

26. Being in/at Work: Repositioning Knowledge about Work, Disability and Chronicity (Workshop)

Stefanie Mauksch, Leipzig University

Disability and chronicity are terms that seek to capture biosocial experiences that intersect with, and affect, how people engage in work, labor or employment. This panel is focused on how people navigate disabling, debilitating and/or are enabling experiences in and through work, and how these experiences are shaped by the social localities from which they emerge. We place emphasis on how work becomes significant for people whose bodily conditions or appearances are produced as 'other' in respective societies, or who experience pain or chronic illness that delimit (but maybe also reshape or expand) their possibilities to contribute to communities and other social arrangements. Departing from the focus on work-related exclusion put forward in previous inquiries in anthropology and related disciplines, we attend to *positive* relations between occupational identities and work embodiments on the one hand, and experiences of disability and chronicity on the other. Exploring new angles on the interplay between 'being disabled' and 'being in/at work', we ask whether and how work 'works' as a form to abandon or to problematize constructions of disability. The workshop will bring together scholars who address one or more of the following concerns:

Co-Constitution: How are forms of disability and/or chronicity defined in connection to notions and ideas of work? And vice versa, how do disability and chronicity shape extant forms of labor?

Meaning-Making: How do people with disability and/or chronic conditions in different localities around the globe perform and talk about their work?

Critique: How can embedded understandings of disability, chronicity and work be brought to estrange the workings of administrative procedures, ideologies and political arrangements?

Reflection and Auto-Ethnography: To what degree is the labor of anthropologists shaped by ableist conceptions? Which potential does disability hold to explore exclusionary dimensions of anthropological work?

Navigating (un)employment in the context of multimorbidity: an ethnographic study into the experiences of working-age adults in a London borough

Esca van Blarikom, Queen Mary University of London

My PhD study explores the experiences of working-age adults with long-term physical and mental health conditions. The participants' experiences with employment, although varied, are commonly ambiguous. People who are 'in work' often derive a sense of meaning from their jobs. They enjoy the routine, and the financial independence work provides them. At the same time, people often feel that they must 'choose' between investing in their health or their careers. Some participants have stressful jobs with sub-standard working conditions, contributing to processes of social exclusion already in force for this patient group. I will share participant stories to explore how work can contribute positively to meaning-making, especially when people can draw on illness experiences to exert an expert position. Participants often situate their outlook on life and work explicitly from their positionality as "knowing subjects", based on profound experiences of vulnerability. Meaningful work potentially subverts a sense of "chronicity" by tapping into this potential and thereby mitigates loneliness and existential fears. On the other hand, work can be detrimental to health by reinforcing processes of social exclusion. This paper offers a critical view on policies that push people to be "in work", without simultaneously exploring the meaning of sustainable work.

Deserved work: The role of peer professionals in the implementation of the 2018 federal participation law (Bundesteilhabegesetz)

Lauren Cubellis, Humboldt Universität zu Berlin

What happens when disability roles are foregrounded as a form of political labor? How does the disability identity shift when positioned as a form of critical expertise? These questions define the ongoing implementation of the 2018 Bundesteilhabegesetz, in which disabled persons were given full participatory power in defining their needs and advocating for their care. Based on fieldwork with a peer-run advising association in Berlin, this research examines how individuals with lived experience as mental health service users have been repositioned as experts regarding the rights and needs of individuals navigating disability services and the return to work. These professionals represent an empowered other: a disabled identity deemed capable of work and employed to support the working needs of others. Yet they are marginalized by lesser pay, token inclusion, and the resistance of bureaucratic and clinical professionals to redistributing power in the provision of services for disabled populations. Their

work unsettles state assessments and understandings of need, the institutional complexities of putting disability and human rights law into practice, the centrality of work to perceptions of deservedness, and the stakes of “empowerment” when political will is ambiguous and the means for implementation rely on a novel form of precarious labor.

Chronic illness and the power of activism: the case of endometriosis

Anika König, Freie Universität Berlin

Caroline Meier zu Biesen, Universität Leipzig

Endometriosis, the uncontrolled growth of endometrial tissue in various parts of the body, is a chronic illness that affects persons with a uterus and is, therefore, highly gendered. The condition is characterized by extreme pain and, like many other chronic diseases, is invisible in daily life, including at work. While sufferers often strategically hide their severe pain at work, anthropological studies show that work can simultaneously serve as a way to escape chronic pain and maintain self-efficacy. However, in severe cases, endometriosis patients are forced into early retirement due to their permanent disability. Since endometriosis is not only invisible on a societal level, but also ignored in the medical system, a vibrant activist scene has emerged, driven especially by active sufferers, trying to make sense of endometriosis and its role in patients' lives. As many activists devote a lot of time to their activism, this sometimes becomes akin to paid work. This paper addresses how work becomes meaningful on two levels: a) how do affected individuals cope with disabling or empowering experiences in and through work? and b) what is the meaning of work (activist and otherwise) for sufferers whose physical complaints are often ignored and trivialized.

Masculinities in Crisis: Chronic Pain & Industrial Labour in Eastern India

Shagufta Kaur Bhangu, King's College London

Hundreds of men find themselves at the outpatient clinic of the Institute of Pain Management in Kolkata, India each week. Facing debilitating chronic pains, these industrial labour force workers who mostly hail from India's dwindling jute industry are unable to return to worlds of work. They are also unable to fully occupy their roles as heads of families, breadwinners, husbands, and fathers. These failures in 'being men' pushes them further into states of social and psychological crises exacerbating the physiological and biological pains they endure.

Through two ethnographic portraits – of Suresh and Manoj, this paper dives into the worlds of work, labour and personhood altered by chronic pains in their lives. It delves deeper into the aetiologies and persistence of chronic pains and their struggles to heal as tied with individual histories of labour and visits to the Institute. While discussing how these two locations – the jute mill and the Institute are navigated, the paper also describes the work of identity as a daily negotiation in 'being men.' It reflects on the structural conditions of industry, family and biomedicine which facilitate and limit Suresh and Manoj's efforts revealing a crisis faced by masculine bodies and persons.