Disability Welfare Policy in Europe

Cognitive Disability and the Impact of the Covid-19 Pandemic

Edited by

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Introduction

Angela Genova, Alice Scavarda and Maria Świątkiewicz-Mośny

Abstract

The introduction presents the pandemic context as the new sanitary surveillance regime that has even more affected persons with disabilities. This book focuses on welfare disability policy, services and practices for and with people with disabilities during the COVID-19 pandemic time, examining the period between Winter 2020 and Spring 2022. A pandemic is a time when changes are accelerated, forcing the emergence of new solutions. The pandemic has called for innovation and reform in all disability welfare policies to overcome increasing and changing social needs. Despite the UN Convention of the Rights of Persons with Disabilities and the European Strategy 2021–2030, the impact of the pandemic has been different in each country according to the features of each national policy framework and local responses. Nevertheless, the European policy framework is the context and the benchmarking reference for the analysis carried out in this work. This book develops a sociological analysis of the impact of the COVID-19 pandemic on policies, services and practices in several European contexts adopting a public sociology perspective. Moreover, the book looks at supportive and self-help activities implemented during the pandemic to answer the needs of the persons with disabilities. By collecting these data, the book outlines and develops the concept of a community of practices as a group of people that share a concern for something they do and learn how to do it better by interacting with each other on a regular basis. Then the structure and the methodological choices of the book are presented.

Keywords: Disability; COVID-19 pandemic; epistemic communities; communities of practice; public sociology; United Nation Convention on the Rights of Person with Disabilities

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1. The Pandemic Context

This book has been planned and written during the COVID-19 pandemic.[1] This has been the first 'modern' pandemic to hit the world (Balla et al., 2020). It has changed the everyday rules and forced subordination to a new sanitary surveillance regime (Armostrong, 1993; Foucault, 1977). Citizens all over the world had to stay in their homes for weeks and even months. Few of them were allowed to go out to work. In their homes they have had to reorganise their daily lives. The use of technology, media and electronic services has exploded (Vargo et al., 2021).

People with disabilities have been even more affected by this new explicit surveillance regime, mainly because of three elements: the potential more severe impact of the disease itself on their health, reduced access to routine health care and rehabilitation services, the different impact that containment measures had on them compared to the rest of the population (Shakespeare et al., 2021; WHO, 2020). The pandemic has exacerbated discrimination against people with disabilities (Eurobarometer, 2019). COVID-19 has increased pre-existing economic, health and social inequalities, amplifying the challenges in tackling discrimination (UN, 2020), such as access to technologies, and therefore online services such as education and health care, as well as work (UN, 2020). Individuals with disabilities have been disproportionately affected by COVID-19 due to attitudinal, environmental and institutional barriers that have been created during the response to the pandemic (UNHR, 2020).

As stated by the Fundamental Rights Report 2021 'the COVID-19 pandemic put to the test the duty of the EU and its Member States to comply with the Convention on the Rights of Persons with Disabilities' (CRPD). Member States introduced a wide range of measures that significantly affected the rights of persons with disabilities. Persons with disabilities and their representative organisations, as well as the structures set up under the CRPD to protect them, took action to ensure that these measures comply with the Convention. Overall, 'the pandemic underlined the importance of involving persons with disabilities and their representative organisations in situations of risk, and the value of strong national CRPD structures' (FRA, 2021, p. 267).

The COVID-19 health system has built up new barriers between people by imposing masks, physical distance, and generating the fear of contagious disease, and all of these factors have influenced relational aspects in society. Barriers that persons with disabilities have usually faced on a daily basis have been worsened by new COVID-19 measures, and recent challenges have emerged regarding the person's full participation in society.

As clearly stated by the UN Report (2020), COVID-19 has further compromised the rights of persons with disabilities and within this context, sociology is called to analyse and discuss a perspective of public sociology (Burawoy, 2005).

2. The Aim of the Book: The Public Sociology Between Community of Practices and Epistemic Community

This book focuses on welfare disability policy, services and practices for and with people with disabilities during the Covid-19 pandemic time, examining the period between Winter 2020 and Spring 2022. A pandemic is a time when changes are accelerated, forcing the emergence of new solutions. The pandemic has called for innovation and reform in all disability welfare policies to overcome increasing and changing social needs. Despite the UN Convention of the Rights of Persons with Disabilities and the European Strategy 2021–2030, the impact of the pandemic has been different in each country according to the features of each national policy framework and local responses. Nevertheless, the European policy framework is the context and the benchmarking reference for the analysis carried out in this work.

This book develops a sociological analysis on the impact of Covid-19 pandemic on policies, services and practices in several European contexts. In 2005, Michael Burawoy, President of the American Sociological Association, highlighted the growing gap between the sociological ethos and the world sociologists' study, calling for public sociology to engage multiple communities in multiple ways and emphasising sociology's particular investment in the defence of civil society. Overcoming barriers between professional, critical, policy and public sociology, this book aims at contributing to the debate on COVID-19 impact on persons with disabilities by focusing on the analysis of policy and services changes during pandemic time, but also on the first-hand data from the protagonist of these changes on practices by persons with disabilities, families and professionals.

To grasp the points of view of the protagonists of these changes, the book looks at supportive and self-help activities implemented during the pandemic to answer the needs of the persons with disabilities. By collecting these data, the book outlines and develops the concept of a community of practices as a group of people that share a concern for something they do and learn how to do it better by interacting with each other on a regular basis (Wenger-Trayner & Wenger-Trayner, 2020). Through a public sociology perspective, this community of practice intends to turn into an epistemic community (Akrich, 2010), a space of knowledge that wants to contribute to the public debate in order to support the policy making process focusing on the rights of persons with disabilities.

Disability covers a very broad area of analysis, in this book we focus on intellectual or cognitive disabilities.

The main research question leading the book is:

Has the COVID-19 pandemic fostered or slowed down reforms in welfare disability policies towards the implementation of the UN Convention of the rights of persons with disabilities and the EU policy framework?

Moreover, we also analysed the role of different organisations (public, private, civil society organization) in the reform and potential innovation process. We wondered whether the changes triggered by the pandemic are boosting people with cognitive disabilities' rights or pushing them backwards. Finally, we tried to disentangle the lessons learnt by these reforms and changes, both in terms of the systemic flaws of disability policy and in terms of the areas of improvement. The focus is not only on the 'catastrophic exceptions and rules' revealed by the COVID-19 pandemic with relation to disability policy making, but the changes triggered by this extraordinary situation, at least in terms of reflexivity and critical thinking.

The debate on welfare disability policies has come across several barriers in gaining a central position in the national policy agenda during the COVID-19 pandemic time. In the recovery time, this work aims at supporting the debate on needs and innovation in disability welfare policy in Europe towards the implementation at national level of the European policy framework focused on the UN Convention and therefore on the rights of the persons with disabilities.

The book fosters discussion of the impact of COVID-19 pandemic on the disability welfare policies at a macro level in terms of European and national policy regulatory framework, at a meso level considering sub-national policy and the institutional level (regional or local policy and practice) and at a micro level considering the impact of COVID-19 on individual, families and disability welfare policy professions.

This book aspires to respond to Buroway's call for public sociology (Burawoy, 2005). It is written for all persons interested in the topic and not only for academic colleagues. Nonetheless, it suggests a critical and reflexive knowledge aimed at supporting the fight against discrimination and the rights of persons with disabilities.

3. The Structure of the Book and the Methodological Choices

The book is organised into three main parts. The first describes the theoretical background and the EU context, the second presents national case studies from European countries and the third one addresses answers and provides inspiration for challenging the building of a more equal world for all.

The first chapter outlines the debate on disability in Europe between path dependency and innovation and outlines 'disability studies' as theoretical background to investigate welfare disability policy. Moreover, it introduces the potentiality of communities of practices and epistemic communities in taking part in the reform process of welfare disability policies. Chapter 2 provides an overview of the impact of COVID-19 pandemic on the rights of people with cognitive/intellectual disabilities, presenting evidence collected by the non-profit organisation 'Inclusion Europe'. The aim of the chapter is to give voice to people with intellectual disabilities through their self-advocacy organisations, focusing on their direct experiences. We focus only on cognitive disability to conduct an in-depth analysis, also in national case studies, because of the additional levels and extents of discrimination experienced by people with this type of disability, which has led them to be among the most affected by the pandemic, as previously outlined (Mladenov & Brennan, 2021).

The second part focuses on national case studies, presenting in-depth analysis of local practices within the national policy framework, outlining a collection of data and voices presenting concrete situations of people with disabilities, their families and personnel working in services, during pandemic time. National case studies focus on welfare policy framework, 'pandemic' rules and individual strategies. By presenting national case studies in a comparative perspective the book outlines possible innovative processes in local social practices, focusing on health, social and educational policy areas, to highlight reform processes in the framework of the European Strategy for the rights of persons with disabilities 2021–2030 and in line with the 'Disability Studies' approach. Case studies are based on quantitative and qualitative data collected through the analysis of official documents and interviews with key informants and local stakeholders.

The six national case studies have been selected to guarantee representative data from different welfare regimes: Hungary and Poland from the Eastern European welfare regime, Italy and Spain from the Mediterranean ones, Norway from social democratic ones, and UK from liberal ones (Fenger, 2007; Ferragina & Kaiser, 2011). Cases are presented in alphabetical order.

In Chapter 3, after describing the Hungarian legal context, the author focus on the COVID-19 pandemic's impact on the daily experiences of parents and special needs educators of children with cognitive disabilities. Results show that this period had a negative impact on children's social behaviour, mental health, and mood. Moreover, parents and educators also experienced hardships in dealing with their children with intellectual disability.

The Italian case study (Chapter 4) analyses two regions: Piedmont and Emilia-Romagna. Even though in both regions measures adopted by the Italian government were applied, the study shows differences in social and health services at a local level. It shows cross-compliance rules and discretion in the enforceability of persons with cognitive disabilities' rights and in the implementation of laws.

In Chapter 5 from Norway the authors discuss the understanding of work as a basic human right, and how work should entail vocational and other regular daily activities for persons with cognitive disabilities. Based on the experiences of the COVID-19 lockdown, the authors argue how the individual right to work must be protected in line with paid work when set under cross-pressure with the individual right to infection control measures.

The qualitative study from Poland (Chapter 6) explores the situation of children and teenagers with autism spectrum disorder (ASD) by analysing organizational discourse and interviews with professionals specialized in autism diagnosis and therapy as well as with parents of individuals with ASD. The results provide an insight into the significance of communities of practices and epistemic communities for the adaptation of individuals with ASD and their families to the pandemic reality.

Chapter 7 is a participatory research on the impact of Covid-19 on the lives of people with intellectual disabilities in Madrid, Spain. The research team was composed of people with intellectual disabilities and a co-researcher from the University of Lisbon, Portugal. The chapter provides an introduction into social policy provisions for people with intellectual disabilities in Spain and then focuses on how people with intellectual disabilities experienced the pandemic and the lockdown. It discusses the need for change on how people are supported and how people with intellectual disabilities were subject to higher restrictions in their right to live independently and in the community.

The UK (Chapter 8) perspective focuses on exploring policies and educational, health and social care-related practices for people with learning disabilities and autism in England, since the outbreak of COVID-19.

All chapters show the differences in managing challenges and potentialities for disability welfare policy in Europe, demonstrating that the full implementation of the UN Convention is still in process and people with disabilities still experience inequality in everyday life.

The last part presents the final chapter suggesting some answers to the main research questions leading the book. Focusing on the analysis of practices, it shows how the space of the community of practices is a starting point toward the development of epistemic communities in the field of welfare disability policy. The last chapter highlights strengths and weaknesses in the policies, services and practices in a European comparative perspective suggesting the key aspects emerging from the sociological analysis at macro, meso and micro levels.

Note

1. Authors of this book are part of the European Sociological Association, Research Network 16 Sociology of Health and Illness and it has been within ESA conference context and relationship that this work has been developed. Authors would like to thank the ESA for the fruitful context of ideas and academic work.

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