
Carers' Narratives of Deinstitutionalization in Bulgaria: Between Over-responsible Parenting and Generational Antisystemic Sentiments

Galina Goncharova*¹

¹Sofia University – Bulgarie

Résumé

In 2018 and 2019 the Bulgarian society faced mass protests of mothers of children with disabilities. Although they cited international instruments that are fundamental to the independent living movement, such as the UN Convention on the Rights of Persons with Disabilities, and explicitly stressed their demands were for 'reforms', they were far from developing and upholding strong emancipatory politics for the disabled. Their main slogan 'The System Kills Us', which gained wide public resonance implied a passive position dependent on the state/state institutions, and assigned the mothers and their children a martyrial status that provokes a strong emotional reaction and over-recognition. The media was flooded with biographical accounts of people, who survive on the edge of their financial capabilities, who bear the brunt of everyday clashes with a hostile institutional milieu and who don't feel they have any kind of future.

What escapes the public's attention is the fact that the majority of the participants in the protest are coevals of the so-called democratic transition and the efforts of deinstitutionalization, they bear the 'battle wounds' and scars of the multiple economic changes, social crises, and shifts in cultural layers and paradigms that have taken place in Bulgaria since the fall of communism in 1989. They were faced simultaneously with the late effects of the socialist ideological framework of disability (including the notion of the nanny state) and the (ab)uses of EU directives and programs promoting dignified and independent living. How does the generation of the transition reflect the personal and group experience of deinstitutionalization in Bulgaria? To what extent does this reflection navigate the battles for social justice? Do the public representations of living with disability and the relevant life stories manage to empower – or, conversely, to disempower – people with disabilities in Bulgaria? Which are the main tropes, central figures and events in these representations? To what extent do they reproduce the medical or the social narrative of disability, or do they form an authentic, original local discourse of resistance against systemic repressions?

To answer these questions, this article draws on 35 biographical interviews and 10 focus groups with informal and formal carers (parents and childminders, psychologists, social workers, NGO members, etc.) of people with disabilities, conducted in four cities in Bulgaria in 2017–2021 period. The latter shed light on the cultural production of the deinstitutionalization narrative that defines care and support through paternalistic images, heroic storylines and de-autonomizing metaphors. The main thesis is that it made visible repressive institutional contexts and stigmatizing attitudes, however, its central notion of 'supermoms' and 'superkids' who suffer or overcome fateful limitations and injustices impeded the construction of strong social or political agency of both the disabled and carers for the disabled.

*Intervenant