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BOOK REVIEW

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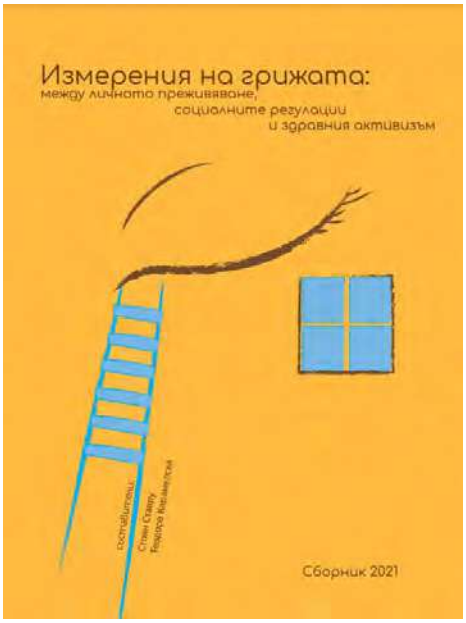
Mapping the Field of Care[1]



Abstract: *The text is a review of "Dimensions of Care: In-between Personal Experience, Social Regulations and Health Activism", a collective volume introducing a variety of perspectives on caregiving in family and institutional contexts, related policies and regulations, on the one hand, and personal experiences, on the other. The value of this collective work lies in foregrounding and mapping out the vast, diverse and unexplored field of care. Moving beyond mono-dimensional biomedical approaches, the authors offer a wealth of conceptual and practical insights that will inspire future work.*

Keywords: *care; disability; medical ethics; social medicine; social policy; health activism.*

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Stavru, S., Karamelska, T. (eds.) (2021). Dimensions of Care: In-between the Personal Experience, Social Regulations and Health Activism. Sofia: Mediina Demokratsia Foundation, ISBN 978-619-90423-5-9, p. 423 p. [In Bulgarian].

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This book[2] does not provide a definition or conceptualization of care. Instead of theorizing care, the volume offers multiple perspectives on different types of care, mobilizing approaches from law and ethics, sociology, psychology and psychiatry, history and philosophy, social medicine, disability studies and social gerontology. From another angle, the chapters of the volume cover the entire life span, from birth to death and from family relations to interactions with institutions. The book is 'populated' by people in need of various forms of care (babies, disabled children, the mentally ill and the elderly) as well as by those providing care, whether families or institutions/professionals.

The first part of the volume comprises four chapters discussing care at home for disabled and terminally ill people. Galina Goncharova introduces the concept of 'alternative social timing' to explore the specific dynamics of care for disabled people and the potential for coping with the crises it entails for the caregivers, most often female family members: mothers, daughters, even granddaughters. Alexandra Traykova draws on two sophisticated insider perspectives – those of cultural theorist J. Stacey and sociologist A. Frank, who have reflected on their own personal experiences of cancer and the cultural narratives surrounding it. Both Goncharova and Traykova frame their cases in ethical terms, evoking the patients' and caregivers' ideas of the 'good life' and the metamorphoses brought about by their condition. While these authors focus on individuals and their (im)possible empowerment, the following two chapters offer a diametrically opposite perspective, addressing the legal and practical aspects of social policies related to care. Ivan G. Dechev, a legal expert at the Ombudsman Institution, discusses the reform in assistance care based on the Personal Assistance Act adopted in 2019. His analysis compares the opportunities and limitations of the National Programme 'Assistants for People with Disabilities', EU-funded projects operated by local authorities, and the provisions of the

[2] Ставру, С., Карамелска, Т. (съст.). (2021). *Измерения на грижата: между личното преживяване, социалните регулации и здравния активизъм*. София: Фондация „Медийна демокрация".

Personal Assistance Act. The author concludes that the Personal Assistance Act is an important step toward better-quality and more accessible care. In the same vein, the following chapter, penned by Martin J. Ivanov and Radoslava Lalcheva, situates home care within Bulgaria's social services system, examining its integration with medical care and the opportunities for personalization and better accessibility. The chapter is based on statistical data of the types of home care, analysis of normative documents and, above all, the authors' own experience in the non-government sector, focused on social services and social entrepreneurship.

The second part of the volume comprises four chapters dealing with childcare and its gendered dimensions. It opens with two very pertinent historical chapters: Milena Angelova explores the medicalization of childhood in the context of anti-tuberculosis campaigns during the first half of the 20th century. She shows how the invention of the category of 'pretubercular children', who were taken away from their families to be educated in 'open-air schools', corresponded to a broader political and cultural agenda of social hygiene. The same period and social context is the focus of Kristina Popova's chapter on social surveys of working-class living conditions conducted by women social democrats in the 1930s. Popova places their activities within the broader framework of women's movements in early 20th-century Europe, highlighting both their solidarity in giving voice to deprived populations and the limitations imposed by eugenic views. Voice is at the core of the next chapter as well, which connects to Goncharova's piece on family care for children with disabilities. However, its author Lyuboslava Kostova focuses on the absence of fathers and their missing voice. She calls for breaking the silence, stressing the importance of including fathers' stories and voices as a prerequisite for social change. Finally, Monika Bogdanova advocates for the relevance of the psychoanalytic paradigm for baby care.

A group of three chapters on obesity and healthy lifestyle stems from a research project led by Sonya Karabeliova and Radina Stoyanova. Under their methodological guidance, a group of psychology students applied various analytical tools to investigate knowledge about obesity, attitudes towards overweight people, and motivations for a healthy lifestyle among 16-45-year-olds. Regardless of the specific correlations established, and despite the limited sample size which pre-

cludes generalization, this part introduces yet another important dimension, that of self-care. Thereby, it contributes to the mapping of the vast and diverse field of care.

Two chapters are dedicated to psychiatric care. Margarita Gabrovska argues that mental illness is less a medical problem than a social one, especially when viewed from the perspective of institutional care. The reason is that mental patients are not treated with a view to re-integration in society but as passive recipients of psychiatric care, which leads to the loss of autonomy and the fragmentation of personality. This is a social problem because of the lack of policies providing psychosocial support. As a specification of, and partly a counterpoint to, the negative aspects of care singled out by Gabrovska, the following chapter details all forms and institutions of psychiatric care in Bulgaria and outlines their organization and functioning. The authors, Vladimir Nakov, Hristo Hinkov and Stefani Nikolova, are affiliated with the National Centre for Mental Health and Analyses where the RECOVER-E project is being implemented. This international project aims to establish well-functioning community mental health teams, offering a possible remedy for practices and policies that fail to meet patients' needs.

The final part of the volume is dedicated to the last stage of the life course – old age and the care of the elderly. Dessislava Vankova's chapter outlines the potential of social medicine to provide principles and guidelines for the health and wellbeing of older people through integrative approaches to health and ageing, promoting active ageing and viewing it in relation to quality of life. The last two chapters focus on one of the most serious conditions of old age – dementia. Boryana Bundzhulova notes the radical differences between the life-worlds of dementia and 'normality', and develops a validation method informed by phenomenology and psychoanalysis, as a way to understand and support people with dementia. Teodora Karamelska takes another perspective, focusing on the psychosocial problems of caregivers. She aptly argues that dementia is also 'a family members 'disease', stressing the daily difficulties faced by relatives caring for the sick. She suggests ways for caregivers to mobilize biographical resources that could potentially result in a positive re-assessment of their experiences.

As a conclusion to this part, and to the volume, Karamelska's interview with Assoc. Prof. Ignat Petrov, psychiatrist and gerontologist, adds the precious personal perspective of a veteran of Bulgarian gerontology and an expert on dementia. His practical advice, captured in the title of the interview, is that the most important for patients is that their

nearest and dearest relate to them with warmth. This message captures very well the essence of the whole book, which combines serious in-depth research with empathy and compassion.

I conclude by recommending this book not only to researchers and students but also to caregivers and general readers seeking to understand care in its multiple modes and dimensions. The ambition of the volume to make visible and map out a broad, complex and diverse field has been successfully achieved. By arguing for the need to overcome mono-dimensional biomedical approaches, the authors offer a wealth of conceptual and practical insights that will no doubt inspire future work.