BOOK REVIEW

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COMMUNITY PARTICIPATION OF CHILDREN WITH CEREBRAL PALSY IN SERBIA: CONCEPTUAL CONSIDERATIONS AND EVALUATION

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ABOUT THE BOOK:

Publisher: Institute of Criminological and Sociological Research, Belgrade, Serbia
Date of publication: 2020

This concise book offers a comprehensive evaluation of community participation of children with cerebral palsy based on theoretical and empirical assessments conducted in the Western Balkans region. The book is written in English and can be downloaded free of charge. Using a clear and reader-friendly style, the author, Dr. Milena Milićević, highlights the characteristics of community participation of children with cerebral palsy in comparison to those of children with typical development. The author also addresses the effect of the environment on community participation through the perspective of the parents.

Following the Introduction, the first chapter provides the theoretical framework for this topic by introducing the concept of “participation” as defined in the International Classification of Functioning, Disability and Health – ICF (WHO, 2001). For more than two decades, participation has been the focus of disability studies since it illustrates the transition from a medical to a biopsychosocial model of disability. With respect to the definition of participation, its position within the ICF structure, and further development of that concept, Milićević points out that this concept is complex and multidimensional, and goes on to explain the need for multidisciplinary strategies and management approaches for research and rehabilitation purposes.

Milićević clarifies the nature of this concept, its place in the ICF structure, and its relationship to other similar and associated concepts. Based on contemporary literature, she differentiates participation from physical functioning, health status, quality of life, health-related quality of life, social participation, handicap, (social) integration, and (social) inclusion. As emphasized in the book, participation can be operationalized, measured, and optimized. This feature may explain the prevailing interest in participation-based research in disability studies. Building on what has already been explored in previous studies, including the fact that the participation of children with disabilities can vary under the influence of different environmental structures, it becomes clear to the readers that further assessment of this topic is necessary.

The third chapter lays the methodological foundations of this extensive research study: the aim
was to examine the characteristics of community participation of children with cerebral palsy in comparison to their peers with typical development, as well as to understand the effect of environment on community participation via the perspective of parents. Readers can obtain detailed information about study design and procedure, research instruments, operationalization of variables, as well as statistical methods and techniques. The sample is described in the last section of the third chapter. The complexities of this research have been addressed by breaking it down into the following research questions: 1) how similar or different is the community participation of children with cerebral palsy and those with typical development; 2) what are the different environmental factors that support or hinder the involvement of children from these two groups in community-based activities; and 3) what is the relationship between functional limitations of children with cerebral palsy and environmental factors that affect the characteristics of community participation.

The fourth chapter is dedicated to the research results. The results are presented using clear, concise, and simple graphs, allowing readers to easily understand their analysis and interpretation. At times, the writing in this chapter may appear excessively academic and hard to follow for a lay reader. The author seems to have considered this in advance and has provided a solution to overcome these difficulties. For instance, the author has summarized key findings from each section in this chapter using take away notes.

The fifth chapter discusses the findings of the study with respect to each of the key research questions. First, the author explains the general characteristics and patterns of community-based participation of children with cerebral palsy, and compares these characteristics to that of children with typical development. Second, she presents a comparison of participation across both groups of children based on the characteristics of individual community-based activities. After comparatively analysing the levels of parental satisfaction with the child’s current participation in community-based activities, the author discusses the environment structures of the community. Another factor that is considered is the difference in the extent of support and barriers to community participation, in particular, differences in the availability and adequacy of resources.

When it comes to the relationship between characteristics of community participation and functional limitations of children with cerebral palsy, gross motor functioning (GMFCS level), fine manual abilities (MACS level) and the level of intellectual functioning were taken into consideration. However, the key messages outlined in this book regarding disability and participation remain the same: children with cerebral palsy face an increased risk of reduced and less diverse participation, as well as lower level of involvement in community-based activities. There are many more barriers and fewer support systems in a community setting for children with cerebral palsy than for those with typical development. This included limitations on the availability and/or adequacy of relevant resources, as well as helpful environments to support the involvement of children in the community-based activities. Additionally, higher levels of functional limitations observed among children with cerebral palsy are associated with lower involvement in community-based activities.

This chapter offers a critical review of the research questions using strong scientific arguments based on relevant literature. All results were analysed from several perspectives and compared to other relevant studies, including previous studies published by Milićević. This book combines theoretical and empirical insights with a variety of other resources to help readers gain a better understanding of the wider context of community participation with respect to children with disabilities regardless of their geographical location. Furthermore, in the section dedicated to limitations and future research directions, the author lists key questions or research topics that must be addressed in the future. This scientific monograph directly contributes to disability studies as a scientific discipline. In the section dedicated to practical implications, Milićević acknowledges that all characteristics of participation are equally important when creating a participation profile for a child with cerebral palsy. At the same time, she emphasises that professionals should take a more active role in arranging, accommodating, and/or modifying the logistics
associated with the child’s desired activities using the participation-based approach.

Overall, this book, entitled “Community participation of children with cerebral palsy in Serbia: Conceptual considerations and evaluation” is unique, comprehensive, and provides adequate details on this subject. As a scientific monograph, it can spark many discussions on the participation of children with disabilities, especially in the Western Balkans where such research studies are lacking. Considering the comprehensiveness of the field of disability studies and its complete thematic and disciplinary openness, as well as its convergence with sociology, pedagogy, psychology, and medicine, I believe that this book can be valuable to raise awareness about the importance of active community participation (i.e.,) the active inclusion of children with disabilities in society. Since it is not excessively long, this book is an excellent introduction to the topic not only for those with a specific interest in this subject, but also for readers with limited prior knowledge, including students of diverse academic backgrounds. Additionally, I recommend it to disability scholars, including those interested in the complexities and ongoing issues associated with the status of children with disabilities in the Western Balkans region, as well as experts and practitioners involved in the planning and organization of systemic support.

REFERENCES