post-Soviet societies. Each of these discourses defines the problem of discrimination of the disabled differently, and places emphasis on a certain set of citizenship rights. By excavating these discourses, I believe, and especially by tracking how they are utilized by various groups and persons, we can gain insight into the salient and competing ideologies that drive the contemporary disability rights movement. We can also better understand the complicated structures of power at play at the level of formal, but especially informal, institutions. I begin with a brief history of disability politics in the Soviet Union, and then introduce some of the narratives that shape citizenship debates among disability rights activists, especially those centering on access (universal design), economics, and employment. I draw on interviews with a range of people with disabilities to illustrate the relational character that concepts of “citizenship” take on in the fraught context of post-socialist economic and social transformations.

A Short History of Disability in Soviet and Post-Soviet Ukraine

In the Soviet Union, through a politics of exclusion and social distancing, persons with visible disabilities were stigmatized, isolated in their homes, hidden from the public, and thus made seemingly invisible (Dunn and Dunn 1989). As Ethel Dunn has noted, in the Soviet Union, “talking about the disabled [“invalids,” in local usage] or showing pictures of them was as taboo as talking about train wrecks or natural disasters” (2000:153). When attempts were made to rehabilitate people with disabilities, rehabilitation was primarily medical and vocational in nature, designed to make technical adjustments to the “defective” individual (Stiker 1982). People with disabilities in the Soviet Union (as in much of the world) were thus the objects of two intertwined and mutually reinforcing types of injustice: cultural/symbolic and socioeconomic. The former, notes Nancy Fraser (1995:71) is rooted in “social patterns of representation, interpretation, and communication,” and can include processes of non-recognition (being made invisible) and disrespect (being routinely maligned or negatively stereotyped). The latter is rooted in political and economic systems, and may include processes of economic marginalization and deprivation (ibid., pp. 71-72). In the Soviet Union, it could be argued, socioeconomic injustices were rooted in cultural and symbolic injustices, which excluded the disabled from most educational and work opportunities and reinforced dependency on a paternalistic state.

In the Soviet Union, legislation defined disability in terms of “loss of bodily function” and the extent of “defects” (McCagg 1989, Polozziuk 2004). Disability was defined according to a person’s ability to work (Kikkas 2001:113), reflecting the primacy given to

gainful employment in the workers' state (Madison 1989). The category "disabled" was employed primarily to distinguish those who *could* not work from those who *would* not work (Stone 1984). Dunn and Dunn (1989:201) have noted that Soviet policy drew "a sharp distinction between the disabled worker—the person who has a certain job seniority and standing in a work collective—and the person who cannot claim this status." They described the "official Soviet view" as one that "human dignity is preserved and maintained by the ability to be useful" (ibid.). Through the compensatory policies of the Soviet ideology, 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).² All of these approaches indexed a medical or individual model of disability, which located disability—a "tragedy"—within the individual (Oliver 1990).

Official statistics in Ukraine indicate that roughly 2.6 million persons (5.3% of the population) in Ukraine are considered disabled (Derzhavna Dopovid 2002), but this statistic includes all types and levels of disability, including disability associated with the 1986 Chernobyl nuclear disaster.³ As Oleg Polozhiuk (2005) has stated, due to a lack of detailed statistical information the mobility disabled in Ukraine constitute an "unknown" segment of the population. Some recent studies in Ukraine report around 32,000 people with spinal and spinal cord injuries, and note that most injured persons are between 20 and 45 years old (Polozhiuk 2005). According to the available statistical analyses provided by neurosurgical departments of medical institutions from 1994 to 2001, an average of 2,066 persons receive spinal cord injuries in Ukraine annually, and the incidence increases by 91 injuries each year. There are no statistics available to quantify the number of disabled children and adults who are wheelchair users as a result of disease. We know the numbers are significant since this population is provided with between 20,000 and 30,000 wheelchairs annually (ibid.).⁴ It is estimated by some activists that around 5,000 wheelchair users live in Kyiv, the capital city.

Interviews with persons with disabilities in Ukraine and a review of the available literature indicate that quality of life for most mobility impaired people has improved con-

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2. Ethel Dunn (2000:153) cites a report from 1993 indicating that 30 percent of persons with disabilities in Russia never left their homes. For a shocking account of life in a Russian institution for disabled children, see Ruben Gonzalez-Galego's prize winning semi-autobiographical book, *White on Black (Beloie na chernom)* (2004).
 3. In Ukraine, disability status is assigned by the Medico-Social Expert Committee (MSEC), which assesses the cause and level of disability. Persons with disabilities are categorized into three groups (I, II, or III), depending on the severity of the disability and the individual's ability to work and care for himself or herself. For a critical account of the politics of disability classification, especially in relation to Chernobyl, see Petryna (2002).
 4. This lack of statistics also characterizes the Russian case. Through compiling the scant available data and carrying out elaborate guesswork, journalist and activist Lev Indolev (2001:7-9) estimates around 10,000 persons with spinal cord injuries living in Russia, and a total of 250,000-300,000 children and adults who use wheelchairs.

siderably since *perestroika* and the collapse of the Soviet Union. Some improvements in infrastructure and life possibilities, however, are accompanied by a range of injustices that compel many people with disabilities in Ukraine to feel as if they live in a “parallel world” where their rights to full citizenship in the new Ukrainian state are circumscribed (Phillips 2002). This parallel world is constructed at the intersection of public discourse and institutional infrastructure. The “unknown population” of the disabled described by Oleg Polozhiuk (2005) is made further invisible by a hegemonic discourse that refuses to acknowledge the presence of the disabled on the political stage. My informants described how difficult it is to demand and exercise one’s formal citizenship rights when government buildings (and indeed, most buildings in the country, whether residential, business, or government) are not handicapped accessible. A recent investigation into accessibility notes that the state—as represented by the State Building Committee (*Derzhbud*)—is actually the worst offender of laws guaranteeing the “full access of invalids to social infrastructure,” as encoded in the Law on the Basis of Social Protection for Invalids (Section 5 and Article 27) (Zhelezniak and Mashtaliarchuk 2005). Not only do disabled citizens face physical barriers (staircases, public transport, and barrier-ridden public spaces); they also confront discursive barriers that position the disabled as either pitiful unfortunates or undeserving “spongers,” or both. Many of my informants described at length the stigma they face as people with a spoiled identity (Goffman 1963) who look “different” and, as one young woman put it, thus “spoil the view for other people.”

Members of the disability rights movement in Ukraine today, especially those groups focused on mobility disability, endeavor to break through the institutional and discursive barriers that marginalize them in Ukrainian society. Major foci of the movement include the improvement of medical services, the 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, equal job opportunities for the disabled, and the introduction of accessible transport and public spaces and buildings. Most of these mirror the concerns of Disabled People’s International (DPI), which has recognized and codified the following basic human rights of the disabled as essential for the full societal participation of people with disabilities: education, employment, economic security, services, independence, culture and recreation, influence or political participation, the right to life, and the right to parenthood (Barnes, Mercer, and Shakespeare 1997:97).

With the fall of the Soviet Union and the establishment of disability rights advocacy networks across national borders, activists in Ukraine were introduced to the “social model” of disability that has been developed in Western countries since the mid-1970s. 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). For academics and activists the social model has been generative of a distinction between impairment, defined as “the functional limitation with the individual caused by physical, mental, or sensory impairment” and disability, understood as “the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (Barnes 1991:2).⁵

In Ukraine, the social model has been very influential on the strategies of disability rights activists to redefine the rights of the disabled. The social model is rarely invoked to debate the merits of its theoretical underpinnings (which have been criticized in recent years by some disability studies scholars); rather activists and representatives of the state draw on the social model to formulate new strategies for the rehabilitation of the disabled and in efforts to eradicate disabling barriers that are oppressive to people with disabilities. The following formulation by 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 thanks to the influence of a range of actors, the models of disability and citizenship embodied in Ukrainian legislation are gradually changing. Post-Soviet legislation governing disability, it could be argued, moves towards a social or empowerment model of disability that targets sources of oppression such as unequal access to education and work (Barnes, Mercer, and Shakespeare 1999). On March 3, 1991, in accordance with the Law “On the Basis of Social Protection of Invalids of Ukraine,” the official definition of disability in Ukraine changed from the loss of work capability to a measurement of loss of health (*mira vtraty zdrov’ia*) (Poloziuk 2004, 2005). Article Two of the Law defines an “invalid” as “a person with persistent disorder of bodily function, caused by illness, the result of a trauma, or birth defects, which result in limited activities (zhyttediial’nost’), and in the necessity for social assistance and protection.”⁶

5. See Tregaskis (2002) for a summary of the social model of disability and its many permutations, and for details on critiques that have been leveled at the model(s).

6. This and other legislation affecting the disabled is archived at <http://naiu.org.ua/html/>.

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. Unfortunately, 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; Polozhiuk 2005). On June 1, 2005, President Yushchenko signed a Decree (No. 900) “On Immediate Measures for Creating Favorable Conditions of Living for Persons with Limited Physical Capabilities” that outlines step to be taken to provide people with disabilities equal access to “objects of social infrastructure.” The Decree highlights the need for handicapped accessible public transport (including train cars and school buses), parking spaces, government buildings, dormitories, underground walkways, and so on. It challenges the State Committee of Ukraine on Building and Architecture and the State Committee on Housing to begin steps for adopting European Union standards for guaranteeing persons with disabilities equal access to public spaces.⁷

Changes in laws, proclamations, and Presidential decrees that seek to extend full citizenship rights to persons with disabilities are only the first step. As Oleg Polozhiuk (2005) points out, self-realization involves not so much the *potential* possibilities offered to a disabled person (formal rights), but those that he or she is actually able to use. New legislation is poorly enforced if at all, and persons with disabilities continue to face stigma and discrimination in their daily lives (Makharynska 2002). Valery Sushkevych (personal communication), People’s Deputy, and head of the Paralympic Committee and the National Assembly of Invalids of Ukraine, estimates that existing laws on disability are only financed at 12-18 percent. Many people with disabilities criticize the Ukrainian state for perpetuating (in reality, if not on paper) the Soviet-era medical/functional model from the USSR, with its narrow focus on immediate post-trauma care, the provision of a (small) pension to disabled individuals, and a few trips to specialized sanatoria (institutions that are falling into a decrepit state) during one’s lifetime. In short, many see the state’s relationship to their problems as changing little, and primarily “on paper.”

Although the social model of disability is valued by many in the movement, how the “social model” is understood, what notions of “citizenship” it is productive of, and how these understandings actually translate into policy, activist initiatives, and the everyday life strategies of people with disabilities, are complex questions that need to be researched. As I suggested above, one method to assess the ways in which people with disabilities see their lives changing after socialism—and to understand how these perceptions conflict or square with hegemonic discourses on “the disabled”—is to focus on ideas

7. The Decree may be found at <http://www.invasport.iatp.org.ua/movedis/036>.

of citizenship. Actors inside and outside the disability rights community may imagine “proper citizenship rights” for the disabled very differently. In my research, surveys, focus groups, and in-depth interviews with a range of actors—various members of the disability community, NGO directors, students, government officials, rehabilitation professionals, social workers, and others—produced various responses to the question of how persons with disabilities might be best positioned (and position themselves) to enjoy “full citizenship rights.” In considering these different visions of the politics of disablement, and varying concepts about what “citizenship” entails, I hope to highlight the relational quality of “citizenship,” and also to get at the structures of power that govern the lives of people with disabilities in Ukraine. In later discussions I will explore further the fraught citizen-state relationships that motivate these discussions, to argue that disability rights activists become both subjects and agents as they stake claims to full citizenship in the new Ukrainian state.

Visions of Citizenship

In this section, I draw on ethnographic data that explores some of the rights that a range of people with disabilities in Ukraine perceive as crucial to guaranteeing them full citizenship in the changing Ukrainian state. The narratives and vignettes presented here are indicative of many of the salient discourses on the body, sociality, personhood, the state, and the market that run through debates on citizenship and disability. Here I want to show how the everyday concerns, challenges, and successes of disabled persons—and, especially, the ways in which they talk about these concerns, challenges, and successes—reflect and reproduce a range of narratives linking people to institutions of the state. The situations and conversations I ponder here reflect the complex real-life effects of “democratizing” processes taken up by institutions and agents of the state, and the contradictory ways in which people with disabilities are positioned (and position themselves) through such processes. Issues to be discussed here include accessible architecture, economic entitlements (the politics of redistribution), rights to education, and equal access to employment.

Bezbar’ernost’ (Lack of Barriers): Issues of Access and Disability

Since the late 1990s, the creation of a built environment that is accessible to all citizens has been a focus of the Ukrainian disability rights movement. As in many industrial countries, disability rights activists in Ukraine perceive equal access to public spaces and buildings as crucial for allowing people with disabilities to secure their proper citizenship rights. As Oleg Polozhiuk (2005) notes, “Putting into practice standards of accessible architecture and universal design is a practical aspect of social protection and will extend access to social infrastructure and transport to persons with special needs.” Projects on accessibility have been initiated and supported by a range of international partners, including the government of the Netherlands (Barmashyna 2000) and the Canadian

Institute for Disability Studies. As noted above, while significant legislative changes have been produced through such initiatives, laws on accessible architecture are poorly enforced. The National Assembly of Invalids of Ukraine recently successfully lobbied the President of Ukraine to issue a Decree (No. 900, 1 June 2005) “On Immediate Measures for Creating Favorable Conditions of Living for Persons with Limited Physical Capabilities” (mentioned above), which outlines steps for addressing widespread accessibility violations. My informants had mixed reactions to the Decree; many were skeptical that real changes will be forthcoming, yet they were encouraged that representatives of the state are willing to review the problem.

Bezbar’ernost’ is an everyday concern of all persons with mobility disabilities, and its lack produces a serious constraint on their lives. Barrier-ridden public spaces result in social isolation for many wheelchair users, for example, who find it difficult or impossible to venture beyond their apartments or neighborhoods. Although the Kyiv City Administration provides free transport (though some informants indicated that they are compelled to pay drivers informally for this service) in the form of adapted mini-busses for persons in wheelchairs, users must request the service 24 hours in advance, which rules out impromptu trips. For those physically able to, as one informant puts it, get around the city “*avtorukami*” (using one’s arms to propel one’s own wheelchair), curbs, stairs, and inaccessible modes of transport (trams, busses) can be cause for injury.

Faced with both apathy on the part of the Derzhbud to conform to accessibility laws and with societal ignorance (many of my acquaintances in Ukraine outside disability communities do not know what the word *pandus* (ramp) means), disability rights activists are forced to confront business owners, architects, and builders about access issues themselves. My informants described a range of strategies, ranging from formal requests made of representatives of the state, to everyday acts of resistance. A few examples will suffice here to illustrate the myriad ways in which people with disabilities in Ukraine are compelled to seek out the fulfillment of their rights to access “objects of social infrastructure,” as encoded in existing laws.

Oleg Polozhuk, a lawyer and disability rights activist (himself disabled), is well placed to address issues of accessibility, and he is a resource for information on disability law for other disabled persons. He takes it upon himself to educate builders about the 1991 Law on the Basis of Social Protection of Invalids, which includes regulations on accessible architecture. During the recent construction and “*remont*” (repairs) of several buildings in their neighborhood in Kyiv, Oleg and a neighbor—who also uses a wheelchair—monitored the building projects (sometimes spending all day at the building sites) and succeeded in pressuring builders to make curb cuts and install ramps. Oleg often goes through legal channels to lobby for accessibility, and he has worked out a system of submitting requests (*zaiavky*) to state officials requesting that certain buildings and spaces be made accessible in accordance with existing laws. He has a bank of *zaiavky* that he makes available for others who wish to confront the state on issues of accessibility. Oleg notes that these endeavors have met with mixed results. On the one hand, it is theoretic-

cally difficult to refuse such requests, since the law is clearly on the side of the claimant. On the other hand, the representatives of many businesses and institutions feel they have very little to lose by ignoring such requests. In one discussion of these issues Oleg told me: “They have many other problems to worry about, like the tax police and rackets, so the *zaiavky* of a couple of disabled people rank very low on their priorities.” On the other hand, some strategies—such as threatening a lawsuit—have met with some success. Oleg explained that businesspeople are afraid that other discrepancies may come to the surface during a lawsuit, discrepancies that are much more serious than any building code, and therefore will comply with the request to avoid further unpleasantness.

Other informants in my study, such as Edik, a disabled athlete and entrepreneur (his story is related in more detail below), engaged in everyday acts of resistance to protest a lack of accessibility for wheelchair users. Riding around in Edik’s car one day during June 2005 I witnessed several such performances. When Edik drove up to a bookstore in a small town we visited together, he found that a car had blocked the curb cut in front of the store. He parked his car and ascended the curb in his wheelchair, only to make a beeline for the offending car, pound on its hood, and shout, “Whose car is this?” When an onlooker chastized him for “beating up the car,” Edik answered, “There’s a curb cut here. Why block it?” Later in the day when we stopped by a huge new supermarket in Edik’s home city, he parked his car about five meters from the entrance, forcing shoppers to navigate around his car to enter and exit the store. When I looked at him quizzically, Edik explained, “I know the owner of this store, and I told him that until he provides a handicapped parking space, I am going to park right in front of the entrance. I do it every time. Since you’re with us today I parked back a bit—I usually get right up to the door!” Again, faced with flagrant violations of accessibility laws, Edik engaged in a range of everyday strategies to claim his rights.

Although there is broad agreement among people with disabilities in Ukraine about the pressing need for *bezbar’ernost’*, and a consensus that *bezbar’ernost’* will allow disabled persons to exercise their citizenship rights more fully, opinions differ as to how the issue of accessibility should be framed. One NGO leader and disabled athlete, Dmitrii, for example, resists the idea that accessibility campaigns should be waged primarily on the basis of the “needs” of citizens with disabilities. Instead of drawing on a minority group model in which a category of citizens—the disabled—are seen as struggling for denied rights, Dmitrii believes that a model emphasizing universality should be mobilized. He said, “How many wheelchair users are there in Kyiv? Maybe 5,000, tops. But we’ve got 50,000 young mothers with babies in prams. Why shouldn’t ramps be built for them, while taking us into account?” Other informants pointed out that anyone can become disabled, and that most people will experience disability at some point in their lives. Thus, they said, struggles for rights for the disabled should not be framed in terms of the rights of a minority group; rather, broader appeals should be made to notions of universal human rights. As one activist put it, “Every healthy person is a potential invalid.” She believes one effective advocacy strategy is to convince society (especially the

Mayor, the President, and lawmakers) that “legal reforms are undertaken not for the benefit of the disabled—it has already happened to them, they are used to their lot, they’ve adapted. Rather, we are doing this work for the benefit of healthy people, who may one day find themselves disabled and won’t know where to turn.”

This “design for all” approach (which is the dominant policy informing disability policy of the Swedish government, for example (Danermark and Gellerstedt 2004)) indexes a move away from conceptualizing people with disabilities as those with “special needs,” and thus highlighting difference, and towards a human variation approach that recognizes the need to “accommodate the range of physical, perceptual and cognitive equipment that human beings possess” (Asch 2004:14). On the other hand, “design for all” thinking has been criticized for caving into the wishes of the more powerful (the non-disabled), who “will balk at making modifications that include everyone unless dominant members of that society can be perceived to benefit as a by-product of those changes” (ibid.). These examples highlight the varying discourses disability rights activists may take up in their social justice struggles. A minority group model is contrasted with a universal model, and these models construe “citizenship” for the disabled differently. This brief discussion of a key issue in debates over disability and citizenship—*bezbar’ernost*—has highlighted the different strategies activists use to advocate for accessibility issues, and the various discourses they take up in these struggles. These processes are also evident in discussions about the economic empowerment of the disabled.

Disability and Economic Empowerment

Issues of economic entitlements are critical to any discussion of disability politics. As in the Soviet Union, in Ukraine today persons who have received disability status by the Medico-Social Expert Commission (MSEC) are assigned a monthly pension and are entitled to a range of entitlements. Pensions and entitlements vary according to the category (disabled veteran, disabled from birth, disabled on the job, disabled as a result of trauma, and so on), and the group assigned (I, II, or III, depending on person’s perceived level of potential for independence).⁸ The base pension for an “invalid of Group I” is 332 UAH (\$66). This dismal sum puts recipients in an extremely precarious position, especially those who have little material support from family or friends and those whose disability prevents them from generating income through paid work. The current pension system is criticized by clients for a number of perceived shortcomings: pensions are based

8. In the Soviet Union the commission was called the Treatment-Labor Expert Commission, and the name change was to reflect the new state’s focus on issues of social rehabilitation over questions of the labor-readiness of the disabled. At present, disability groupings in Ukraine are categorized as they were in the Soviet Union. Group I includes those considered unable to work and who are deemed to require constant nursing care. Group II includes those who have lost some capability to work but may work in special conditions; members of Group II are not perceived to require constant nursing care. People in Group III are considered the partially disabled who have lost some work capability but may engage in part-time or casual work (Madison 1989:171-2).

on minimum living standards, the system is highly abused and people “faking” disability drain the fund of resources for those who really need them, the pension system creates dependence among citizens who could otherwise be self-sufficient, and so on.

The example of Edik highlights many of the narratives that circulate in debates assessing the extent to which the state should extend economic compensation to the disabled. Edik is well-known in the “*spinal’nik*” community as someone who has managed to become economically prosperous since his injury in the early 1990s. He lives with his wife and daughter in a lovely two-story home in the private sector of a major city, drives an imported car with hand controls, and runs his own small business. In response to my question, “How were you able to do it?” Edik answered that he realized soon after his injury that the state was not going to help him solve his problems. He forged a solution on his own and turned first to sports. Although he did not receive adequate state support in his endeavors, he did enter some international competitions and used prize money to support his family. He combined the prize money with financial support from friends and business profits to build a house and establish economic independence for himself and his family.

In telling his life story and commenting on the contemporary disability rights movement, Edik K. takes up a narrative of personal initiative and innovation. He thinks that the majority of people in Ukraine—and the disabled especially—are too passive; the Soviet system, he says, instilled in them an attitude of dependence that has to be changed. Edik is critical of what he calls the *daval’nitskyi* (“gimme”) idea that he thinks is the basis for most of the disability rights movement: “*Daite invalidu i vse*” (“We disabled need this, and this, and this...”). He believes that the current harsh economic realities in Ukraine call for new, tough measures: “You have to tell some people who request disability that they simply have to look out for themselves.”⁹ Edik is also critical of how disability categories are “ranked” in Ukraine (and in Russia), a holdover from the Soviet military-industrial state. Edik interpreted this “hierarchy” of disability claims as a clear case of the state’s privileging of the needs of some disabled persons (veterans, for example, many of whom are very elderly) over those of others (such as children and victims of trauma, many of whom are relatively young). He found this “ranking” outdated, and blamed it on the legacies of the Soviet military-industrial state. He used the example of state-provided automobiles to further criticize the system: both disabled veterans and trauma victims are guaranteed a heavily-discounted car at the state’s expense. He finds it ludicrous that elderly veterans are first in line for these cars—most are too old to drive them anyway. Because of the long lines (one of my consultants received his car in 2005 after waiting for

9. See Petryna (2002) for nuanced accounts of how the system of disability status in Ukraine is manipulated. The Yushchenko government has announced plans for an overhaul of the pension system, starting with a re-examination of cases of all persons in Ukraine who receive disability benefits. My informants were cynical about this endeavor; they see it as a Herculean task that will never be completed, and one that is still open to abuse and corruption (as one informant said, “People will just find ways to buy their disability again, so what’s the point?”)

17 years) those younger people with disabilities who could really benefit from the automobile may never receive a car. Faced with what he calls “the state’s mistaken priorities,” Edik formulated his own strategies for generating income to purchase a car (and equip it with hand controls) outside the state’s entitlement system.

Despite his criticism of the “passivity” and “dependence” of many people with disabilities, Edik realizes that structural constraints place limits on people’s possibilities to become economically self-sufficient. In describing his success, he cites his access to support networks, his physical condition (he is stronger and more mobile after his injury than many other spinally injured persons), and his positive outlook on life. Edik sees himself as an “exception,” and asked me to treat him as such in my study. Despite his criticism of citizens’ over-dependence on the state, Edik firmly believes that economic well-being is the basis for any kind of rehabilitation of the disabled, and says that economic security has to precede any social adaptation. He believes the state should take full responsibility for supporting “people who truly cannot work” economically. Edik, who has traveled to various countries in Europe and North America for sports competitions, cites the “civilized” approach to the disabled he saw there. He said, “The civilized approach is when states give people who are unable to support (*podbaty*) themselves adequate financial help.” He believes that lack of such support has prevented the development of a strong disability rights movement in Ukraine (“People have too many financial worries to become socially active”) and chokes off any possibility for people with disabilities to truly enjoy “equal rights.” Edik contrasts the Ukrainian situation with the situation he sees in European countries. He says that wheelchair users he knows, “enjoy full citizenship rights, because they get adequate state support that allows them to live full lives like anyone else. That is lacking in Ukraine, despite declarations about ‘equal rights.’ Here the state guarantees nothing.”

Edik’s vision of citizenship for the disabled clearly prioritizes the importance of a firm economic base around which people can then build satisfying lives. His narratives draw on questions fundamental to questions of citizenship in a changing state: the politics of recognition (who is deserving, and how “needs” are defined), and the politics of redistribution (to what extent are certain categories of citizens deserving—that is, what entitlements should they be offered) (Fraser 1997). Edik also ruminates on what role the state should play in disabled citizens’ lives. Here his narrative indexes how processes of globalization are changing how people with disabilities in Ukraine conceptualize their rights vis-à-vis the state. Drawing on the example of European and Western colleagues he has met, he wishes the Ukrainian state would intervene more, and in a more positive way, but recognizes that in the face of inadequate state support individuals must find their own solutions. His narrative indexes discourses of individual initiative in the face of a reluctant state. This vision, of course, is not totally individualizing, because achieving it requires a good deal of social support, and adequate financial means, in Edik’s case provided by others at first as a form of start-up. Edik’s narrative, I argue, helps us track the changing and contingent notions of “citizenship” articulated by some people with dis-

abilities in Ukraine. He draws on a neoliberal discourse of individualism and self-reliance, yet calls for a strong state and a robust social welfare system. This narrative reflects the complex and fluid politics of redistribution that motivates contemporary discussions of disability and citizenship.

Equal Employment Opportunities

Several key issues in debates over the meanings of “citizenship” for people with disabilities in Ukraine are encapsulated in discourses and practices concerning disability and employment. These issues include questions of social welfare, independent living, economic independence, accessibility, and public perception, among others. Examining the range of narratives espoused by disabled persons and representatives of state institutions reveals how people with disabilities are variously positioned by structures of power. In recent years, high unemployment rates among the disabled have become a cause for concern and a target for intervention by state agencies and NGOs in Ukraine. In 2002 official statistics indicated that disabled workers only constituted 1.6 percent of the entire workforce in Ukraine (Derzhavna Dopovid 2002:96). Initial attempts to usher disabled workers into the workforce were made through the introduction of a 2001 change to the Law on the Basis of Social Protection of Invalids (No. 2606-III). This new law requires that each employer hire a certain percentage of workers with disabilities. For a workforce of greater than 25, at least four percent of workers must have a disability. In an organization with 100 workers, for example, at least four must have disability status. Small firms that hire only 15-25 workers are required to reserve one job for a disabled worker. According to Article 20 of this law, employers who are unwilling to comply with this law must pay a fine into the All-Ukrainian Fund of Social Protection of the Disabled. The fine is to equal the estimated average annual salary of a worker at the firm. These monies are then (according to the law) channeled back into programs for social, vocational, physical culture/sport, and professional rehabilitation for Ukraine’s disabled population (Derzhavna Dopovid 2002:99). This quota system is modeled on legislation in Western European countries, especially France, Germany, and Poland (ibid.). There are several loopholes in Article 20 that allow firms to avoid paying the requisite fines, including provisions that excuse firms that do not make profits from paying the fines (Baranova-Mokhort 2005).

While some businesses in Ukraine comply with this law, others are unwilling to hire workers with disabilities, citing fear of absenteeism and expectations that disabled workers will be unable to carry out work responsibilities. Most significantly, many employers are unwilling to make accommodations for workers with disabilities, who may require architectural renovations, and special chairs and equipment, to access the workplace and perform their jobs. Employers who decline to hire workers with disabilities have two options: they may pay the requisite fine, or they may “fake” the hiring of disabled workers, an arrangement that saves costs. This entails officially hiring the worker

but paying a reduced salary. The worker is usually paid half the official salary for “work” he or she never does. Almost every informant in my study was involved in this arrangement, which they called “having my workbook lie at X.” International corporations also engage in the practice: one young woman was “employed” at the Nestle office in Kyiv. She explained: “Do you know Nestle? I was working (in inverted commas) there. I think you understand me. I just gave them my workbook, and that’s it. It’s the usual way... They paid me a very small amount. But the teacher in the school gets the same money I got there, and goes to work everyday. I don’t need it. It is terrible! It is the usual way of getting the disabled to work. They are just using our privileges. They could afford to hire me for real; they are paying really big taxes, just like abroad.” Svetlana’s assessment that “they are just using our privileges” is key here. Able-bodied people who learn about the sorts of arrangements often respond with comments such as, “What luck. They get paid for doing nothing. What’s the problem?” But this sort of manipulation of the system—despite the active compliance of the disabled—devalues people with disabilities and their potential contributions to the workforce and to society. The message is that it is “not worth it” to hire the disabled on a par with other workers and to invest in workplace accommodations to do so.

As noted in a government report (Derzhavna Dopovid 2002), the quota system places disabled job-seekers in a vulnerable position; employers, who’s primary concern is competitiveness in business, are not interested in employing workers who they perceive as being “unqualified” and “inadequate” (p. 102). The report concludes that “this highlights the need for raising standards of professional preparation [of the disabled] in competitive specializations” (ibid.). On one hand, this proposed solution stresses the need to provide the disabled with access to educational and vocational training opportunities and thus empower them as potential workers. On the other hand, it shifts the focus from employers’ discrimination in hiring to looking instead at potential problems of the workers—are they unqualified? Why aren’t they competitive. It proposes an individualizing solution to a problem that is arguably much larger in scope. Other ironies are present as well. As noted above, programs specializing in preparing specialists among the disabled have been initiated in institutions of higher education. Many graduates note, however, a lack of institutional support in job placement. Additionally, the state has not made it easy for employers to hire disabled workers, although enterprises may apply for state funds to support the costs of revamping the workplace to accommodate disabled workers. Employers who are serious about integrating workers with disabilities into the workforce, and going through the process of getting these positions accredited (accreditation is required for each “work space” (*roboche mistse*) for which a disabled worker is permanently hired), face confusing and contradictory laws. To date there is no single, concise, organized source for information for such employers (Myroniv’skyi 2005). More work also needs to be done to link up employers with disabled job-seekers, and to dispel negative stereotypes about disabled workers and their “limited potential” among employers.

One informant, Tanya, the head of an NGO for the disabled in a small city in central Ukraine, set up a partnership with the local unemployment office, when she learned

that employers regularly contacted the office to seek out disabled workers. She quickly learned, however, that the vacancies offered were exclusively for janitors or “lifters” (*gruzchik*). She described the solution she pursued—a job fair:

We had a job fair—we invited directors of firms and enterprises, and people with disabilities...We let them know that among the disabled there are many qualified people. People become disabled at different times in their lives—not necessarily from childhood. People have some educational background. They were really surprised that we have people who can do computer work. And several people were hired right on the spot at the job fair, because we began a dialogue. We tried to understand one another and it worked.

Tanya thus worked through her NGO to address a lack of dialogue between organs of the state (the unemployment office), those of the market (the employers) and citizens with disabilities. She also formulated a strategy to educate local employers about the potential of her members as workers, and to dispel negative stereotypes of the disabled as people who could only perform manual work such as “lifting” (problematic for many people with disabilities in any case) and carrying out janitorial work.

Another phenomenon involving employment of the disabled also points up some of the discourses surrounding disability and citizenship. There is a long history of disabled work collectives in the Soviet Union, formerly called artels. Work artels were formed by the disabled—without state assistance or support—beginning in 1921, before the end of the civil war (Indolev, Oleinikova, and Panov 1998). By the end of the 1950s there were 4,252 artels with 218,900 workers consolidated in the Manufacturing Cooperative of Invalids (*Promkooperatsiia invalidov*). By July of 1960 the artels had been liquidated by the Soviet state, which appropriated all their assets (*ibid*). The only organizations for the disabled to formally exist until perestroika were the All-Union Organization of the Deaf (VOG), and the All-Union Organization of the Blind (VOS), whose programs were focused on employment of their constituents into artels. The problem of employment of the disabled was a major impetus for attempts to form organizations for the disabled outside these two state-sanctioned groups, and was a major goal for the All-Russian Organization of Invalids (VOI) in 1988. Since then the Russian government has ceded more than 300 enterprises back to the VOI (a move seen as a reversal of the state’s appropriation of disabled artels in the 1950s). As in Russia, in Ukraine today the Ukrainian Organization of the Blind (UTOS) and the Ukrainian Organization of the Deaf (UTOG) are two of the strongest disability groups, and both focus on providing employment—through factories and enterprises owned by the organizations—to the deaf and blind in Ukraine. Because they have monopolies on the production of certain goods (matches, specialized work wear, and others) these organizations are sometimes popularly referred to as “mafias.” There are also firms in Ukraine known as “disability enterprises” that provide so-called “specialized work places” for the disabled. To be officially designated as a “disability enterprise,” at least 50 percent of a firm’s employees must be disabled. This entitles the business to tax advantages. Some disability rights activists see the disability enterprise as an empowering tool for the disabled to secure work in a very tight job market. Additionally, many disability enterprises are administered by persons

with disabilities, who are admired for their achievements in producing profits, overcoming a range of barriers, and helping other disabled people in the process.

At the level of the state, however, there is a move in Ukraine today to do away with disability enterprises; in summer 2005 a protest was held in Kyiv to criticize government plans to scale back benefits to disability enterprises. Language in a 2002 government report is quite strong: “employment of invalids in specialized enterprises should not be considered a solution for providing jobs for invalids or as a foundation for such a solution. Working in specialized enterprises, invalids are in an isolated social system. Moving from a specialized to a regular type of employment must be the goal of the state in relation to invalids...” (Derzhavna Dopovid 2002:103). The call here is for the integration of people with disabilities into the general workforce, a problem that the 2001 change to the Law on the Basis of Social Protection of Invalids (No. 2606-III)—which established quotas for all enterprises—was designed to address.

During 2005 I interviewed a group of entrepreneurs who were planning to establish a “rehabilitation center” in Kyiv to provide a range of services to the disabled, including “vocational rehabilitation.” The center, if it is realized, will be attached to a factory, and at least half the workforce will be people with disabilities. The factory administrators will thus be eligible for tax benefits under existing laws as owners of a “disability enterprise.” Some of my interlocutors were skeptical about schemes such as these, questioning the motives of the entrepreneurs and interpreting the “rehabilitation center” as a front for what would really just be a means of securing a cheap labor force. These perceptions echo the frustrations of Dmitrii and Natasha, who felt that those more powerfully placed (entrepreneurs, university administrators) were able to “use the benefits” offered to citizens with disabilities to a greater extent than the disabled were. These examples show how, given a range of constraints, people in disabilities in Ukraine today are often unable to exercise the agency that is accorded them in the legislation that affects their lives. These processes, and the effects on possibilities for “citizenship,” are interpreted differently, depending on a range of factors such as socioeconomic status, educational background, and one’s position within a range of hierarchies.

The entrepreneurs mentioned above had picked up on one of the “latest trends” in state and NGO-provided services for the disabled in Ukraine: the establishment of centers that provide various forms of rehabilitation. As one informant noted, “It has become fashionable to open ‘rehabilitation centers’ all over the country,” and any of these rehabilitation centers, which receive state support, include some kind of “vocational education” in their programs, along with physical rehabilitation. Undoubtedly, the focus on vocational rehabilitation is a strategy to address the very real problems of unemployment among the disabled outlined above. It is also a way to ease the financial burden placed on the state, which is obligated to support disabled citizens through monthly pension payments and a range of other entitlements. This focus on employment is coupled with proposed changes in disability benefits that would make it illegal for Group I invalids (those considered unable to work, and in need of care) to work and continue to receive pension

benefits. As Oleg Poloziuk explained, “Now Group I invalids will have to choose—work or pension, but not both. It is a case of the state telling us: ‘You want too much.’ It’s absurd.” He went on to explain that the proposed changes misrecognize the difficulties faced by people with disabilities, who need special accommodations and a certain measure of state financial support to place them in a position where regular employment is a viable and desired option. Edik was also cynical about the new focus on vocational rehabilitation, and sees it as a violation of the social contract. He says that by emphasizing *pratsevlashtuvannia* (job placement), the state is trying to shirk its responsibilities by “requiring the disabled to earn money in order to buy their own wheelchairs.” Edik, an entrepreneur himself and a strong proponent of initiative, hard work, and self-sufficiency among the disabled who are able to work, sees the state’s recent focus on vocational rehabilitation as a case of putting the cart before the horse. In other countries, he notes, the state provides all necessary fundamental support (such as appropriate wheelchairs, personal means of transportation such as vans) and those disabled who can then work are better able to rehabilitate and “realize themselves.” He believes this basic financial aspect of the problem is one that only the state can solve—NGOs cannot do it, and most disabled citizens cannot do it themselves.

Given market reforms in Ukraine, the introduction of neo-liberal discourses on self-sufficiency and productivity that accompany such reforms, and the state’s plans to scale back the pension system, strategies to get people with disabilities into the workforce should come as no surprise. These strategies, however, entail contradictions and generate a range of narratives that reveal much about how people with disabilities are positioned by structures of power in today’s Ukraine. The disconnect between state policies of education, vocational rehabilitation, and job placement for the disabled bring into relief the politics of recognition and redistribution in post-socialist states. On the one hand, it is hoped that better educational opportunities and vocational rehabilitation will make the disabled more “visible” and lead to social integration. Additionally, they are expected to generate their own source of income, allowing the state to shrink the welfare system. These important changes, however, are occurring along with market reforms emphasizing a “leaner and fitter economy,” one that at present has no room for workers who require special accommodations. These contradictory processes put persons with disabilities in a precarious position, and result in what Holston and Caldeira (1998:280-1) call “disjunctive democracy,” because citizenship is institutionalized and enacted differently for different groups of citizens. In the above reflections on how people with disabilities talk about issues of accessibility, economic empowerment, education, and employment, I have tried to show how the very notion of “citizenship” is a relational one, a conceptual shifter always dependent upon its referents (the disabled, women, ethnic minorities) and on relations of power in which these persons and their possibilities and experiences are embedded.

Conclusion

The varying notions of “citizenship” in relation to people with disabilities in Ukraine shed light on the changing politics of recognition and redistribution that characterize post-socialist transformations in social policy. These shifts result from and are productive of a range of discourses about citizens’ rights and responsibilities in the new Ukrainian state. In this paper I have focused primarily on the narratives of several disability rights activists and the ways in which they formulate citizenship claims in a range of contexts. In order to track these narratives and their effects it is imperative to investigate the nodes of power that produce and shape them, an analysis I will refine as this project progresses. In the case of the Ukrainian disability rights movement these include a range of state institutions and representatives of the state, international and local NGOs and NGO coalitions of the disabled, medical institutions, rehabilitation centers, various “experts,” a range of powerful social networks, and others. In further inquiries on disability identity in Ukraine I also intend to track how other trajectories such as gender, sexuality, and class intersect and inform the identities of disabled persons, and how such intersections inform narratives of “citizenship.” Keeping this in mind, here I would like to reflect briefly on what the citizenship debates related here can tell us about citizen-state relations among people with disabilities.

With the eminent changes in social policy regarding disability, social services, and pensions, many persons feel compelled to stake disability claims and confront the state. As Petryna (2002:5) has demonstrated for claimants of Chernobyl disability entitlements, “In Ukraine, where an emergent democracy is yoked to a harsh market transition, the damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims.” Via a range of political, medical, and social institutions, a whole apparatus has emerged to classify and manage “invalids,” and it is largely through this apparatus that the disabled subject is created (Foucault 1982; Tremain 2005:5-6). This phenomenon is not unique to the Ukrainian case. What problematizes this process, however, is the reality that in Ukraine this apparatus does not work very well; it is unwieldy, entails contradictions, and is ultimately ineffective. Although people are tied up in this state apparatus via their claims to disability, many turn to an alternative, informal system that affords access to information and social support. As Oleg Polozhiuk (2005) notes, “Each family is compelled to fill the informational vacuum it faces by drawing on a range of sources: from other victims and their families who have had similar experiences, doctors, representatives of NGOs, and only then from representatives of the medico-social commission, the department of labor and social policy, and social services.”

This alternative system thus runs parallel to yet also intersects with institutions of the state. Through these intersections, people in the disability system—and especially disability rights activists—become both subjects of and subject to disability discourses, not merely their objects (Cruikshank 1999:23). The narratives presented above show how people with disabilities from a range a backgrounds may resist hegemonic discourses that

position them in certain ways, and also the institutional practices that constrain their possibilities. As Barbara Cruikshank has noted in her critical study of welfare recipients in the United States, “Being ‘just another number,’ ‘dependent,’ or ‘in need of help’ is not the antithesis of being an active citizen. Rather, it is to be in a tangled field of power and knowledge that both enables and constrains the possibilities of citizenship” (1999:20). Through a range of informal and formal practices—both discursive and action-oriented—people with disabilities in Ukraine today are staking citizenship claims in ways that would have been impossible 15 years ago. It is difficult to do so successfully, however, without the backing of a willing state. As anthropologists have noted, post-socialist citizens tend to have fraught and contradictory relationships with the state, bemoaning the state’s absence yet actively inviting the state into their lives (Ninetto 2005). Even though most of the people I interviewed in Ukraine narrate their relationships with representatives of state institutions as antagonistic, they expressed a desire for more state, not less. Many disability rights activists seem to want the state to be an understanding facilitator, but are skeptical that it will ever happen—they are very cynical about corrupt officials and the unqualified new cadres of the Yushchenko government. A common view is that representatives of the state are simply uninterested in citizens’ plights, being preoccupied with lining their pockets “while they still can.” Despite these doubts, given their constraints—both historical and structural—many disability rights activists find themselves “reaching out for the familiar allocative state of before” Verdery (1996:214) yet being urged to stop doing so, even when no viable alternatives are provided.

This fraught citizen-state relationship is encapsulated in the understanding of *dobytyisia*, which means something akin to “squeezing things out of the state.” My informants frequently related their attempts to *dobytyisia* not only entitlements and resources guaranteed them by law as disabled citizens, but also information about their rights and the laws and structures that govern their lives. As Barnes (1991) has pointed out, and Kjellberg (2002) and others have reiterated, lack of access to information is a serious constraint on the ability of any person to exercise one’s formal citizenship rights. My informants in Ukraine frequently stated that “it is very convenient” for representatives of the state to keep the disabled uninformed about their rights. Talk about *dobytyisia* reveals the contradictory terms in which many people with disabilities (and other categories of citizens who feel they are losing out in the “transition”) conceptualize their relationship with the state, both individually and collectively. They are critical of a state that denies them full citizenship rights yet persist in appealing to institutions of the state as a guarantor of such rights.

Here I have space for only a few preliminary remarks about what my research on the disability rights movement can contribute to post-socialist studies of “civil society.” My research reinforces the argument that NGOs should not be automatically celebrated as “democratizing” forces: indeed, many members of the disability community in Ukraine avoid contact with NGOs, which they associate with corruption and profiteering. Informants’ narratives also expose the blurry boundaries between the state, market, and NGO “spheres” in Ukraine by presenting examples of disability rights activists and

organizations that routinely transverse these spheres for a variety of ends. My data also illustrate how many activists achieve their goals by informal means; they rely on a variety of networks and connections to circumvent limitations imposed by laws (or their failure), structural constraints, and personal circumstances. As the story of Oleg Polozhiuk and his efforts to persuade builders in his neighborhood to construct handicapped-accessible structures, some of the most significant strides towards integrating the disabled into mainstream Ukrainian society (and thus extending them increased citizenship rights) have been made by individuals working more or less independently of any NGO efforts. These are issues that I will pursue in further inquiries, as I focus in issues of activism, NGOs, and “civil society” in relationship to disability rights.

Analyses of civil society and citizenship after socialism must include a careful investigation of the multiple stakeholders involved. These include international foundations that fund local and national “civil society” interventions in Ukraine, government officials at the local, municipal, and national levels, and powerful citizens’ coalitions, all of whom may have competing interests. In this frame, I will continue to ask the following questions: In the post-socialist (and post-Orange Revolution) context, how is the subjectivity proper to democratic citizenship being infused into particular groups of citizens (here, the disabled) (Cruikshank 1999)? Ultimately, are citizens with disabilities being empowered, or are they being subjected to a new form of governmentality (Foucault 1982)? These questions can serve as a frame within which to evaluate “civil society” initiatives in Ukraine and the region more broadly, and can help us integrate these discussions with analyses of new citizenship regimes after socialism. As Bérubé (2003) has noted for the United States, all too often people with disabilities are excluded from debates on issues of citizenship (in his formulation, “participatory parity”), a problem that activists in Ukraine also point out. Oleg Polozhiuk (personal communication) notes that the new Ukrainian administration missed an opportunity to include the “veterans” of the disability rights movements in the conversation; with a few exceptions the recent restructuring of ministries dealing with questions of disability was carried out without the participation—or the appointment—of persons with disabilities themselves, arguably the ultimate “experts.” In a situation where even the most known of this “unknown population” (Polozhiuk 2005) are marginalized from decision-making processes, the fraught and altogether uncertain nature of “participatory parity” for the disabled in Ukraine is brought into relief.

Works Cited

ASCH, Adrienne

2004. "Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity." *Gendering Disability*, eds. Bonnie G. Smith and Beth Hutchinson, pp. 9-44. New Brunswick, NJ and London: Rutgers University Press.

BARANOVA-MOKHORT, Serhiy

2005. "I znova pro nabolile—pratsevlashtuvannia invalidiv." *Svoia Hazeta*, No. 03 (019):6.

BARMASHYNA, Liudmyla

2000. *Formuvannia Seredovysbcha Zhyttediial'nosti dlia Malomobil'nykh Hrup Nacelennia*. Kyiv: Soyuz-Relkama.

BARNES, Colin

1991. *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation*. London: Hurst and Company.

BARNES, Colin, Geof Mercer, and Tom Shakespeare

1999. *Exploring Disability: A Sociological Introduction*. Cambridge: Polity Press.

BARTON, Len

1993. "The Struggle for Citizenship: The Case of Disabled People." *Disability, Handicap, and Society* 8(3):235-248.

BECKETT, Angharad E.

2005. "Reconsidering Citizenship in the Light of the Concerns of the UK Disability Movement." *Citizenship Studies* 9(4):405-421.

BÉRUBÉ, Michael

2003. "Citizenship and Disability." *Dissent* 50(2):52-57.

CAREY, Allison C.

2003. "Beyond the Medical Model: A Reconsideration of "Feeble-mindedness," Citizenship, and Eugenics Restrictions." *Disability and Society* 18(4):411-430.

CRUIKSHANK, Barbara

1999. *The Will to Empower: Democratic Citizens and Other Subjects*. Ithaca: Cornell University Press.

DANERMARK, Berth, and Lotta Conaivitis Gellerstedt

2004. "Social Justice: Redistribution and Recognition—A Non-Reductionist Perspective on Disability." *Disability and Society* 19(4):339-353.

DAS, Veena, and Renu ADDLAKAHA

2002. "Disability and Domestic Citizenship: Voice, Citizenship, and the Making of the Subject." *Public Culture* 13(3):511-531.

DERZHAVNA, Dopovid

2002. *Pro stanovysbche invalidiv v ykraini ta osnovy derzhavnoi polityky shchodo vyrishenia problem bromadian z osoblyvymy potrebamy*. Kyiv: Sotsinform.

DIXON, John and D. Macarov, eds.

1992. *Social Welfare in Socialist Countries*. London: Routledge.

DUNN, Ethel

2000. "The Disabled in Russia in the 1990s." *Russia's Torn Safety Nets: Health and Social Welfare during the Transition*, ed. Mark G. Field and Judyth L. Twigg, pp. 153-171. New York: St. Martin's Press.

DUNN, Stephen P. and Ethel DUNN

1989. "Everyday Life of the Disabled in the USSR." *The Disabled in the Soviet Union: Past and Present, Theory and Practice*, ed. William O. McCagg and Lewis Siegelbaum, pp. 199-234. Pittsburgh: University of Pittsburgh Press.

FOUCAULT, Michel

1982. "The Subject and Power." Appended to *Michel Foucault: Beyond Structuralism and Hermeneutics*, 2nd edition, ed. Herbert L. Dreyfus and Paul Rabinow. Chicago: University of Chicago Press.

FRANK, Gelya

2000. *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America*. Berkeley: University of California Press.

FRASER, Nancy

1995. "From Redistribution to Recognition? Dilemmas of Justice in a 'Post-Socialist' Age." *New Left Review* I/212: 68-93.

_____.

1997. *Justice Interruptus: Critical Reflections on the "Postsocialist" Condition*. New York and London: Routledge.

GIGNACA, Monique A.M. and Cheryl COTTB

1998. "A Conceptual Model of Independence and Dependence for Adults with Chronic Physical Illness and Disability." *Social Science and Medicine* 47(6):739-753.

GOFFMAN, Erving

1963. *Stigma: Notes of the Management of Spoiled Identity*. New York: Simon and Schuster, Inc.

GONZALEZ-GALEGO, Ruben David

2004. *Beloe na chernom*. Saint Petersburg and Moscow: Limbus Press.

HOCKENBERRY, John

1995. *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence*. New York: Hyperion.

HOLSTON, James, and Teresa CALDEIRA

1998. "Democracy, Law, and Violence: Disjunctions of Brazilian Citizenship." *Fault Lines of Democracy in Post-Transition Latin America*, ed. F. Aguero and J. Stark, pp. 264-296. Miami: North-South Center.

INDOLEV, Lev

2001. *Zhit' v Koliaskе*. Moscow: Soprichasnost'.

INDOLEV, Lev, M. OLEINIKOVA, and V. PANOV

1998. *Kak Eto Bylo*. Moscow: Soprichasnost'.

JAYASOORIA, Denison

1999. "Disabled People: Active or Passive Citizens—Reflections from the Malaysian Experience." *Disability and Society* 14(3):341-362.

JONES, K.

1990. Citizenship in a Woman-Friendly Polity. *Journal of Sociology* 42(4).

KIKKAS, Kaido

2001. "Lifting the Iron Curtain." *Disability and the Life Course: Global Perspectives*, ed. Mark Priestly, pp. 113-122. Cambridge: Cambridge University Press.

KJELLBERG, Annete

2002. "Being a Citizen." *Disability and Society* 17(2):187-203.

KOHRMAN, Matthew

2005. *Bodies of Differences: Experiences of Disability and Institutional Advocacy in the Making of Modern China*. Berkeley: University of California Press.

LANGAN, Celeste

2001. "Mobility Disability." *Public Culture* 13(3):459-484.

LISTER, Ruth

1990. *The Exclusive Society: Citizenship and the Poor*. London: Child Poverty Action Group.

MADISON, Bernice

1989. "Programs for the Disabled in the USSR." *The Disabled in the Soviet Union: Past and Present, Theory and Practice*, ed. William O. McCagg and Lewis Siegelbaum, pp. 167-198. Pittsburgh: University of Pittsburgh Press.

MAKHARYNSKA, Natalia

2002. *Social Defense of Invalids in Ukraine*. Senior thesis submitted to the Department of Sociology, National Technical University of Ukraine, "Kiev Polytechnical Institute."

MARSHALL, T.H.

1992. *Citizenship and Social Class*. London and Concord, Mass: Pluto Press.

MARUNYCH, V., A. Ipatov, O. Serhieni, and T. Voitchak

2004. "Poiusy ta minysi Indyvidual'nykh proham reabilitatsii invalidiv." *Sotsial'ne Partnerstvo* 1(1):22-23.

MCCAGG, William O.

1989. "The Origins of Defectology." *The Disabled in the Soviet Union: Past and Present, Theory and Practice*, eds. William o. McCagg and Lewis Siegelbaum, pp. 39-61. Pittsburgh: University of Pittsburgh Press.

MYRONIVS'KYI, Viktor

2005. "Iak atestuvaty roboche mistse invalida?" *Sotsial'ne Partnerstvo* 3(4):14-16.

NINETTO, Amy.

2005. "'An Island of Socialism in a Capitalist Country': Postsocialist Russian Science and the Culture of the State." *Ethnos* 70(4). In Press.

OLIVER, Michael

1990. *The Politics of Disablement: A Sociological Approach*. New York: St. Martin's Press.

PETRYNA, Adriana

2002. *Life Exposed: Biological Citizens after Chernobyl*. Princeton: Princeton University Press.

PHILLIPS, Sarah D.

2002. "Living in a Parallel World: Disability in Post-Soviet Ukraine." *Russian and East European Center News* (University of Illinois at Urbana-Champaign) 100:1-2. Available online at http://www.reec.uiuc.edu/publications/news_fall02.pdf

POLOZIUK, Oleg

2004. "Iurodychna konsul'tatsia: Shcho oznachae poniattia 'invalid' ta iaki orhany vstanovliuiut' invalidnist'?" *Sotsial'ne Partnerstvo* 1(1):21.

_____.

2005. "Problems of Socio-Legal Protection of Disabled Persons with Spinal Cord Injuries in Ukraine." Paper presented at the Sixth Congress of the International Association of Ukrainian Studies, Donetsk, Ukraine, June 29-July 1, 2005. (English translation Sarah D. Phillips.)

QUICKE, J.

1992. "Individualism and Citizenship: Some Problems and Possibilities." *International Studies in Sociology of Education* 2(2):147-164.

SHAKESPEARE, Tom

1997. "Rules of Engagement: Changing Disability Research." *Disability Studies: Past, Present and Future*, ed. L. Barton and M. Oliver. Leeds: Disability Press.

SMITH, Susan J.

1989. *The Politics of "Race" and Residence: Citizenship, Segregation, and White Supremacy in Britain*. Cambridge: Polity Press.

SOMERS, Margaret

1994. "Rights, Relationality, and Membership: Rethinking the Making and Meaning of Citizenship." *Law and Social Inquiry* 9(1):63-112.

_____.

1995. "Narrating and Naturalizing Civil Society and Citizenship Theory: The Place of Political Culture and the Public Sphere." *Sociological Theory* 13(3):229-274.

STIKER, Henri-Jacques

1982. *Corps infirmes et sociétés*. Paris: Aubier Montaigne.

STONE, Deborah A.

1984. *The Disabled State*. Philadelphia: Temple University Press.

TREGASKIS, Claire

2002. "Social Model Theory: The Story So Far..." *Disability and Society* 17(4):457-470.

TREMAIN, Shelley, ed.

2005. *Foucault and the Government of Disability*. Ann Arbor: University of Michigan Press.

VERDERY, Katherine.

1996. *What Was Socialism, and What Comes Next?* Princeton: Princeton University Press.

ZHELEZNIAK, Yaroslav, and Boris MASHTALIARCHUK

2005. "Bezbar'ernost': chas rishuchykh diy nastav." *Povir u sebe* No. 21-22 (333-334), June 1-15, 2005.