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"Engaging with Both the Residual and the New": An Ethnography of Disability in Postsocialist Ukraine

As scholars have worked to forge a "new disability history," we have heard much from the West, and taken note of ventures that attend to the global South; yet few scholars have offered meditations on disability in the so-called second world, the post-Soviet realm. In her recent monograph, anthropologist Sarah D. Phillips offers a framework for understanding the cultural specificities of disability as an identity and social category in the arena of contemporary postsocialism. Layering personal histories, insights from participant observation, historical research, deconstructions of popular representation, and experiences of gender and sexuality vis-à-vis disability, Phillips offers an unprecedented, sustained investigation of this subject matter. In doing so, Phillips seeks to translate across culture and discipline not only what it is that the postsocialist context has to teach disability studies, but also what it is that attention to disability might offer to conversations about postsocialism. Crafted with an interdisciplinary audience in mind, the volume will be of interest to historians of disability, Europe, and the Soviet Union, as well as to cultural and medical anthropologists. Written with accessibility in mind, Phillips weaves theoretical concerns into narrative accounts and historical and ethnographic detail.

Phillips focuses her study on *spinal'niki*, a Ukrainian word that refers to people with mobility impairments due to spinal injury. That is to say, her ethnographic data, composed of extensive interviews, informal conversations, and participant observation, comes from interactions with Ukrainians who have spinal injuries and their allies and family members. At the same time, in attending to history and epistemology of disability in the post-Soviet era, Phillips considers a broad array of bodily alterity. Within these bounds, she asks questions about how case studies of *spinal'niki* (some of whom identify as activists and some of whom do not) can illuminate the relationship of the individual to the state in postsocialist Ukraine.

Phillips argues that given this context, the disabled and their allies make what she calls "hybrid claims" on the state (p. 7). She defines this phrase ideologically and temporally, demonstrating that her interlocutors are "engaging with both the residual and the new, often in unexpected ways" (p. 238). The "hybridity" here also speaks to theoretical concerns about the way that disability can be mobilized as an identity to make claims on the state; Phillips observes that disabled Ukrainians are "alternatively emphasizing … either physical limitations," in order to claim benefits, or "potential social and economic contributions" to make claims to unattenuated rights as citizens (p. 7). Phillips emphasizes that these hybrid strategies are *unexpected*, not in relation to disability movements elsewhere (indeed, she offers little comparative framework, although the United States is an implicit reference point, and she mentions British social model theory), but that the Ukrainian movements are unexpected in the way that citizens negotiate between Soviet modes of claiming social support and Western/neoliberal models of rights and entrepreneurship.

Phillips introduces the concept of "mobile citizenship," originally coined by anthropologist Aihwa Ong to describe the type of selective affinity to various discourses subsumed under the category of global neoliberalism, and renders it a double entendre by relating the phrase to the material and social mobility of her informants. She describes strategies that *spinal'niki* deploy toward becoming more socially mobile, in spite of the expectation that being physically immobile implies social immobility. Phillips takes care to emphasize the immense variation of personalities and personal narratives among eight adult *spinal'niki*. By calling for state investment in wheelchair distribution and technologies, lobbying for greater accessibility in public spaces, creating sporting groups that entertain and energize longtime *spinal'niki*,

and developing outreach groups that aid the recently paralyzed in transitioning into new lives as wheelchair users, Ukrainian activists counteract and disprove expectations. In doing so, they become more mobile as citizens. This conceptual formulation is most explicitly addressed in the introduction and conclusion to the volume; individual chapters indirectly bring the reader closer to understanding the ways that investigations of both the post-Soviet context and disability articulate one another in novel ways.

Phillips, in sketching out a framework for encountering postsocialist disability, takes on an enormous task. Rather than attend to a particular theoretical apparatus, in each chapter, she applies a different theoretical heuristic from the toolbox of disability studies to the post-Soviet context. This is both a strength and weakness of the volume. On the one hand, in this way, Phillips employs several different manners of approaching disability, adapting the means of analysis to the specificities of postsocialism. On the other hand, each chapter could be developed into a book of its own. In plowing the path, Phillips has broken new ground that deserves much further scholarly attention.

In chapter 1, Phillips introduces a young man with a spinal injury, who, along with his mother, becomes an activist in the *spinal'niki* community; by means of this personal history account, she introduces the reader to themes that resonate throughout the volume. Chapter 2 describes constellations of disability in Soviet state socialism and its aftermath. In this chapter, substantively historical in nature, Phillips focuses on the institutional structures that articulate the experience of disability in the Soviet and post-Soviet eras; examining "housing, education, rehabilitation, and work vis-à-vis the disabled," she encourages "readers to reconsider some assumptions about the evolution of disability rights outside the West" (pp. 10-11). Chapter 3 focuses on contemporary institutional structures and interactions between activists and the state. Here Phillips describes, through ethnographic case studies that build on interviews and participant observation, the various strategies used by contemporary activists. These include lobbying, public-private partnerships, international networking to draw on independent living frameworks, and participation in the grey economy.

Chapter 4 moves from the technical to the epistemological, examining the ways that disability is represented in public discourse, especially news media, in contemporary Ukraine. Building on Rosemarie Garland-Thompson's framework of visual representations of disability in the United States, Phillips sketches out four ways in which disability is deployed as a trope or story device in popular media.[1] Historians and disability scholars unfamiliar with the post-Soviet context will find this chapter to be an accessible documentation of how disability is represented in contemporary Ukraine (I find Phillips's framework here to be broadly applicable to post-Soviet Russia as well). Of note is Phillips's proposal of a "critical" genre conversation about disability, which describes a particular manner of deploying disability rights concerns to demonstrate ways that the Ukrainian government "contrasted unfavorably with [corresponding organs] in the West, especially [in] Western Europe and the United States" (p. 150). Departing from Garland-Thompson's framework, this category speaks to the contextual politics of post-Soviet Ukraine, and the pressure from below for the state to align itself–in policy and alliance–with Europe rather than with the Russian Federation.

Chapter 5 explores performative gender roles and sexuality as experienced and negotiated by disabled Ukrainians. By parsing the way that gender expectations articulate the experiences, goals, stigma, and challenges facing women and men as *spinal'niki* in contemporary Ukraine, Phillips not only tells us much about local masculinity and femininity, but also deepens the ethnographic description of the experience of disability. She includes first person narrations of sexual experiences, public perceptions, and accounts of parenting as a disabled woman. In the conclusion to the volume, Phillips both reiterates the arguments of previous chapters and introduces new concepts. Here, for the first time, she suggests that feminist reimaginings of kinship relations, which stress *inter*dependence rather than independence, may offer new ways for addressing disability in post-Soviet contexts.

Phillips includes a postscript note on methodology and sources. It is here that she explicitly describes her standpoint vis-à-vis disability theory, positioning her analysis outside of the "impairment-disability dyad." She writes, "the assumption that biological difference and physical 'deviance' can be measured against an objective standard, in a scientifically neutral way, runs counter to the rich research in anthropology and related disciplines documenting the complicated cultural and political influences that shape biomedicine variously in different places and times" (p. 251). Rather, she emphasizes "body cultures" (following Susan Brownell), or experiences of the body that are culturally contingent and complexly constituted (p. 252).

By limiting her consideration to *spinal'niki*, Phillips is able to focus on a particular set of conditions, needs, and embodied negotiations. Additionally, the nature of traumatic spinal injury offers a ripe entrée into the temporal uncertainty of the body–a device that helps readers to enter into the predetermined attitudes that post-Soviets hold toward disabilities. For instance, Phillips writes, "One man who became a *spinal'nik* described his attitudes toward disabled persons prior to his spinal injury: 'I was eating breakfast, looking out the window. I saw a girl down below, and something struck me. She probably had cerebral palsy. I found myself thinking–cynically, and now, I realize, stupidly–Why do people like that live near us? Why can't they all be rounded up, all those old, weak ones who can barely walk? Let them live separately, far away, to keep them out of sight"' (p. 23). However, naturally, this leaves many dimensions of disability unaddressed (which Phillips recognizes), and we wonder if the notion of "mobile citizenship" developed here extends to those with cognitive disabilities or mental illness; or how, for instance, terminal illness is conceptualized. This is not the scope of Phillips's work, and certainly her mastery in detailing this aspect of disability in Ukraine awakens us to our lack of knowledge about these issues in the post-Soviet context more broadly.

Ultimately, Phillips offers a comprehensive and thoughtful monograph on disability in the post-Soviet context. Historians will find that chapter 2, "Out of History" (expanding on Phillips's 2009 article in *Disability Studies Quarterly*) sketches out a genealogy of disability as both an administrative category and an epistemological construct in the Soviet Union. This is a welcome addition to the field, as little work has documented this history in a sustained manner. The chapter is skillfully written so that historians of disability will find a fascinating counterpoint to disability in the "West," while historians of the Soviet Union will encounter a largely untapped resource–the lens of disability–through which to explore the popular subjects of Soviet work, productivity, education, and ideology. Phillips, a scholar with a background in ethnography of nongovernmental organizations and women's movements, brings lenses of gender and organizational mobilization skillfully into play. As an anthropologist, she is adept at sketching out the institutional structures that have an impact on the lives of people with disabilities and their families, and the international networks that activists draw on to devise lobbying strategies. Likewise, by weaving the structural with personal anecdotes, the minutiae of daily life, and "thick description," Phillips reminds us why ethnography is uniquely suited to document contemporary disability struggles.

Note

[1]. Rosemarie Garland-Thompson, "Seeing the Disabled: Visual Rhetorics of Disability in Popular Photography," in *New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), 335-374.

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