

COLLECTIVE ACTION AND CIVIL SOCIETY

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Disability Advocacy in
EU Decision-Making

BY

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INVESTOR IN PEOPLE

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FOREWORD

It is a great pleasure to introduce this book, which draws on evidence from disability movements and campaigns to reveal how civil society can challenge and change the course of policy making. It draws on extensive and detailed research into the dynamics of disability activism within the European Union (EU) and sheds light on the interplay between social movements and governance structures. The focus is both timely and significant, examining how activists have navigated a changing political landscape to advocate for recognition, rights and legislative change.

It explores how the EU became a key arena for policy engagement with civil society, and for disability advocacy in particular. It shows how disabled people and their organisations advanced their cause through collective action by identifying, and taking advantage of, strategic opportunities. The analysis of campaigns, co-ordinated by the European Disability Forum, reveals the successes and the challenges in influencing EU-level decision-making.

The book offers a nuanced understanding of how formalised advocacy coalitions provide civil society with platforms for new kinds of policy advocacy while sometimes constraining the scope of their more radical claims for social change. In this way, it highlights both the achievements of disability movements and the advocacy constraints of civil society structures that become entwined with institutions of governance.

One of the most impactful contributions of this research was the development of a collective action framework for future campaigns led by disabled people's organisations. This is a testament to the author's commitment to producing research that is not only academically rigorous but also practically valuable for the policy communities with which it engaged.

This is an important book that offers a deeper understanding of the interplay between civil society, social movements and governance. Its insights are relevant not only for scholars and activists within the disability community but for anyone interested in the broader dynamics of social movements and political advocacy.

It has been a pleasure to see this work come to fruition and to have played a role in supporting it. I hope it will be widely read and provide a stimulus for further research and for renewed collective action on disability equality towards a more inclusive society for all.

Mark Priestley
Professor Emeritus, University of Leeds

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INTRODUCTION

Studies in governance have identified a shift in power over recent decades: new actors bring necessary resources into public decision-making networks. Interest in changing forms of governance has produced a general consensus that most state governments utilise actors beyond ministerial departments to create and implement policy. Of these new actors, civil society has become a stakeholder representative to be consulted on behalf of citizens. With this has come discourse around the role of civil society. Europe has proven itself to be an important site for disability activists, particularly as the European Union (EU) has developed into a body politic. An experimental sphere of governance, it has been prone to periods of structural openness where gains have been made by the movement in terms of recognition, claims upon the state and legislation. Disabled people and their organisations have utilised windows of opportunity to campaign for legislative change, and these mobilisations have produced varied results. The disabled people's movement (DPM) has organised representation in the EU civil society sphere, which works to secure legislative acknowledgements of EU commitments to realise the rights of disabled people. Through this case study, this book examines the tensions faced by organisations representing social movements in the civil society sphere between cooperation with institutions of governance, co-optation of voice and debates around representation. Questions of legitimacy, mandate and influence are raised in attending to these dynamics.

As the EU has expanded and deepened its governing competencies, a legitimating function for the formal EU civil society sphere has developed. Particular social movement organisations have been selected to participate in this sphere on behalf of the interests of their communities. Here, they face a dilemma: participation in forums and consultations can lead to policies that better align with social movement interests, but such forums frequently lack accountability mechanisms to ensure that the claims of social movement organisations are taken up by decision makers. Understanding how these forums can best be utilised is of key importance to organisations with often limited resources.

While interest in social movements and changing forms of governance are both rich areas of scholarship, less frequently have the two taken an interest in one another. Social movement literature tends to focus on so-called ‘contentious’ forms of collective action, rather than transactional forms of engagement with the state. Studies of governance include reference to ‘stakeholders’ and ‘civil society’ but do not seek to understand the legitimating role these actors play in decision-making processes, the level of influence they exert relative to other actors and the prioritisation of particular voices from civil society over others.

Taking a Gramscian understanding of civil society as a realiser of hegemony *and* a space where counterhegemonic resistance is possible, the book is based on a study that analysed campaigns led by an umbrella organisation that represents the interests of disabled people in EU-level decision making. It also utilises Fraser’s feminist critique of civil society and Habermasian notions of the ‘public sphere’ as a sphere historically constructed for an ‘emergent elite’ (Fraser, 2020, p. 68). In other words, civil society has always been a risky terrain for structurally oppressed groups, holding possibilities of tokenism as well as systemic change. Alongside this, organisations in this space make claims to represent the interests of vast communities with many competing demands. This book will show how civil society acts as an enabler and a constrainer of social movement organisations in realising their potential as historic blocs. While collective action campaigns have been run with success, the dynamics of formal civil society forums also limit the potential of systemic change led by social movements. In the present research I use the term ‘disabled people’ in keeping with the tenants of the social interpretation of disability (unless quoting others). I refer to the DPM when discussing the movement for full emancipation by disabled people and their organisations.

Chapter 1 lays the theoretical ground for the ideas considered in this book from the perspective of social movement literature. Social movement literature studies the dynamics and operations of collective action groups, as well as how and why movements form. This literature places particular interest on the dynamics of protest movements and contentious forms of collective action. Similar interrogations have yet to be extended to organisations that represent social movements in state-sanctioned spaces, who engage in different forms of activism. This chapter draws on social movement literature and positions the research in the context of what is known – and not known – about the dynamics of collective action and the disability movement in Europe. Social movements have been touted as vehicles to enact lasting social change in favour of structurally oppressed blocs. They can be conceptualised as collectives of people, drawn together to challenge an element of society

at a political or cultural level and enact change through this challenge. They are composed of many parts – that is, groups within a social movement hold a range of goals and strategies to enact change. Civil society is a contested space that simultaneously provides a field for social movement organisations to engage in counterhegemonic practices but constrains their potential to act as historic blocs.

Chapter 2 explores civil society as a space in which selected organisations represent social movements to inform policy and decision making and raises questions of representativeness, co-optation and cooperation. This type of ‘transactional activism’ merits consideration as it is one that can be found in governance regimes where contentious activity risks hostile consequences from the state. A range of governance regimes exist in Europe and beyond, including what could be described as ‘flawed democracies’. The chapter considers the role of non-contentious social movement activity and transactional activism in decision making. Examining the dynamics of civil society enables empirical conclusions to be drawn about the actual role of civil society organisations (CSOs) in EU policy making. The chapter raises questions about the relationship between CSOs and the broader social movement they seek to represent. Understanding that civil society agendas are substantially shaped by those of governance institutions, organisations face a complex task of balancing institutional influence with demands of wider movements. The focal point of this research has been a pan-European CSO representing the DPM in the European governance sphere. The chapter then turns to the history of the DPM and the global collective consciousness that arose among disabled people in the 1970s and 1980s. This led to the creation of a unified political movement at a time when the EU was expanding its competencies as a regional actor. The chapter provides definitional clarification in terms like disabled people, the social model and how these have impacted institutional discourses in recent decades.

Chapter 3 completes the theoretical framework for the book using concepts of institutions of governance, networked decision making and the opportunities for social movements within this, as well as potential challenges. In the context of governance, civil society has been activated in recent decades as an increasingly formalised policy actor. Attention has been paid to the transformation of governments and the inclusion of new societal actors, but questions as to *how* certain organisations gain a ‘seat at the table’ remain largely unanswered in this field. The chapter explores the possibilities for collective action in relation to contemporary governance frameworks. A novel method of measuring outcomes of social movement activity using a problem representation approach is proposed. CSOs serve several functions in

decision-making processes and by participating can advance social movement interests. Many of the collective challenges faced today by society are being navigated by complex networks of actors from public, private and societal spheres. This is a departure from direct power exercised by traditional nation state institutions, towards the involvement of market and civil society actors alongside traditional hierarchies. Governance thus refers to the co-ordinated efforts of public and private actors operating in networks of interdependence that interact with markets and hierarchies in the governing of society. This book contributes important insight about the role of stakeholder groups within policy networks. The role of CSOs as stakeholders differs from the role of interest group representatives from the private sphere (e.g. business interest groups or labour groups), as are the resources that connect them to a policy issue. Organised civil society represents an additional participatory opening for citizens to democratically engage with, as well as a monitoring function. The legitimacy provided by stakeholder groups in policy processes is necessary for decision-making processes; however, this can lead to the co-optation of CSOs representing social groups in policy processes.

Chapter 4 outlines the empirical research that informs this book. This research was conducted within a three-year doctoral project funded by a Marie Skłodowska-Curie Innovative Training Network (ITN), titled Disability Advocacy Research in Europe (DARE), that ran from August 2019 – August 2022. Using interviews and archival work, the research looked at the organisational activity of a prominent CSO in EU disability advocacy, selecting three case study campaigns to understand strategies for collective action changing nature of activity in EU civil society spaces, and adaptations to institutional change over recent decades. The chapter also discusses the background to the empirical study, particularly the introduction of legal frameworks that have impacted disability advocacy and disability policy in the EU: the early development of social policy, Treaty revisions establishing formal civil society roles in EU governance and the EU's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which establishes points of contact with disabled people's organisation (DPOs) in the monitoring and implementation of the convention for state parties. The chapter introduces the three main case study campaigns: their aims, strategies and outcomes.

Chapter 5 considers the opportunities and barriers to forming counterhegemonic blocs for collective action in EU civil society. Hegemony enables the state to rule by legitimacy, not force alone. The tension between the creation of 'the new' in tandem with the pull of hegemony is constant in social relations. Defining the boundaries of 'reality' and common sense either by ignoring

views outside those boundaries or by labelling deviant opinions ‘tasteless’ or ‘irresponsible’. The chapter focusses on the potential of civil society to articulate counterhegemonic projects of change by forming historic blocs. How are claims selected and prioritised in collective action campaigns? When do campaigns contribute to a wider (counterhegemonic) movement? In seeking political resources and attention to address the specific interests of their constituent populations, social movement organisations operating within the formal sphere of civil society face competition with one another, which can interrupt the formation of broader, intersectional coalitions of change. The chapter concludes with a discussion of problem frames, how they are used in campaigns and their potential role in creating changemaking historic blocs.

The final chapter introduces a typology of campaigns, and a framework of collective action based on the discussions in previous chapters. It discusses the relationship between civil society and states that has been established in the book and what types of change might be possible to enact within this. It outlines a future agenda for research to interrogate the questions raised by the book. Governance literature has established the emergence of policy networks and, critically, the detachment of these networks from traditional democratic structures. The presence of ‘stakeholder groups’ in these networks is expounded as a potential a method to address the resulting democratic deficit. Governance literature has not yet adequately distinguished between types of non-state policy network actors and the vastly different resources they provide to networks. The role given to stakeholder actors in policy networks is one of legitimacy; they often do so as an unelected body with claims of being representative. Students, activists and scholars alike benefit from this examination of the dynamics of civil society, social movement activity and possibilities of enacting social change.

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SOCIAL MOVEMENTS AND THE EUROPEAN UNION

This chapter begins to explore the theoretical ground for the ideas considered in this book. Social movement literature studies the dynamics and operations of collective action groups, as well as how and why movements form, in particular, the dynamics of protest movements and contentious forms of collective action. The relationship between civil society organisations and the broader social movement they seek to represent can be an uneasy one due to the proximity to the state.

This chapter explores the possibilities of this branch of collective action in relation to social movement literature. First, relevant social movement literature is considered, including a discussion of definitions by key thinkers. From this consideration, I provide a working definition of social movements to ground the present inquiry. An examination of the two primary approaches to the study of social movements follows, and the utility of each of these approaches is discussed. I then turn specifically to the space of civil society and its purposes for social movement organisations (SMOs). The chapter concludes by connecting the concepts to the European context, particularly in relation to the organisations of disabled people operating in the sphere of European governance.

DEFINING SOCIAL MOVEMENTS

Social movement theory extends from the idea that society can be transformed through the liberation of social groups from exploitative relations (Touraine, 1981). Initial social movement scholarship from the USA built on the perspective that ‘relative deprivation’ primarily mobilises protest activity, via

alienated members of society and their feelings of disenfranchisement (Blumer, 1969; Kitschelt, 1987; Smelser, 2011). From the early collective behaviour thinkers, Smelser (2011) distinguishes between types of collective behaviour, from panic responses to norm-oriented or value-oriented movements stemming from 'structural strain'. Blumer (1969, p. 199) considers that:

Social movements can be viewed as collective enterprises seeking to establish a new order of life. They have their inception in a condition of unrest, and derive their motive power on one hand from dissatisfaction with the current form of life, and on the other hand ... hopes for a new system of living. The career of a social movement depicts the emergence of a new order of life.

Blumer's definition covers some important points in relation to the DPM, being a movement that emerged from dissatisfaction with the social, economic and political situation felt by disabled people. In comparison, McCarthy and Zald (1977, pp. 1217–1218) provide an alternative, more passive understanding of social movements as:

[A] set of opinions and beliefs in a population representing preferences for changing some elements of a social structure or reward system in a society.

In this interpretation, the possession of a specific viewpoint is enough to warrant membership of a social movement, rather than any consideration of mobilisation, or conditions leading to a call for change. In a more action-oriented definition, Castells (2004, p. 3) defines social movements as:

[P]urposive collective actions whose outcome, in victory as in defeat, transforms the values and institutions of society.

This definition is useful in capturing the essence of social movements and their power, and it usefully demarcates the success or failure of activities. This book explores successes and failures of social movement activity carried out by a pan-European disability advocacy organisation in the EU which can be understood as a social movement actor. It builds on the definitions of social movement activity provided above, specifically dissatisfaction with current forms of life; hopes for a new order of life via a preference for changing some structural elements of society; and purposive action based on this dissatisfaction that, successful or not, transforms society.

Early concepts like relative deprivation hold use for the analysis of social movements today. Many mobilisations stem from inequalities within a demographic, be it specific material conditions or rights. Touraine (1985, p. 752)