Sarah Phillips, Disability and Mobile Citizenship in Postsocialist Ukraine

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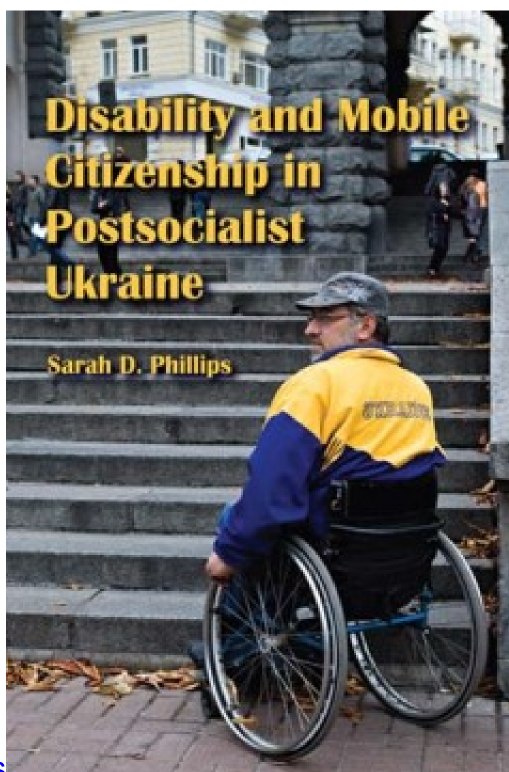
By Sarah D. Phillips

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In this compelling and intimate ethnography, Sarah D. Phillips analyzes the lives and worlds of disabled persons in contemporary Ukraine, placing them within the context of Russian and Soviet histories of disability and activism. Focusing on the experiences of *spinal'niki*, or persons with spinal injuries or diseases, Phillips guides the reader through the life histories and experiences of particular individuals, while also providing illuminating historical perspectives on large-scale policy shifts, contemporary forms of disability rights activism and NGOs, and broader transnational networks. Through an analysis of portrayals of disabled persons in the media and a strikingly intimate study of gender and sexuality, Phillips shows the stakes

of disability in public and private spheres. The “mobile citizenship” of the title refers to “the creative strategies…used by people on the margins to assert claims to full citizenship” (8). Phillips highlights how such citizenship can be achieved despite the “apparent contradiction” of such possibilities for persons with limited physical mobility (8). Throughout the book, Phillips makes obvious the deep respect that she has for her research participants; her fundamentally humanistic approach is evident in her straightforward portrayal of the marginalization and extreme discrimination that *spinal’niki* face in so many realms of life, but also in the creative, unexpected, and successful ways that disabled persons forge meaningful lives in the “parallel world” (40) in which they live.

Chapter 1 (A Parallel World), which could be seen as a microcosm of the entire ethnography, opens with the life history of Sasha Pavlov, who became “broken” (14) in a swimming accident at age sixteen in 1991. From the very moment of the accident, the medical care and material world of newly independent Ukraine proved inadequate for Sasha’s optimal recovery. Phillips leads the reader through the transitional medical system that Sasha and his mother, Zoia, had to navigate (13-21). Poorly equipped ambulances, which often lacked stabilizing boards so important for improving outcomes, traveled on potholed roads (thereby subjecting patients to dangerous movement) to take patients to hospitals with inadequate neurosurgery wards (14-17). Surgeries frequently occur later than indicated in the West, resulting in poorer prognoses. And after surgery, under-financed, under-resourced, and under-staffed hospitals force relatives and friends to provide much of the necessary care of patients, including the treatment of bedsores and providing medical supplies (17-20). The results of this (lack of) medical care are sobering: 76% of those with spinal-cord injuries die within the first year after the injury in Ukraine, while in the US, of those who survive the first twenty-four hours after injury, 85% will still be alive ten years later (18-19). The injustice of such inequity in health outcomes is matched by the injustice of other Soviet legacies; systematic historical exclusion of and intense stigma towards disabled persons, reinforced by the stubbornly hostile built environment, continue to shape experiences of disability in Ukraine today.

Soviet legacies of disability (addressed in detail in Chapter 2: Out of History, which also includes a fascinating account of disability in the Russian Empire) are evident in the current state of high unemployment, poor social support, and marginalized status of disabled persons. Although Sasha did find employment, it was with his parents’ firm, and he was fired after the person who had hired him passed away (31-32), showing both the precarious nature of employment and the vital significance of social networks for disabled persons. Despite quotas requiring companies to hire certain numbers of disabled persons, these laws are often circumvented, as employers officially hire disabled persons but only pay them 50% of

their entitled wages for no labor (31). The “Soviet functional approach” to disability meant that labor capacity was paramount, and as such, disability categories were based on ability to perform certain kinds of work (59-60). Promised pensions were too low to sustain a living wage, while medical equipment (namely wheelchairs) was poor and outdated. Residential institutions (*internaty*) promised proper care and often provided a social network of peers, but also served to remove the “blemish” (62) of disability from the public sphere. The post-World War II Soviet state could not tolerate signs of difference (in any disabled bodies) or negative images of the war (as in disabled veterans); such systematic exclusion of persons with disabilities “creat[ed] a permanent underclass of invalids” (68). State-sponsored athletics provided one of the only acceptable and publicly visible roles for disabled persons (73-74). In this historical chapter, Phillips covers an impressive swath of time from the eighteenth century to the present day, showing how these legacies help in “understanding the barriers to social inclusion and full citizenship rights that disabled persons living in former socialist states continue to face” (42).

Since 1991, there have been many NGOs in Ukraine attempting to address the negative aspects of these legacies (Chapter 3: Disability Rights and Disability Wrongs). Yet like NGOs in other postsocialist spaces, they must compete for funding with others that have similar goals, struggle without an official structure, and work within multiple, fragmented, and often contradictory bureaucracies (104-106). Motivated by Sasha’s experience with an influential Swedish program called Active Rehabilitation (AR) that focuses on independence for wheelchair users (26-27), through which he obtained a new “active” wheelchair, he and his mother, Zoia, formed their own NGO to help other *spinal’niki*. The organization successfully worked with the state to facilitate the provision of active wheelchairs for all who needed them, though this became less successful after a switch to low-quality wheelchairs from China (35-37). The popular AR movement, which locates agency, empowerment, and moral possibility in the individual, “dovetails with the general trends of privatization and individualization that characterize much of postsocialist life during the shift to market economies and the promotion of neoliberal ideologies and cultural logics (Dunn 2005, Phillips 2008, Rivkin-Fish 2005)” (119). Phillips argues that such ideological harmony puts the disability movement at risk of “stalling out” (42); in other words, because AR’s emphasis on the individual fits neatly within the moral economy of neoliberal privatization, grassroots social movements may become more difficult to organize because politics has become so individuated. Yet despite these bureaucratic and ideological challenges, successful coalitions of NGOs have formed (120-125) and political changes can be enacted, though support is needed at top political levels (102-104, 113-115), which Phillips argues can create problems of “elite capture” (123).

Representations of disability in the public sphere tend to reinforce negative stereotypes of disabled persons (Chapter 4: Regeneration). Through a detailed analysis of a public-service billboard that used the specter of a disabled body to warn against the dangers of drug use, and of the controversy in response to the billboard, Phillips demonstrates how the disabled are commonly portrayed as “monstrous, invisible, and nonhuman” (146). Based on an analysis of print media, Phillips identifies four genres of representation (Symbolic, Sensational, Critical, and Personalizing) into which representations of disability fall (147-154). Within the complex set of personalizing representations, gender differences emerge where men are more likely to be portrayed as heroes, while women are more likely to be seen as worthy of pity or blame (151-152). In a striking set of ethnographic vignettes that comprise the second half of the chapter, Phillips shows how encounters in public spaces can dehumanize disabled persons (e.g., a woman is forced to use a metal trashcan as a toilet in a public restroom because the toilet is elevated [156-158]), but also how some disabled persons can challenge conventional stereotypes (e.g., Phillips joins a group of disabled friends who perform in a drum circle and dance in downtown Kyiv [160-162]). These cases, along with certain visual artists who use disabled persons as models (163-169), show how disabled persons can challenge dominant negative stereotypes by “assert[ing] a politics of belonging” (168) through embodied practices in which they claim full personhood for themselves (169).

Detailed life histories of four *spinal’niki*, two men and two women (Chapter 5: Disability, Gender, and Sexuality in the Era of “Posts”), show how “disabled men and women in postsocialist Ukraine both sustain and subvert gendered expectations” (171). The men’s life histories show how patriarchal gender norms are often reinforced (e.g., emphasizing physical strength and athletic prowess [187-188], maintaining independence [197]), but at times are subverted (e.g., engaging in activity that is not traditionally gendered male, such as dance [190-191], or valuing different kinds of sexual acts [199]). Interestingly, at times these patriarchal norms are reversed by taking on traditionally female roles, such as caregiving (200). The women’s life histories show how important maintaining an attractive physical appearance is for women as opposed to men (e.g., wearing fashionable clothes), while also highlighting how women feel more comfortable than men in a dependent role (e.g., asking for physical assistance with architectural barriers) (202-203). For both women in the chapter, motherhood is a key practice through which they subvert stereotypes (one disabled woman was “scolded” for having a child with her disabled husband [206]) and work towards a more complete personhood for themselves through traditional feminine roles. These life histories are perhaps the most compelling part of the ethnography (especially that of Nadia, who Phillips presents through their

correspondence) since they show so well the intimate and relational stakes of contemporary experiences of disability.

It is the relational level of experience and analysis with which Phillips closes the book. The increasing isolation of Pasha, who moved between his home village, Kyiv, and Kharkiv, in attempts to find care, work, and community, shows the simultaneous necessity and potential fragility of social relations for disabled persons in postsocialist Ukraine (231-237). The very same rhetoric of independence that can empower disabled persons can also "detach" them from their social relations; "social policy reform works in tandem with a transforming public sentiment" (237). Phillips follows anthropologists Rayna Rapp and Faye Ginsburg's (2001) work on "rewriting" kinship by suggesting that "rewriting kinship as an advocacy tactic" (242) could be fruitful in Eastern Europe. That is, "exploding notions of relatedness, mutual responsibility, and interdependence beyond the bounds of 'the naturalized stratification of family membership' (Rapp and Ginsburg 2001:551) will help the disabled enact a more mobile citizenship" (244). This is neither a strategy in which the family should bear sole responsibility for care, nor one that supports the "neofamilialism" (243) of contemporary postsocialist Eastern Europe, but rather a strategy that promotes "an expanded notion of family, relatedness, and responsibility" (244). Thinking in terms of interdependence, rather than a tired independent/dependent binary, creates lines of inquiry for both activism and scholarship that Phillips explores in the closing pages. This final insistence on connections rather than rupture, on relatedness rather than isolation, is a fitting end to a book that takes as a central goal elucidating the "valuable shared humanity" (10) of the persons presented within its covers.

The lucid writing and argumentation make this book appropriate for both undergraduate and graduate courses, while the clear organization of this book means that several chapters could work well as stand-alone readings for courses. In particular, Chapter 3 would be useful in courses on applied anthropology and development, while Chapter 5 would be well suited for courses in gender studies. The entire study is a much-needed and welcome addition to the postsocialist literature and would fit well in anthropology, as well as interdisciplinary, courses on Russian and Eastern European studies. With its emphasis on lived experience, narrative, and broader socio-historical shifts, as well as thorough discussions of methodology, this book would also be wonderful for courses in medical anthropology and disability studies.

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