

Social Citizenship and Collective Action:

The case of the Portuguese Disabled People's Movement

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Abstract

Theoretically anchored in New Social Movement theory, citizenship studies and a social model perspective, this research sought to answer the question: “How and in what ways has the Portuguese Disabled People’s Movement contributed to the struggle for social citizenship rights in Portugal since 1974?”. Such an endeavour was achieved through a detailed exploration of a case study combined with comparisons with the development of disability policies and politics in the UK post-1945 and the emergence of contemporary welfare.

Chapter 1 provides the context of and an overview of the study. Chapter 2 explores and engages with bodies of literature which constitute the theoretical anchorage of this thesis. Chapter 3 gives an account of the research design, research questions, data sources, data collection strategies and sampling, providing a self-reflexive account of ethical and political concerns during this research. Chapter 4 offers an historical overview of disability policies and politics in Portugal and in the UK, highlighting factors that enabled the emergence of the Disabled People’s Movements in both countries. Chapter 5 reviews contemporary disability policies and politics in Portugal, comparing and contrasting them with the UK’s. Four main areas are discussed: Benefits and social rights, Education, Work and employment, and Accessibility. Chapter 6 focuses on the development of the Disabled People’s Movement in Portugal. The last two chapters, 7 and 8, consist of a critical evaluation of disability policies and politics, with reference to international influences, as well as assessing the movement’s impact and drawing out the theoretical implications of my findings.

Overall, this thesis investigates the role of social citizenship as a point for resistance to destructive capitalism by the Portuguese Disabled People’s Movement.

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List of abbreviations

- ACAPO** – Portuguese Association of Blind and Low Vision People
- ADFA** – Association of Impaired War Veterans (Portugal)
- ANDST** – National Association of People impaired at Work (Portugal)
- APD** – Portuguese Association of Disabled People
- APEC** – Association for Promoting Education of the Blind (Portugal)
- APS** – Portuguese Association of Deaf People
- BCODP** – British Council of Organisations of Disabled People (Currently **BCDP** – British Council of Disabled People or **UKDPC** – United Kingdom Disabled People’s Council)
- BDA** – British Deaf Association
- CNOD** – Confederation of Organisations for and of Disabled People (Portugal). In the past CNOD was also known as ‘National Coordinating Commission of Disability Organisations’ and ‘National Coordinating Union of Disability Organisations’ – **UCNOD**.
- CNRIPD** – National Council for Rehabilitation and Integration of Disabled People (former **CNR** - National Council for Rehabilitation) (Portugal)
- DA** – Disability Alliance (UK)
- DAN** – Direct Action Network (UK)
- DCODP** – Derbyshire Coalition of Disabled People (UK)
- DDA** – Disability Drivers’ Association (UK)
- DIG** – Disability Income Group (UK)
- DPI** – Disabled People’s International
- EDF** – Disabled Peoples’ International (DPI) or the European Disability Forum
- EEC** – European Economic Community
- EFTA** – European Free Trade Association
- ENDEF** – National Strategy for Disability, 2011-2013 (Portugal)
- EU** – European Union
- FIMITIC** – International Federation of Persons with Physical Disability (originally Fédération Internationale des Mutilés, des Invalides du Travail et des Invalides Civil)
- ICF** – International Classification of Functioning, Disability and Health

ICIDH – International Classification of Impairments, Disabilities and Handicaps

IFB – International Federation of the Blind

ILM – Independent Living Movement

INR-IP – National Institute for Rehabilitation (Portugal) (former **SNR** - National Secretariat for Rehabilitation; **SNRIPD** - National Secretariat for Rehabilitation and Integration of Disabled People)

LGP – Portuguese Sign Language

NLBD – National League of the Blind (Portugal)

NSM – New Social Movement

OECD – Organisation for Economic Co-operation and Development

PAIPDI – National Plan for the Integration of People with Disabilities or Impairments (Portugal)

PNPA – National Plan Promoting Accessibility 2007- 2015 (Portugal)

PPA – Political Process Approach

RADAR – Royal Association for Disability and Rehabilitation (UK)

RI – Rehabilitation International

RMT – Resource Mobilization Theory

SIA – Spinal Injuries Association

SNRIPD – National Secretariat for the Integration and Rehabilitation of Disabled People (Portugal)

UK – United Kingdom

UN – United Nations

UPIAS – Union of the Physically Impaired Against Segregation (UK)

USA – United States of America

WCWB – World Council for the Welfare of the Blind (which was united in 1984 in the World Blind Union - **WBU**)

WCPD – World Coalition of Persons with Disabilities

WFD – World Federation of the Deaf

WHO – World Health Organisation

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1. Introduction

1.1. Background

Disability today is an ever present reality that must not be ignored. The increase in people's life expectancy has transformed each of us into a potential future disabled person. We are all 'temporarily able-bodied' (Rae, 1989: unpagged). Therefore a failure to embrace disability issues and to combat the oppression and exclusion faced by disabled people already has, and will certainly continue to have, a high cost for our future lives and for the quality of democracy.

Social inequality disenfranchises millions of people worldwide, disabled or not. This situation is aggravated by the current economic crisis which represents a further threat to those already deprived. The major cause of such disenfranchisement and deprivation is, undoubtedly, a capitalist mode of production, which "shapes social relations over the entire planet" (Castells, 1996: 471), transforming economic accumulation into the ultimate political and social goal. As a result, economic polarisation is a crushing reality, widening the divide, not only between poor, underdeveloped countries and rich, developed (often Western) ones, but also between different groups within any given country. Data released by the Organisation for Economic Co-operation and Development (OECD) has shown an increase in social inequalities within the OECD countries since 1985 (OECD, 2008, 2011). This is particularly serious in countries such as Portugal, which presents some of the highest rates of social inequality within the EU (Eurostat, 2011; INE, 2010). Amongst its EU counterparts, Portugal presents one of the highest rates of inequality in the distribution of income (6%), and is only exceeded by Lithuania (6.3%), Romania (6.7%) and Latvia (7.3%) (Eurostat, 2011: unpagged). In fact, the income of 20% of the population with the highest income in the country is six times higher than the income of the 20% of the population with the lowest income rate (INE, 2010: 1). In this context of socio-economic inequality, young people below 18 years-old and people over 65 years-old are especially vulnerable, evidencing a higher risk of poverty (22.9% and 20.1% respectively) (INE, 2010: 2).

The connection between disability, poverty and social exclusion has been widely demonstrated (Coleridge, 1993; Stone, 2001). Disabled people are overrepresented within the most poor and most excluded populations, both in the majority world but also in the minority world (Beresford, 1996; Coleridge, 1993; Stone, 1999; Turmusani,

2001; Zaidi and Burchard, 2002; Sheldon, 2005, 2009). The socio-economic status of deprived disabled people is not, however, a consequence of their inability to integrate into society or the labour market, but is instead, as some scholars have claimed, the result of the operation of a capitalist mode of production (Finkelstein, 1980; Gleeson, 1997; Oliver, 1990; Russell, 2002). In order to emancipate disabled people, capitalism needs to be replaced by a more equal mode of production and disability mainstreaming needs to become a reality.

My interest in disability studies, and in this topic specifically, was prompted by four main reasons. First, the fact that disabled people have been one of the groups most discriminated against in society for a long time (Hunt, 1966; Finkelstein, 1980; Barnes, 1990, 1997, 2001b [1991]; Burchardt, 2000; Vernon and Swain, 2002; ONS, 2005). Second, my determination to fight against any kind of social discrimination, including disablism, homophobia and sexism. Third, my personal experience of disability through friends and family members. Indeed, lately, through my professional work in Early Intervention I have also had the opportunity to make close contact with young disabled children and with their families. These experiences have made me aware of the discrimination and oppression encountered by disabled people in a disablist society, such as Portugal. My research is an academic response to this fact. Finally, the fourth factor is my belief in a better and more equal society, in which people's differences are valued rather than repressed. I think that the idea of citizenship may play an important role in this task, and this is why I have decided to focus my study on the construction of disabled people's social citizenship in Portugal.

One could argue that by establishing a division between citizens and non-citizens the concept of citizenship, understood as "membership of a political community" (Taylor-Gooby, 2009: 4), creates inequality. The history of citizenship has shown that those benefiting from this status have persistently tried to restrict it to specific social groups, namely to those who are white and male and who are economically privileged (Glenn, 2000; Hall and Held, 1989; Young, 1989). However, the notion of citizenship also carries within it the potential for equality. It has acted as an important tool in the struggle to create, and maintain, the rights of those considered as lesser, or non-citizens, as is the case with disabled people (Meekosha and Dowse, 1997; Emery, 2009).

Since Marshall (1950), citizenship has come to the fore as a multidimensional concept. For the purpose of this thesis, I am interested in the advanced notion of social

citizenship. This concept encapsulates the right of citizens to a minimum level of social welfare and security, encompassing the right to material welfare, such as access to economic resources, and to non-material welfare, such as fulfilment, happiness, safety, and trust in the future (Marshall, 1963, Dean, 1996; Taylor-Gooby, 2009)

1.2. Focus of Research

In line with Fraser (1997), I believe that social inequality is one of the main hindrances to the development of democracy and thus to the development of the notion of citizenship. I also believe that social citizenship is the key tool necessary to combat these socially created inequalities and to protect citizens against some of the nefarious consequences of the capitalist system. Even if legal change *per se* will not eliminate the roots of disability in the long run (Russell, 1998; Finkelstein, 2001a; Sheldon, 2005), adequate laws and social policies are an essential element in tackling the civil, economic and social discrimination felt by disabled people on a daily basis. Hence, the starting point for my research is that people need access to social rights to be able to exercise basic civil and political rights.

Putting it more clearly, my focus on social citizenship arises from three main reasons. Firstly, in order to exercise their multiple citizenship rights and duties people need access to education, health, welfare, and safety. Civil and political rights are meaningless unless they are accompanied by the social rights necessary to give people the conditions to exercise their multiple citizenship rights and duties. The second reason for my focus stems from the reluctance or unwillingness of the state, which is usually justified on economic grounds, to expand citizens' social rights. Indeed this reluctance has been translated into different welfare-state solutions (Esping-Andresen, 1990; Ferrera, 1996). Thirdly, social citizenship is crucial to the process of including those groups who are traditionally excluded by the capitalist system, such as the economically deprived, those with accredited impairments, or those in old age. The lack of provision of these rights has proven to compromise the exercise of basic civil and political rights by those social groups, who are thus made more vulnerable to social inequalities. Within these excluded groups, I am interested in studying a specific one – disabled people – due to the oppression felt by this group (disablism), which is bound up with

medical or individual explanations that tend to obscure the social nature of disability (Oliver, 1990; Barnes, 1990, 1991; Abberley, 1993; Finkelstein, 2001a; Hahn, 2002).

I am not suggesting that the other components of citizenship are not equally important, or that these do not overlap, but social rights, as one of the last components to be developed and being constantly under threat during periods of economic recession (such as the one we are currently experiencing), need to become, and remain, a major consideration of governments. This is particularly important for people traditionally regarded as dependent and/or passive, such as disabled people, since building a framework of enforceable citizens' rights can be regarded as "the basic structure around which welfare services and facilities can be organised." (Bynoe, Oliver and Barnes, 1991: 5). This is also about transforming the idea of services and facilities as a privilege, dominated by professionals, to a rights-based claim, based on equality between citizens.

Marshall in his theorisation recognised that citizenship has a dynamic character. Citizenship formation is an ongoing process, which is never completed, due to the conflicting interests in society in which individuals and their group formations must fight for their rights, and confront many of the established powers within a specific society. However, as Beckett stresses:

Marshall's intention was only to moderate the worst excesses of capitalism through the promotion of the idea of citizenship and in so doing only to modify, rather than remove, the social class system. (2006: 38)

Notwithstanding the dynamic character of citizenship, Marshall was not interested in a radical change in society, and so he failed to accommodate participation as a key dimension of citizenship (Delanty, 2000; Giddens, 1982). However, unlike Marshall, I do not believe in the meritocracy of the system. I argue that any extension of people's rights is mostly the result of their own efforts to change that system. This is in accordance with the writings of other disability researchers, which state that the most important achievements of disabled people are due to their own efforts and to the efforts of their organisations (Driedger, 1989; Campbell and Oliver, 1996; Barnes and Mercer, 2002).

1.3. Research question

Strategies undertaken by the Disabled People's Movement in the UK, in the United States of America (USA) and elsewhere (Driedger, 1989; Campbell and Oliver, 1996; Fleischer and Zames, 2001), in line with initiatives of other social movements during, and after, the 1960s (Banaszak *et al.*, 2003; Bernstein, 2003; Antrobus, 2004; Santos, 2008), signalled the importance of collective action as a catalyst for change in society. With that in mind, plus the fact that the welfare-state plays a key role in the construction of social citizenship and that these phenomena evolve differently in diverse contexts (Üstün *et al.*, 2001; Ghai, 2001), I felt the need to understand its evolution in Portugal. Thus, I am interested in researching the way that the Portuguese welfare-state has addressed the rights of disabled people, as well as the role played by the Portuguese Disabled People's Movement in shaping and influencing social policies. In other words, I want to study the processes by which disabled people have constructed their social citizenship (Lister, 2003), and the way this notion has become part of a shared identity within the development of a democratic regime in Portugal. Consequently, this thesis tries to answer to the following question:

How and in what ways has the Portuguese Disabled People's Movement contributed to the struggle for social citizenship rights in Portugal since 1974?

Accordingly, this study attempts to consider both the Portuguese welfare-state and the Portuguese Disabled People's Movement. By Disabled People's Movement, and in line with Oliver (1990), I mean the activities and networks created by organisations of disabled people, i.e., those in which "at least 50 per cent of the management committee or controlling body must, themselves, be disabled" (Oliver, 1990: 113). This definition introduces an important difference regarding the notion of a Disability Movement, which includes both organisations *of*, and *for*, disabled people. According to Oliver's typology of disability organisations, my study considers three major types of organisations: consumerist/ self-help; populist/ activist; and umbrella/ co-ordinating (Oliver, 1990:117-118).

Because my research focuses on understanding the processes of citizenship formation and on the interpretation of subjects' experiences, actions and words, qualitative research methods are the most appropriate for this task. This research is based on the

triangulation of different data generation methods, which were applied to different data sources (Mason, 2006). The research involved the following data generation methods:

- 1) Thematic analysis (Attride-Stirling, 2004) which was applied to legal documents/laws, programmes of the government, transcriptions of parliamentary debates on disability policies, documents produced by organisations of disabled people and media coverage of issues relating to disabled people in Portugal.
- 2) Participant observation which was conducted in: I) Portuguese organisations of disabled people (ones created and controlled by disabled people), both those with national scope and umbrella organisations (federations or confederations of organisations); II) at events arranged by these organisations and; III) at general meetings and meetings organised between different organisations.
- 3) Semi-structured interviews with the leaders of selected organisations and with other activists of the Portuguese Disabled People's Movement.

Finally, to enable a comparison to be drawn between the Portuguese and the British cases, I did:

- 4) A literature review of major books and reports produced about the British Disabled People's Movement.

Chapter 3 of this document will elaborate further on how this was done.

1.4. Researching Disability in Portugal: aims of this study

Despite the vitality of a new approach to disability in the UK – based on the idea that disability is socially constructed under cultural regimes that advance oppression, inequality and exclusion (Thomas, 2004a) – which is encapsulated by the emergence of the discipline of disability studies, in Portugal this approach is almost absent. Therefore, while numerous studies about disability policies, the Disabled People's Movement and the oppression and discrimination suffered by disabled people exist in countries like the UK (Oliver, 1990; Barnes, 1991; Campbell and Oliver, 1996; Oliver and Barnes, 1998;

Drake, 1999; Barton, 2001) and the USA (Dejong, 1981; Hahn, 1986, 2002; Albrecht, 2002; Longmore and Umansky, 2001; Krieger, 2003) there is no equivalent in Portugal.

My study intends to rectify this lack of research. Hopefully, it will contribute to an understanding of disability policies and politics in Portugal, as well as of the social movement of disabled people. Secondly, it is also my goal to establish and develop this research field in Portugal, thus helping to create the basis for further work and to promote disability studies within the Portuguese academia, specifically in relation to sociology and social policy scholarship. Thirdly, and taking advantage of the existing disability research in the UK, I hope to offer a comparison between the Portuguese and the British cases. My fourth goal is to bring new insight to the academic debates on social movements and to those on social citizenship. My fifth and sixth goals are more pragmatic. Respectively, I hope that my work may bring visibility to the question of disability in Portugal and create awareness in public authorities and in civil society for the needs and rights of disabled people. Finally, and above all, I expect that this research, and its results, mirror the views of disabled persons so that it can become an active instrument in the fight against disablism in the Portuguese state and society and to foster disabled people's citizenship rights.

1.5. Chapter Outline

This thesis is divided into eight chapters. In the first two chapters (2 and 3) I outline my theoretical and methodological anchorage, which will be followed, in Chapter 4, by an historical contextualisation of disability and disabled people in Portugal. After contextualising my research, I will present the results of my analysis in chapters 5, 6 and 7. Chapter 8 provides a theoretical exploration based on my main findings, which will be summarised in the final conclusion.

Chapter 2 – *Embodying the research: a theoretical overview* – presents the theoretical debates on the interconnected subjects in my study. The chapter is divided into three main sections, reflecting the three main bodies of literature that have been combined in this thesis: disability studies, citizenship studies and social movements studies.

Chapter 3 – *Designing the research: questions, data sources, methodologies and ethics* – discusses the epistemological and methodological aspects of this thesis and research.

It is divided into five sections: the epistemological positioning of this study; the main research questions and aims; sampling methods and strategies; data sources, data collection strategies, fieldwork and data analysis and, the final section presents a self-reflexive account based on my ethical and political concerns.

Chapter 4 – *Disability and disabled people in Portugal: a brief historical analysis* – presents an historical contextualisation of disability and disabled people in Portugal, drawing comparisons with the British case. The analysis is divided into three main historical periods: before the nineteenth century; the nineteenth century and the institutionalisation of disabled people; and the twentieth century up until 1974.

Chapter 5 – *Defining the disabled people's social citizenship project in Portugal since 1974* – considers the main features of the Portuguese welfare-state, comparing and contrasting it with other welfare regimes. It will then focus specifically on disability policies, identifying and discussing their main traits. The final section analyses the implementation of disability policies in Portugal.

Chapter 6 – *The struggle for social citizenship rights: characteristics and strategies of the Portuguese Disabled People's Movement* – offers a critical analysis of the development of the Portuguese Disabled People's Movement and presents its main features. The first section looks at the development of the Portuguese Disabled People's Movement, pinpoints its main features and compares and contrasts it with the Disabled People's Movement in the UK. The second section examines the politics, action strategies and resources mobilised by the movement, and concludes with an analysis of collective identity and unity within the movement.

Chapter 7 – *Balancing the movement: influences and impacts of the Disabled People's Movement in Portugal* – considers the growing influence of external elements in disability issues in Portugal and offers a critical evaluation of the Portuguese Disabled People's Movement's achievements. The first section elaborates on the role played by the UN (United Nations), the EU (European Union) and the international Disabled People's Movement in the development of disability policies and the Portuguese Disabled People's Movement. The second section assesses the impact of the movement on the political, social and cultural spheres.

Chapter 8 – *Citizenship on the edge: insights from the analysis of the Portuguese Disabled People's Movement and future directions* – explores the theoretical

possibilities offered by the particular case of the Portuguese Disabled People's Movement for the debates around social movements and social citizenship, and analyses critically the future of the Portuguese Disabled People's movement.

The final conclusion summarises the main results and theoretical contributions to the field.

2. Embodying the research: a theoretical overview

Introduction

Throughout history disabled people have been amongst the most discriminated against, excluded and oppressed groups, as studies on poverty illustrate (Beresford, 1996; Coleridge, 1993; Turmusani, 2001; Zaidi and Burchard, 2002). Stone (2001) pushes this argument further by acknowledging the existence of a never-ending cycle within which poverty produces impairment and impairment, in a disabling society, is transformed into poverty. However, to stress this connection between impairment and economic deprivation and social exclusion is not to say that the first is the cause and the latter the result. Conversely, deprivation and exclusion experienced by those accredited with any kind of impairment result from the way disability has been socially constructed and the psychological and environmental barriers created around disability (UPIAS, 1976; Finkelstein, 2001a, 2001b). This is precisely what has been suggested by the social model of disability, on which this thesis is largely theoretically anchored. It is my argument that the oppression experienced by disabled people within contemporary societies, and their exclusion from citizenship rights and debates, has pushed disabled people to organise as a social movement in order to push against disabling barriers, improve living conditions and struggle for social change.

Therefore, this thesis draws on three different bodies of literature: disability studies, citizenship studies and social movements studies. The following three sections cover the theoretical debates in the different fields that I bring together in my study. The first section addresses the competing definitions of, models and debates on issues of disability and impairment. The second section deals with theorisations of citizenship from across different political spectrums and focuses on the construction of social citizenship. The third and final section offers an analysis of contemporary theoretical approaches to the field of social movements studies.

2.1. Theorising disability – competing approaches and definitions

The understanding of disability as a social construction is relatively new within social sciences. To interpret disability as a form of social oppression is even more recent. For centuries, disability was reduced to the abnormalities and inabilities of the body (Haffter, 1968; Davis, 1995; Garland-Thomson, 1996, 1997; Winzer, 1997; Barnes, 1997, 2000b; Sticker, 1999; Barnes, Mercer and Shakespeare, 2000). Disability remained individualised, medicalised and unpoliticised. This is not to say that there was no sociological interest in the study of disability, on the contrary, sociological studies in this area can be traced back to the early 1950s. In fact, in the field of sociology, the lives of disabled people have been scrutinised at least since the 1950s as a result of the works of Parsons (1951, 1958) and Goffman (1963, 1987). The first, focusing on the social system, provided an analysis of illness as a social, as much as a biological category and suggested the idea of a ‘sick role’ as a result of medical practice. The second, in contrast, focused on the everyday life of the individual and introduced the notion of stigma and the management of a ‘spoiled identity’. The problem with these studies was, however, that they were:

rooted in conventional wisdom; namely, that accredited impairment , [...] is the primary cause of ‘disability’ and therefore of the difficulties: economic, political and cultural, encountered by people labelled ‘disabled’. (Barnes, 2003: 4)

With the development of the Disabled People’s Movement in the 1970s (Campbell and Oliver, 1996: 64; Beresford and Holden, 2000: 979; Thomas, 2004b: 21), a new era for disabled people began. In the next section I examine this evolution.

2.1.1. Perspectives of Disability

Medical/Individual Model

The development of modern medicine in the western world over the last two or three centuries produced a significant shift in the social understanding of health and illness and in the way society deals with it (Giddens, 1993). As a result, science-based medical diagnosis came to the fore, with ‘curing’ as its main objective (Giddens, 1993); and medical professionals achieved the power to “determine the boundaries between ‘normal’ and ‘abnormal’ individuals, the sane and insane, healthy and sick people.”

(Barnes and Mercer, 2010: 18); disability became individualised and medicalised (Stone, 1984; Oliver, 1990); disabled people became institutionalised and segregated into medical spaces (Finkelstein, 1980; Goffman, 1987; Hughes, 2001); and the medical/individual model became dominant in relation to disability. According to this model, which is centred on the ideas of “abnormality”, difference and incapacity, the barriers and limitations faced by disabled people derive directly from people’s real or assumed impairments. Disabled people are thus converted into non-valid, dependent and passive people, for whom the only envisaged solution is adapting to the ‘disabling conditions’ of their living environment. This task is only possible through a medical and/or rehabilitation intervention, producing the ‘cure’ or physical adaptation. Rehabilitation can be understood as an instrument of transformation of disabled bodies and minds towards ‘normalisation,’ and the surmounting of physical limitations (Oliver, 1990).

In countries such as the UK this model was transposed into national legislation and incorporated, at least from the mid-twentieth century, in the definition of eligibility criteria for welfare benefits (Barnes and Mercer, 2010). In Portugal, as will be explored later on in this thesis, despite the absence of a welfare state until 1974 (Pimentel, 1999; Santos, 1999), the medical model was also paramount at the state level. This is obvious in the creation of medical-pedagogical institutes for the ‘cure’ of disabled children, as well as in the common reference to disabled people as ‘abnormals’, clearly drawing on medical language (Fontes, 2006).

Growing criticism in the UK to this “mechanistic approach to the effects of impairment” (Barnes and Mercer, 2010: 19) led to the development of additional measurements to assess individuals’ ability to perform given activities. This was done in 1969 by the Office of Population Censuses and Surveys in the first national survey on handicaps and impairment (Barnes and Mercer, 2010), which introduced a distinction between impairment, disability and handicaps. The continuous need for such measurements by the capitalist system in order to differentiate the deserving individuals from the undeserving, and by the welfare state in order to allocate its limited resources, prompted the World Health Organisation (WHO) to publish in 1980 the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) (WHO, 1980). In a similar fashion, ICIDH distinguished between impairment, disability and handicaps. Impairment was defined as the loss or abnormality in the functioning of any psychological, physiological and/or anatomical structure. Disability was defined as the

inability, resulting from impairment, to perform a 'normal' activity. Finally, an handicap was defined as the disadvantage experienced by an individual in performing his/her normal tasks, caused by impairment or by disability. Notwithstanding this rupture with the mechanistic and rigid medical model, as several authors argue the ICIDH continued to present a limited vision of disability (Oliver, 1996; Barnes, Mercer and Shakespeare, 2000; Oliver and Sapey, 2006) and to downplay the impact of social factors on impairment (Armstrong, 1983). Despite acknowledging the social consequences of disability and/or impairment, expressed in the idea of an handicap, this classification continued to rely on medical definitions and on the individualisation of disability. Moreover, by locating the source of 'disability' and 'handicap' in 'impairment' the ICIDH persisted in attributing all the barriers faced by disabled people to their real or supposed impairments, rather than to society (Barnes and Mercer, 2003; Barnes, Mercer and Shakespeare, 2000), leading disability activists to criticise it (Finkelstein, 1980; Oliver, 1990; Oliver, 1996; Pfeiffer, 1998).

In sum, the implementation of the medical model has had significant consequences for the lives of disabled people. Firstly, defining disability as a medical problem presupposes the existence of a corresponding medical solution. Disabled people's needs, which were regarded as special, came to be defined, controlled and managed by disability medical 'specialists' and 'professionals' (Finkelstein, 1980; Oliver, 1990; Barnes, Mercer and Shakespeare, 2000). Disabled people became trapped in a non-symmetrical power relationship (Barnes and Mercer, 2010). As a result, disabled people are invalidated, put in situations of dependency and seen as passive regarding their own lives and in their capacity for problem-solving (Hughes, 1999, 2000, 2001). Secondly, by limiting disability to the individual sphere, medicalisation thwarts politicisation, as will be analysed throughout this thesis. Thirdly, and most importantly for this research, it not only, "downplays the potential of social policy reforms and of legislation to guarantee disabled people full citizenship rights" (Barnes and Mercer, 2010: 23), but also denies disabled people citizenship status because of impairment.

Social Model

By the time the ICIDH was published, a new approach was taking shape at the hands of disability activists in the UK and USA, who criticised the impact that the medical and individual model had had on their lives and emphasised instead the organisational

aspects of society. In this process two key factors played a crucial role: first, the increasing criticism of medicine from within (Mishler, 1981; Armstrong, 1983) and the avowal of preventive medicine over remedial medicine (Moon, 1995) and, second, the emergence and consolidation of new social movements demanding the recognition of rights (Langan, 1998). In this respect, it is important to draw attention to the appearance of organisations of disabled people in the UK, which resulted in the creation of the social model of disability (Oliver, 1990, 2004; Finkelstein, 2001a), and to the development of the Independent Living Movement (ILM) in the USA and to the demand for civil rights for disabled people (DeJong, 1981; Coleridge, 1993).

Focusing on the creation of the social model of disability, the formation of the Union of the Physically Impaired Against Segregation (UPIAS) in 1972 by dissidents from the Disability Income Group (DIG), established in 1965, played a major role in its development. In fact, disappointment with DIG – namely its concentration on symptoms, rather than on the causes behind poverty, and the specialist economic jargon used in many of its meetings (Campbell and Oliver, 1996; Oliver, 1990) – prompted former DIG members, like Paul Hunt and Vic Finkelstein, to form UPIAS in order to focus on what they considered the biggest problem faced by disabled people – oppression.

In 1976 UPIAS made an important contribution to the creation of the social model of disability by publishing its manifesto, entitled *The Fundamental Principles of Disability*. One of the biggest achievements of this document was the distinction that was made between ‘impairment’ and ‘disability’. The former referred to biological and bodily individual aspects, like “lacking part or all of a limb, or having a defective limb, organ or mechanism of the body” (UPIAS, 1976: 14), and the latter referred to the socially produced phenomenon of exclusion and oppression of disabled people from mainstream society. As Oliver suggests, “disability has nothing to do with the body but everything to do with society” (1996: 35). Disability is, therefore, not created by impairment but by society, which disables people with impairments. With this conceptual redefinition, UPIAS managed to transform ‘disability’ from a medical and individual problem, into a socio-political issue (UPIAS, 1976; Oliver, 1990), revolutionising its theorisation and laying the work for the creation of the Social Model of Disability. Therefore, by separating the biological and the individual from the social, this approach managed to highlight the central place of society and culture in the ongoing exclusion of disabled people and to create common ground for the

development of the Disabled People's Movement in Britain. This last step was achieved through the formation in 1981/1982 of the British Council of Organisations of Disabled People (BCODP) (currently United Kingdom Disabled People's Council (UKDPC)) (Campbell and Oliver, 1996), as will be analysed later on in this thesis.

The social model of disability has been responsible for many empowering changes in the lives of disabled people, as well as for the emergence of a new field of study in the UK – disability studies (Barnes, 2000a; 2004a; 2004b). This politically engaged disability research approach has not only produced an enormous volume of scholarship, evidencing the oppression and exclusion of disabled people within British society (Barnes, 1990, 1991), and contributed to legal change, but it has also been the theoretical arm of, and functioned as a think-tank for, the Disabled People's Movement in the UK.

Notwithstanding the liberating character of the social model of disability for disabled people, it is not free from criticism. Some criticisms state that it represents an 'oversocialised' vision of disability (Bury, 1997). Much of this criticism argues that the social model forgets the daily-life experiences of disabled people, which reveals the limitations of a social barriers approach (Morris, 1991, 1996; Crow, 1992, 1996; French, 1993; Shakespeare, 2006). Criticism also argues that the social model fails to recognise the importance of the cultural and discursive processes in the creation of disability and disablism (Shakespeare, 1997a; Corker and French, 1999; Shakespeare and Watson, 2002) and that it ignores the multiple, intersectional and simultaneous oppressions experienced by disabled people on grounds of ethnicity (Stuart, 1992, 1994; Bell, 2006), sexuality (Shakespeare *et al.*, 1996; Tremain, 1996), gender (Morris, 1991, 1996; Thomas, 1999; Wendell, 2006) and age (Zarb and Oliver, 1993; Priestley, 2003), for instance. Finally, it is also worth noting the criticism it has received from specific groups, who accuse social model theorists of disregarding the socially constructed roots of impairment itself, pushing it into the realm of medical interpretation. This is the case for deaf people (Ladd, 1988; Corker, 1998), but also for people with learning difficulties (Goodley, 2000).

In sum, these new perspectives focused the debate on culture and difference. They proposed an upgrading of the social model in order to include the diversity of experiences within the community of disabled people as well as attending to the

differences within gender, ethnicity, sexuality and impairment. In response to these criticisms the social model theorists state that:

the social model of disability is just that, a model, not a social theory. Therefore it has the capacity to be used to understand a range of different experiences rather than necessarily dictating to disabled people what their experiences should be (Oliver and Sapey, 2006: 35)

Relational / Bio-Psycho-Social Model

Continued criticism of the ICIDH and the internal dissent within disability studies highlighted the need for a reconciliation of the medical and social models. Such criticism led to a new model of disability, referred to as the relational model (Thomas, 1999) or the bio-psycho-social model (WHO, 2001). Thomas, who works from a feminist materialist perspective, argues for the use of the notion of disability as a social relational phenomenon, i.e., as a result of “the social imposition of restrictions of activity on impaired people *and* the undermining of their psycho-emotional well-being” (1999: 56). Thus, Thomas tries to accommodate the social oppression identified by social model theorists alongside ‘impairment effects’ – “the restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense.”(1999: 43).

According to Thomas:

impairment and impairment effects should not be naturalized, or dealt with as pre-social ‘biological’ phenomena. They are profoundly bio-social, that is, shaped by the interaction of biological and social factors, and are bound up with processes of socio-cultural naming. (1999: 43)

The experience of disabled people is thus a result of the interaction between disability, understood as the sum of social and psycho-emotional conditions, and impairment effects, understood as socialised biological features. Therefore, Thomas adds social aspects to the discussion of impairment and introduces individuality into disability analysis.

The WHO made a similar attempt to integrate biological and social factors in 2001 with the replacement of the ICIDH with the ICIDH2, which was later renamed as the

International Classification of Functioning, Disability and Health (ICF). Despite its markedly medical concentration on the classification of the consequences of health conditions (Barnes, Mercer and Shakespeare, 2000; Pfeiffer, 2000; Thomas, 2002), in this version of the ICIDH the social aspect of disability is recognised within 'contextual factors'. As this document proposes, disability, here presented as 'activity', is the result of the 'interactions between health conditions (diseases, disorders and injuries) and contextual factors'. It recognizes two types of contextual factors: personal factors (like: gender, age, coping styles, social background, education, profession, past and current experience, etc.) and environmental factors. It is precisely within the environmental factors that the social aspects of disability are recognised. They include: social attitudes, architectural characteristics, legal and social structures as well as climate, terrain, etc. (WHO, 2001). Notwithstanding the improvements introduced in this document in order to consider the social aspects of disability, disability continues to be regarded as a health, rather than, a political issue, and an individual, rather than, a social issue (Hurst, 2000; van de Ven *et al.*, 2005; Barnes and Mercer, 2010).

Despite the merits of this last approach in combining the medical and social models, it can still be criticised for lacking the political scope offered by the social model. As is the case with the medical model, the focus in the relational approach continues to be on the individual. It is at the individual level that psycho-emotional well-being (Thomas, 1999) is formed and that health conditions (WHO, 2001) are experienced. Moreover, regardless of the merits of such perspectives, people still live in an unequal society with different social powers, and, historically, most politicians have been on the side of medicine rather than on the side of disabled people. This perspective is therefore too risky in political terms, particularly in an analysis of the Portuguese case, where the social model never had the expression it did in the UK. Arguably, only a social oppression approach – by refocusing attention on society, its structures and culture, and rendering visible the barriers that exclude disabled people from the citizenship process – can offer common ground for negotiation and produce social change with emancipatory impact on the lives of disabled people.

2.1.2. Theories, history and development

The lack of a theorisation of disability from a social perspective soon gave rise to new theories and histories concerning the emergence of the category of disability. In the North American context, drawing upon American functionalism and deviance theory, important works emerged linking the social construction of disability with the evolution of society. According to Barnes (2000a), the works of Stone (1984), Wolfensberger (1989) and Albrecht (1992) epitomize this tradition.

Stone, in her book *The Disabled State* (1984), outlines the idea of disability as an administrative category constructed by the state to accommodate the needs of those who cannot work. Since labour is the core system for the production and distribution of goods, a second system, based on the perception of needs, where access is conditioned by medical and political criteria, was conceived to accommodate those who cannot, or do not want to, work (Stone, 1984). For Stone, the construction of disability is thus the result of the concentration of power on medical professionals and of the need to reduce access to public provision.

Wolfensberger (1989), extending Stone's argument, states that this construction is a latent function of the acceleration, from 1945 onwards, of the human service industries. Accordingly, the existence of large numbers of dependent and non-valorised people is indispensable to the existence of these industries and to the security of its jobs (Barnes, 1997). Albrecht goes even further stating:

In our society, social problems have become the objects of massive human services that drive our economic system. These businesses identify social problems embedded in individuals and their social relationships, reify them, and make them and their solutions commodities to be bought and sold in the marketplace. (1992: 27)

Hence, current societies first create specific types of illnesses, impairments and disabilities and then commodify them through their transformation into trade opportunities and the creation of a 'disability business' and a 'rehabilitation industry' (1992: 28).

In the European context, and deeply influenced by Marxist and materialist perspectives, the British tradition presents a more radical and emancipatory approach. Within this

tradition I would stress the importance of four authors: Hunt, Finkelstein, Oliver and Barnes. Hunt (1966) was one of the first to focus on social rather than biological factors surrounding disability. Through considering several personal accounts of disabled people he stresses that:

the problem of disability lies not only in the impairment of function and its effects on us individually, but also, more importantly, in the area of our relationship with 'normal' people (1966: 146)

The work of Finkelstein (1980) represents the first historical materialist account of disability. Here, Finkelstein conceives disability as a social problem connected to the evolution of the dominant modes of production over time. He states that disability was produced by, and is a direct result of, the development of Western industrial societies. Based on this materialist perspective, Finkelstein pinpoints three stages in the history of disability. The first corresponds to a pre-industrial stage, characterised by the participation of disabled people in the economic life of their communities. The second phase, emerging with industrial capitalism, marked the beginning of the exclusion of disabled people from the labour market due to their alleged inability to adapt to the needs and pace of the new production machinery. This period witnessed the beginning of the segregation of disabled people into institutions outside of society. The third phase corresponds to a post-industrial society where technological development is expected to produce a social and economic revolution that will free disabled people and contribute to their inclusion in society.

In 1990, Oliver provided a more insightful understanding of the transition to a capitalist system and its implications for disabled people. Oliver extended Finkelstein's argument about the changes in the modes of production by taking into account the modes of thought and the relation between both. For Oliver, as with Finkelstein, the restriction of activity imposed on people with impairments, i.e. disability, emerged with industrial capitalism. As Oliver argued, within the capitalist system, disability took a new specific form, that of tragedy (Oliver, 1990). Disability is thus an ideological construction of capitalism. Ideology, understood as "a set of values or beliefs underpinning social practices" (Oliver: 1990: 43), is the key to understanding the social creation of disability and the economic and social disadvantages associated with impairment. Hence it was the combination of this central individualistic ideology, with the peripheral ideologies of rehabilitation, medicalisation, and personal tragedy, that led to the medical and

individual perspectives on disability and thus helped to push disabled people towards segregation.

Finally, the work of Barnes (1991; 1997) widened the perspectives conceived by the previous authors by tracing the oppression of disabled people back to the foundations of Western society. For Barnes, the nineteenth century, with the legacy from Enlightenment, utilitarian philosophy and belief in progress, simply provided new ground for the crystallization of old myths and practices. Nonetheless, it was after the nineteenth century that current hegemonic conceptions of disability were forged: namely, the individualization and medicalisation of bodies and minds, and the segregation of disabled people from their communities (Barnes, 1997: 18).

These approaches are representative of two different foci within the social model, or two social models: a materialist and an idealist social model (Priestley, 1998; Finkelstein, 2001a; Sheldon, 2005). The materialist position stresses the creation of disability by the capitalist mode of production (Finkelstein, 1980; Oliver, 1990) and the idealist position understands disability as being culturally constructed on a daily basis by religion and traditional beliefs (Barnes, 1991, 1997; Barnes and Mercer, 2003). Both perspectives impact directly on disability research:

Models which stress the social creation of disability in material terms will engender research which focuses on structural or institutional barriers; models which stress the social construction of disability in cultural terms will engender research which focuses on disabling attitudes and representations. (Priestley, 1998: 76)

The research presented in this thesis acknowledges the importance of both perspectives within the social model.

During the 1990s, there emerged what I would call a second generation of disability writers (Morris, 1991; 1996; Stuart, 1994; Crow, 1996; Shakespeare, 1997a; Corker and French, 1999). These new perspectives (which include the previously mentioned criticism of the social model of disability), centred on the role played by culture in disability, on the need to include personal experience in the disability debate and the need to acknowledge not only disability but also impairment in disability research. These questions, the authors claim, had been forgotten by the first generation of disability theorists.

The 1990s also witnessed the emergence of more eclectic perspectives (Shakespeare and Watson, 1998; Priestley, 1998; Thomas, 1999) emphasising the need to combine both visions. The main idea here was the need to understand the individual experience within a structural analysis of the disadvantages and oppression faced by disabled people in a disabling society. These views are particularly important in my research since I believe that the social model is not obsolete and I doubt it ever will be, although I also recognise the need to consider the diversity that exists within commonality and the importance of culture in shaping disability.

In the 1990s there was also a set of new perspectives deriving from a post-modernist and post-structuralist background. These new perspectives questioned the earlier materialist grand theorising proposed by scholars such as Finkelstein (1980), Oliver (1990) and Barnes (1991, 1997) and, drawing on the works of the French philosophers Jacques Derrida and Michel Foucault, suggested a new approach which rejected modern binary oppositions, focusing instead on culture, language and discourse (Barnes and Mercer, 2010). This post-modern thinking can be found in the works of disability scholars such as Davis (1995) and his exploration of cultural responses to impairment across time; Shakespeare (2006; Shakespeare and Watson, 2002) and his constructionist analysis of the body, impairment and disability; and Garland-Thomson (1996, 1997), with her study of the cultural and historical construction of the 'physically disabled body' in American society and literature.

Again, notwithstanding the significance of such analyses for deconstructing established conceptions of impairment and of the body, I am persuaded by Barnes and Mercer when they suggest that these proposals:

sidestep the material reality of impairment and provide little or no insight into how the problem of disability might be resolved in terms of policy or politics. (2010: 95)

Therefore, as they have been presented so far, post-modernist and post-structuralist theories have little pragmatic use in terms of disability activism which aims to foster the citizenship status of disabled people.

2.2. Theorising citizenship

Theoretical debates have been particularly important in raising political consciousness amongst disabled people of the oppression exercised by society; they have also revealed the flaws in the citizenship status of most disabled people, as well as disabled people's exclusion from enjoying most citizenship rights (Barnes, 1991, 1992a; Barton, 1993; Doyle, 1995; Oliver, 1996; Barnes, Mercer and Shakespeare, 2000; Barnes and Mercer, 2003). In the last two decades the rhetoric of citizenship has framed the dominant discourse in these academic debates (Isin and Turner, 2002; Beckett, 2006) but also in government policies, in EU strategy (Treaty on European Union, 1992; Twine, 1994; Wiener, 1997; Roche, 2000; Foreign and Commonwealth Office, 2007; Willen, 2007) and in social movements' discourses (Campbell and Oliver, 1996; Foweraker and Landman, 1997).

The idea of citizenship is, however, much older than this. Rooted in the development of democracy in Athens and Sparta during the fifth century BC (Dwyer, 2004a; Held, 2006), the classical idea of citizenship revolved around the individuals obligations towards their community of belonging, in this case, towards the *polis* or the city-state. Citizenship was equated with participation in public affairs (Held, 2006). This idea was replicated by the Romans in the notion of *civis*, i.e., a member of the *civitas* or the city-state (Dagger, 2002), which was gradually transformed in order to be equated with a set of rights and duties, and extended in order to include everyone living within the empire (Dwyer, 2004a). Citizenship entails, therefore, both a legal and an ethical dimension, also understood as a civic virtue (Dagger, 2002). If the first includes the legal status and privileges associated with being a citizen of a particular community or state, the second refers to the urge to take part and actively participate in this life, and in the administration of the community, the commitment to pursue the common good of the community. As has been widely noted, however, this notion of citizenship is exclusive in nature, being restricted to free, property-owning, adult men, and excluding women, slaves, outsiders (Faulks, 2000; Dagger, 2002; Dwyer, 2004a; Hoffman, 2004; Beckett, 2006; Held, 2006) and, I would add, disabled people. As it has been widely reported (Barnes, 1997; Veyne, 1989; Winzer, 1997; Stiker, 1999), such an ideal of citizenship, based on the natural strength of its citizens, impacted directly on the way society dealt with disability. Disabled people were denied citizenship rights at the moment they were born, with the widely sustained practice of infanticide and the exposure of newborn children with visible physical impairments (Veyne, 1989; Winzer, 1997; Stiker, 1999).

The ideal of republican citizenship can be found in the writings of the classical authors, such as Aristotle, Plato and Cicero, who denied disabled people citizenship status. Aristotle, for example, wrote in his work *Politics* (1998): “As to the exposure and rearing of children, [...] let there be a law that no deformed child shall live.” (cited in Winzer, 1997: 82). After centuries of being disregarded, this republican citizenship re-emerged in the writings of Rousseau, Montesquieu and, more recently, in the works of Marx and Engels (Held, 2006).

From the seventeenth century onwards, a new form of political thought and, ultimately, of citizenship came to life, currently referred to as liberalism and liberal citizenship (Schuck, 2002; Dwyer, 2004a; Held, 2006). As Held argues:

liberalism sought to restrict the powers of both [clerical and Church power and ‘despotic monarchies’] and to define a uniquely private sphere independent of Church and state. (2006: 59)

The emergence of liberalism signaled a shift from a “monarch-subject relationship to a state-citizenship relationship” (Heater, 1999: 4) and the transformation of the notion of citizenship into a more inclusive and egalitarian concept (Beckett, 2006). This new ‘view’ of citizenship is based on the primacy of the individual and on the importance of their autonomy of action; the idea is that “individuals should be free to pursue their own preferences in religious, economic and political affairs” (Held, 2006: 59), free from the interference of the state. However, as has been noted this is a highly state-centric notion of citizenship (Dwyer, 2004). Moreover, its apparently more inclusive and egalitarian character can also be disputed from the point of view of disabled people. Arguably this ideal of citizenship ignores the role of differentiating factors within society in the exercise of freedom. In fact, disabled people have been continuously excluded from the exercise of their citizenship rights as a result of impairments and due to their economic and social positioning. This was the case with disabled people living within disability institutions (Miller and Gwynne, 1972; Hunt, 1966, 1981). It is still the case for most disabled people, whose citizenship rights are restricted by social, economic, psychological and physical barriers and who are dominated by poverty (UPIAS, 1976; Beresford, 1996; Coleridge, 1993; Finkelstein, 2001a, 2001b; Turmusani, 2001; Zaidi and Burchard, 2002).

Contrary to other understandings of citizenship, the type of liberty suggested by liberal citizenship can only be achieved through the granting of civil and political rights to citizens by the state. As Held states, the great dilemma of liberal thinkers has been that “of finding a balance between might and right, power and law, duties and rights.” (2006: 59). This is echoed in the writings of the three classic expositors of liberal theory: Hobbes (1588-1679), Locke (1632-1704) and Stuart Mill (1806-1873). For these three authors, who built on the work of each other, the main issue was how to balance “the liberty of the individual and [the] sufficient power for the state to guarantee social and political order.” (Held, 2006: 61). If Hobbes, despite his concern with the liberty of the individual to express itself, was keen to sacrifice some liberty to the sovereign for security and peace (Held, 2006), Locke rejected this idea of a concentration of power, having doubts about the necessary social consensus implied by Hobbes, and emphasised instead a more instrumental understanding of the state, whose task was to protect individuals’ rights in order to permit their personal and, by implication, their social progress (Schuck, 2002; Held, 2006). Stuart Mill took Locke’s ideas even further by advocating that “individual liberty and state action tend to be opposed; increasing the latter reduces the former.” (Schuck, 2002: 134). He thus made a distinction between those activities solely affecting an individual’s own interests and those which also affected others, stating that, if in the latter case interference by the state might be justifiable in the former it was not. These thinkers provide the basis of classical liberal theory, which presupposes the primacy of individual freedom, of private property and shows a constant suspicion of the state’s interference in individuals’ activities. Here, citizenship was no more than a status, the status of belonging to a state whose main task was to protect individuals’ rights and their liberty of action in order to facilitate their projects.

Again, this idealisation of citizenship, despite the differences between the different authors, continues to exclude disabled people, not only from its debates but also from the exercise of citizenship rights. By resorting to a formal notion of citizenship, it disregards the barriers and the access mechanisms to the exercise of the citizenship rights it entails. An example of this is the exclusion of disabled people from the right to vote due to learning difficulties, physical barriers or the lack of accessible information (Scott and Crooks, 2005; Barnes and Mercer, 2010). In the twentieth century the debate was widened by the development of conservative neo-liberalist perspectives and neo-republican theorisations. Simultaneously, a social-liberal (Beckett, 2006) or egalitarian

liberal (Dwyer, 2004a) perspective also emerged creating a fracture within liberal thinking by dislocating the relationship between the individual and the market, proposed by libertarian liberalism, to recentre attention on the individual's relationship with the state and recognising the need for state interference in order to reduce market-linked inequalities (Delanty, 2000; Dwyer, 2004a). This tradition, prompted by the likes of Marshall (1950; 1963) and Rawls (1971; 1985), is of particular significance to my research because, notwithstanding coming out of a liberal perspective and arguing for the primacy of the individual, it centres the debate on issues of social inequality.

Marshall (1950), in his seminal work on citizenship, presents an understanding of citizenship as a set of rights and duties uniting subjects with the state, and identifies three generations of rights – civil, political and social. Each right was seen by Marshall as having developed during a specific stage of society. Civil rights started to develop first and achieved the biggest universal expansion, comprising the right not to be discriminated against in terms of race, religion and political ideas, the right of freedom of speech and movement, the right to be respected, etc. Political rights were less universal and more slowly implemented. They encompass the right to participate in political life, to elect and to be elected for political positions, to create political parties and political movements. Finally, social rights were seen to be even more unevenly distributed and correspond to the right to a minimum level of social welfare, material welfare (such as access to economic resources) and to non-material welfare (such as fulfilment, happiness, safety, and trust in the future) (Dean, 1996). Marshall's theorisation, despite focusing on the modernisation of the UK (Mann, 1987; Roche, 2002), presents an interesting portrayal of citizenship as an ongoing and unfinished process, as a result of antagonistic interests in society, which can be affected by different processes and whose constellation may vary geographically. Social citizenship is a good example of this fact, since its development, until now, has been limited to the central countries, where it has been associated with the post-war welfare-state. One main problem with Marshall's theorisation of citizenship is, as Ellison suggests that "It is not intended to eliminate all possible inequalities [...] but to convey an overarching sense of community and social cohesion" (1997: 699). Marshall's theory has been, however, subjected to much criticism, including its lack of consideration of the power differences within a given society (Beckett, 2006); its disregard of cultural diversity (Delanty, 2000; Roche, 2002); its failure to accommodate participation as a key dimension of citizenship (Delanty, 2000; Giddens, 1982); its assumption of a separation

between the public/private spheres of life (Delanty, 2000; Lister, 2003); and its underlining error – its conceptualisation of social rights as belonging to the same family as civil and political rights (Oliver and Heater, 1994), or even citizenship rights (Rees, 1995a, 1995b; Barbalet, 1988). Arguably, and in line with Ellison (1997), Marshall's theory can also be criticised for overlooking disabled people's oppression and consequently for being unable to tackle structural disabling factors. In fact, Marshall's linkage of social change with the evolution of citizenship rights overlooks the oppression of disabled people and their exclusion from the citizenship project.

The work of Rawls is also worth considering here. Despite his theory being centred on the notion of justice, rather than citizenship, Rawls' importance resides in the fact that he pushes the limits of liberal thinking. In fact, by highlighting the need for liberalism to develop a notion of distributive justice, Rawls questions the supremacy of the principle of the market, defends the need of the state to recognise social rights and legitimises, contrary to most liberal thought, the state's intervention in individuals' lives (Dwyer, 2004a). This idea is extremely important from the point of view of disabled people, bearing in mind that it was precisely this lack of distributive justice in countries such as the UK and Portugal that prompted disabled people to take collective action. This is, however, a limited vision of citizenship, a 'statist' vision that is more concerned with creating social consensus than with tackling the roots of existing exclusions. In fact, as Faulks (2000) remarks in relation to social citizenship, the problem with liberals is that they tend to view social citizenship rights as a form of compensation for exclusion, rather than as part of citizenship itself.

If the 1970s saw a revival of neo-liberal thinking, the citizenship debate in the 1980s was marked by the emergence of communitarianism (Delanty, 2002). Communitarianism can be seen as the return of republicanism to the citizenship debate and a need to combat the elitist notion of democracy that became dominant in the post-war period (Hoffman, 2004). This new way of thinking about citizenship was characterised by a total rejection of individualism. As they argued, our identities as individuals are socially embedded (Dwyer, 2004a; Hoffman, 2004). Instead it proposes "a more contextualized concept of citizenship as the expression of community" (Delanty, 2002: 162), more specifically, of community's culture and identity. This branch of liberal thinking has been advanced by several authors, of which Taylor (1989, 1994) and Etzioni (1996) are perhaps the best known. This group of authors sought a deeper understanding of the notion of the community and of the cultural anchorage of

that community, preferring to talk about identity and participation in the community, rather than about rights of individuals (Taylor, 1995). For them, citizenship is more than just membership of a political community, or a state, and their quest is more of an archaeology of that community from which citizenship derives (Delanty, 2002, Dwyer, 2004a; Hoffman, 2004).

The advent of novel social processes affecting the nation-state and changing spheres of social, economic and political life in the last few decades brought these different theorisations of citizenship under growing criticism. As Ellison explains:

decline in 'organising capacity', or at least in the state's erstwhile role as the *dominant* co-ordinating institution in economic, social and political spheres, has consequences for the theory and practice of citizenship, for the changes associated with globalisation, or extensive 'internationalisation', implicitly question the relevance of a homogeneous 'membership' defined in terms of rights derived from, and duties owed towards, specific national communities. (1997: 704)

This led to the emergence of new perspectives that focused on the need to address the rights of special groups within the framework of citizenship within pluralistic societies. They constitute what is usually called a pluralist/multicultural account (Ellison, 1997; Beckett, 2006), which is represented by thinkers such as Young (1989, 1990) and Kymlicka (1995, 1998). Drawing upon the theorisations of citizenship analysed above, with the exception of some communitarians, results in a universalistic conception of citizenship, an idea of citizenship that privileges the universal, which is formed from above in order to accommodate everyone. Authors such as Young and Kymlicka came to question the value of such understandings and demonstrate how these supposedly universalistic notions conceal other strategies of exclusion. Young's basic argument is that the promise of universal citizenship encapsulated in contemporary liberal society has not been fulfilled. She concludes that such universalistic approaches are nothing more than a denial of difference, that homogeneity is nothing other than the hegemony of privileged groups and that the only way forward is to totally rethink the way we understand citizenship (1989, 1990). Young's dissatisfaction is visible in the following extract:

This ideal of the civic public [...] excludes women and other groups defined as different, because its rational and universal status derives only from its opposition

to affectivity, particularity, and the body [...] In practice republican politicians enforced homogeneity by excluding from citizenship all those defined as different (1990: 117)

Citizenship needs, thus, to be differentiated in order to be inclusive (1989). Young (1990) suggests a 'group differentiated citizenship', i.e. a plural citizenship which encompasses different rights for different groups within the same political community. In order to combat universalism and promote inclusion, Young (1989) proposes a two-pronged counter strategy: the incorporation of "mechanisms for group representation" (1989: 251) and the replacement of equal treatment with "special rights that attend to group differences" (1989: 251).

Equally critical of the universalistic angle, Kymlicka (1995) proposes the notion of differentiated citizenship following a multiculturalist model. Such a notion, he argues, consists of extending recognised rights, previously ascribed exclusively to individuals, to groups as well, hence enhancing citizenship rights for all. Differentiated citizenship entails claims for including disadvantaged groups (what he terms "representation rights"), demands for special rights to enable participation in mainstream culture ("polyethnic rights") and "self-government rights" within multinational states. Kymlicka has been criticised for his allegedly essentialising notion of culture, a key aspect in his theorisation of citizenship (Fierlback, 2008), a critique which has also been addressed to Young (Philips, 1993). In fact, from the point of view of disabled people, oppression and exclusion constitute the fabric of their identity and self-identification as a group. However, the removal of disabling barriers would render obsolete such forms of differentiated citizenship and these special rights would be transformed into different factors within a specific community. Despite the very promising suggestions of Young and Kymlicka for an inclusive society for all, this form of citizenship should be understood as 'transitory citizenship', a step towards a wider form of citizenship and social inclusion of different groups, according to which everyone would be equal.

Also, reflecting changes that have occurred in contemporary societies in the last couple of decades, but challenging the the essentialism of Young and Kymlicka, a post-structuralist alternative has emerged. This post-structuralist perspective is visible in the works of Mouffe (1988, 1992; 1993), and Laclau and Mouffe (2001), who proposed a non-essentialist and plural conception of citizenship where individual liberty does not

collide with the rights of groups. The authors propose a 'radical democracy', understood as:

a way of life, a continual commitment not to a community or state but to the political conceived as a constant challenge to the limits of politics. (Rasmussen and Brown, 2002: 175)

Radical democracy emerges in Laclau and Mouffe's (2001) theorisation associated with change, with the expansion of the political terrain by rendering visible different sources of power and pushing the boundaries of the political. As Mouffe elaborates:

Radical democracy demands that we acknowledge difference – the particular, the multiple, the heterogeneous – in effect, everything that had been excluded by the concept of Man [sic] in the abstract. (1988: 36)

In their radical overhaul, and despite their Marxist backgrounds, Laclau and Mouffe (2001) managed to retain the concept of citizenship. Citizenship became, in fact, central to the process of change and transformation of the political. Understood

as political activity involving a struggle for hegemony, [and] possible at any site from an engagement with the state, in the economy, or in the everyday practices of identity formation[,] (Rasmussen and Brown, 2002: 178)

citizenship became, thus, decoupled from the community or the state. The authors claim that only by understanding it as activity, instead of as identity, can the category of citizenship be expanded, making it more egalitarian. As Mouffe (1992) argues, democratic citizenship includes everyone despite their differences. The idea of radical democracy

enabled a recognition that the terrain or space of politics was not predetermined and therefore theorisation of a shifting object of politics needed to acknowledge the way radical democratic action emerged in real conflicts. Therefore, citizenship was not understood purely as a relationship among political agents but as an interaction between agencies embedded in historical and spatial contexts. Citizenship could not be understood as an abstract set of features or principles but was a concept continually reshaped through actual political engagement. (Rasmussen and Brown, 2002: 179)

In sum, the post-structuralist contribution to citizenship theory resides mainly in its understanding of citizenship as non-essentialist, highly fragmented and constructed on a daily basis by increasingly fragmented identities in a continually changing society. If this proposal seems highly appealing, it renders the importance of traditionally unifying elements encapsulated in the idea of citizenship, like ‘solidarity’, almost obsolete (Ellison, 1997). Alternatively, in order to maintain such vital elements, Ellison (1997) proposes an understanding of citizenship as a reflexive process. As the author clarifies:

‘Reflexivity’, [...] refers to the general process, driven by social, political and economic change, by which social actors, confronted with the erosion, or transformation, of established patterns of belonging, readjust existing notions of rights and membership to new conceptions of identity, solidarity and the institutional foci of redress. (1997: 711)

As Ellison states, citizenship emerges “as a strategy of defensive engagement” (1997: 713), meaning that it is used by social actors as a tool “to maintain or create solidaristic and participatory, if often temporary, alliances at the grass roots.” (ibid., 712). Citizenship continues, in Ellison’s theorisation, as was suggested too by the post-structuralist citizenship scholarship, to be recognized as a mutating reality, which adapts to the subject’s needs and which is increasingly independent of the nation-state. In sum, citizenship is here represented as a form of social and political resistance, but also as a form of solidarity unifying peoples’ fights.

In my research, I am more interested in the theoretical explorations opened up by this last group of thinkers. Notwithstanding the importance of Marshall’s work, I believe it has not adapted to the changed and continually changing nature of contemporary societies or to the specificities of specific groups, such as disabled people. According to Marshall’s perspective, citizenship is a fixed status “ensuring that everyone is treated as a full and equal member of society” (Kymlicka and Norman, 1994: 354). Such a theorisation of citizenship is clearly dated, as it remains anchored by the assumption of a unified, territorial nation-state. In the context of increasingly plurinational states and transnational social policies and law, such notion of citizenship could be seen to be in danger. However, there is evidence that citizenship has been a central element in social movements’ strategies in order to expand social rights (Isin and Turner, 2002) and that new forms of social citizenship and solidarities are being forged in this increasingly globalised world (Keating, 2010).

Moreover, Marshall's concept is problematic for disabled people because such a static notion, based on status, does not accommodate any potential for change. Since disabled people are highly oppressed and discriminated against via institutionalised discrimination (Oliver, 1985, 1990), in order to ensure their equal citizenship societal structures and traditional liberal understandings of citizenship need to be challenged and changed. Again, the formal citizenship proposed by liberal thinkers seems inadequate for tackling disabled people's social oppression and for removing the disabling barriers that prevent disabled people from accessing citizenship rights. Thus, in my research I am less concerned with citizenship-as-status than with a notion of citizenship-as-activity, which Marshall's theory lacks (Kymlicka and Norman, 1994), and of citizenship as a process of reflexive engagement (Ellison, 1997) by disabled people. In practice, this means that this study focuses on the way disabled people engage as a social movement in the construction of their own citizenship, fighting for their own rights and exposing and challenging disabling mechanisms. This idea is also advanced by Bagguley and Hussain (2005) when they underline the need to surmount the 'institutionalist' perspective of citizenship analysis. These authors raised the need to focus on the way people think and feel about citizenship and, I would add, how they act and react.

In sum, considering the difficulty of reaching a universally agreed definition (Dwyer, 2004a; Beckett, 2006), and being aware of its partiality, I would define citizenship in socio-political terms, as proposed by Faulks (1998), although I would suggest its understanding be based on a looser notion of the political, as is offered by the post-structuralists. This understanding takes on board not only the link between the state and the individual (in a rights/duties symbiosis), in which the former protects the latter from the existing political, economic and cultural power relationships in a specific society and the latter acts upon the former to address their needs, but also the link between the individual and the group, the individual and community and the individual and culture. Citizenship should therefore be understood not only as the "status bestowed on all those who are full members of a community" (Marshall, 1950: 28), but also as the activity developed by people, individually or collectively, to achieve recognition of that status.

This thesis focuses precisely on the role of the Portuguese Disabled People's Movement in the process of citizenship formation. Therefore, alongside citizenship studies, social movements theories are a fundamental element of the subject addressed in this thesis. The next section is devoted to this important body of literature.

2.3. Theorising social movements – contemporary perspectives

An important enabling element of collective action is the ability to imagine citizenship beyond the state (Hoffman, 2004), or, at least, “the ability of the individuals to lead their lives free from the interference of an overbearing state.” (Dwyer, 2004a: 22). It is precisely this idea of social citizenship that legitimised the development of the welfare-state in the post World War II period and which was captured by Esping-Anderson (1990) in his three pronged welfare-state typology. Furthermore, the theoretical and political impulse towards new ways of conceptualising citizenship, as the previous section reviewed, has underscored citizenship as “a critical, fluid and dynamic process of agency, contestation and resistance” (Abraham *et al*, 2010: 12), opening the field for challenge and transformation. New developments in citizenship studies have fed collective actors the symbolic tools necessary for demanding full citizenship in the sphere of disability policies, amongst others. In turn, as Abraham *et al* point out:

globalization and new social movements highlight the limitation of citizenship as traditionally conceived, i.e., as a relationship between the state and civil society and between public and private life (2010: 10-11).

It seems important, therefore, to examine contemporary theoretical perspectives on social movements, before explaining my epistemological and methodological decision to situate this research within the new social movements theory.

Social movements are part of the broader category of collective action, which includes other types of activities such as interest groups, crowds, collective behaviour, riots, gangs, revolutions and any other “goal-directed activity engaged in jointly by two or more individuals.” (Snow *et al.*, 2004: 6).

Several characteristics differentiate social movements from other collective acts. Scott (1990) highlights two main features: the possibility of mass mobilization being used as a threat to power and the aim to defend or change society, or the position of a particular group of people. Melucci stresses that social movements refer to “a specific class of collective phenomena which contains three dimensions” (1989: 29): 1) solidarity, i.e., the “actors’ mutual recognition that they are part of a single social unit” (1989: 29); 2) engagement in conflict with an adversary; and 3) breaking the limits of compatibility of a system in order to produce social change.

Until the 1960s, the theoretical debate on social movements was based on two main perspectives: the collective behaviour perspective expressing the American perception and the European social democratic approaches (Becket, 2006). Changes in the 1960s made these perspectives outdated, leading to the emergence of new theories. On the American side, this ‘watershed’ gave rise to the resource mobilization theory and the political process approach put forward by Tilly (1978, 1993), Oberschall (1973) and Tarrow (1988, 1994, 1995). Its European counterpart is the new social movement (NSM) theory proposed by Touraine (1985, 1987, 2002), Habermas (1981, 1984, 1987) and Melucci (1984, 1985, 1988, 1989, 1994, 1995).

The next sections provide overviews of these theoretical developments, in relation to which I then explain my own understanding of the Portuguese Disabled People’s Movement.

2.3.1. Resource mobilisation theory and political process approach

Contemporary theoretical perspectives of collective action include the important contributions of resource mobilization theory (RMT) and the political process approach (PPA). Both perspectives were developed in the US and, according to some authors, their common features make them almost undistinguishable. For instance, Foweraker explains how in “North America [...] theory has sought to explain *how* social actors mobilize, rather than *why*” (1995: 2, my emphasis), and Beckett argues that “both theories see social movements as being about well-organised, purposeful, rational action” (2006:75), which is evidenced too in Tilly’s definition of a social movement as:

[What we call a social movement actually consists in] a series of demands or challenges to power-holders in the name of a social category that lacks an established political position. (1985: 736)

In this quotation, the author seems to take the part for the whole. In fact, Tilly’s definition stresses the outcomes of social movement’s action, while ignoring the action itself and other elements that make it happen. In so doing, he offers a rather static and disorganised understanding of social movements, which is unable to distinguish a social movement from any other form of collective action.

Despite theoretical disagreements with such an understanding of social movements, it is worth retaining the specificities of each approach and to explore the key arguments of their proponents.

Within the RMT, resource allocation and cost-benefit reasoning seem to be crucial aspects of collective action, impacting on the ways social movements participate in the public sphere. According to this perspective, resources such as repertoires of action, leaders, structures and knowledge are strategically used in order to serve previously established aims. Social actors are conceived as rational and strategic, and are highly dependent on existing resources and opportunities (Oberschall, 1973; Tilly, 1993). According to Charles Tilly, social actors operate through repertoires defined as “a limited set of routines that are learned, shared, and acted out through a relatively deliberate process of choice” (Tilly, 1995: 42). Of chief importance to Tilly are what he terms “repertoires of contention”, i.e. “the established ways in which pairs of actors make and receive claims bearing on each other’s interests” (Tilly 1995: 43). These repertoires of contention are characterized by their discontinuous status. As Tilly explains, repertoires of contention are:

the discontinuous making of claims that bear on other people’s interests. Continuous claim-making includes parliamentary representation, routine activities of trade unions, day-to-day operation of friendship networks, and similar unceasing exertions of influence; I discuss them where relevant and possible, but focus on claim-making in which people gather, act together, and then disperse—that is, discontinuous claim-making (Tilly 1995: 16).

Where resource mobilization theory emphasises the costs and benefits of social movements and pays particular attention to the available resources, the political process perspective focuses around institutional political actors, including elections, conflict, protest, agenda and decision making (Della Porta and Diani, 2006).

The PPA is about political possibilities understood as a key resource for the emergence and successful outcome of social movements or, on the contrary, it is about the constraints that hinder collective action. Moreover, the PPA was formulated as a way to allow for some sort of conceptual convergence between collective action and politics (Tarrow, 1994, 1995), emphasising the political environment that contextualises collective action and, in particular, the role of state institutions. A central notion within

the PPA was offered by Sidney Tarrow and is called “cycles of protest”. According to Tarrow, social movements are defined as “a continuing overt relationship of conflict between collective actors and authorities” (1988: 283).

The major difference in relation to RMT is that PPA introduces the macro level of political environment, while RMT focuses on the micro level of individual participation (Foweraker, 1995).

Both the RMT and the PPA have been criticised for their lack of attention to aspects of agency, culture, flexibility and change (Touraine, 2002). Dismissing the cultural aspects of collective action, which is never purely based on strategic decision-making, instrumental organisation and rational choice, these theories offer a rather static image of social movements that overemphasises tactical planning and cost-benefit calculation. As Foweraker suggests, “social movements occur much more than resource mobilization theory can properly explain” (1995: 17).

2.3.2. New social movement theory

According to Foweraker, NSM theory “was born of disenchantment with a highly academic and structural version of Marxism [...] [and] in response to the upsurge of social movement activity in the 1960s” (1995: 9). One major aim of NSM theory is to capture the energy, creativity and diversity proposed by collective actors struggling for post-materialist rights, in a context in which culture and the “grammar of forms of life” (Habermas, 1981) – i.e. issues related to human rights, quality of life, individual self-realisation and societal norms and values – acquire a central role.

Contrary to their American counterparts, European authors such as Jürgen Habermas (1976, 1981, 1987), Alain Touraine (1985, 2002) and Alberto Melucci (1994) suggest the idea of a crisis of modernity and emphasise the role of the NSMs in the defence of the ‘life-world’. Their theoretical responses centre on notions of identity, values and culture (Becket, 2007).

According to Habermas (1976), the present historic moment – late capitalism – is characterised by a crisis of legitimation of the state as a result of the discrepancy between public expectations created by modern society’s different subsystems (economic, administrative-political and sociocultural) and the state’s capacity to fulfil

these expectations. For Habermas (1987) this crisis has led the state, i.e. the system, to take over spheres previously separate from state intervention, concerning social life, the family and the community. In sum, this is what Habermas (1987) refers to as the ‘colonization of the life-world’ by the system. The colonization of these spheres, previously belonging to communicative action, by state authority resulted in new forms of exclusion and oppression. New social movements are a defense of the ‘life-world’ against this colonization from the system and a result of the need to defend the foundations of the life-world and the quality of life. As Habermas points out, new social movements “arise at the seam between System and life-world” (Habermas, 1981: 36), they inhabit therefore an intermediary space between the state and civil society, and are ignited by questions related to the grammar of forms of life (Habermas, 1987). These new social movements represent a move away from traditional politics, based on political parties and parliamentary debates, to a new politics based in the life-world and in line with people’s real needs. New social movements encapsulate, therefore, the self-emancipatory potential of civil society against the threats of the state, of the market and of the system. I will return to this point in Chapter 6 when analysing the emergence of the Disabled People’s Movement in the 1970s, as well as in Chapter 5 and 7 when analysing the impact of the current economic crisis on disability policies and on the Disabled People’s Movement in Portugal.

In a similar line of argument, for Alain Touraine (1981, 1985, 1987, 2002) new social movements are also the result of a crisis of modernity. According to Touraine (1981), contemporary societies are what he calls ‘post-industrial’ or ‘programmed societies’, a type of society in which the “principles of planning and organisation applied in the workplace spread to all spheres of life” (Dant, 2003: 53), a type of society which produces “symbolic goods which model or transform our representation of human nature and the external world” (Touraine, 1987: 127). Central to his argument is the idea that societies are divided by core conflicts created by social antagonisms and that social movements, defined as “organised conflicts or as conflicts between organised actors over the social use of common cultural values” (Touraine, 2002: 90), are one possible type of social conflict. In this respect, ‘programmed societies’ are no different. At the core of ‘programmed societies’ there is an antagonism between technocrats and bureaucrats on one side, and workers, students, consumers and a whole range of other social groups on the other. The reason for this is that technocrats monitor different areas of social life including cognitive and symbolic resources. As can be deduced from this,

conflict within 'programmed societies' does not result from the ownership of the means of production, as for Marxist theory, but rather from the access and control of information, from the control of what Touraine refers to as 'historicity,' understood as:

knowledge, investment and a cultural model. [...] Historicity is formed from a model of knowledge, a model of accumulation and a cultural model: knowledge, economics and ethics are all incorporated in it. (1981: 60-73)

Therefore, for Touraine, conflict and protest have moved away from the factory and have been decentred from material needs. The transformation of society also equates to new types of social movements. These new social movements are "segmented, localised, diverse expressions of conflict [...], represent[ing] excluded minorities and victimised cohorts" (Ruggiero and Montagna, 2008: 197), who transform themselves into actors in societies' core conflicts.

In fact, it was an actor-oriented approach that characterises much of Touraine's theorisation of collective action, which stresses the role and agency of the social actor in post-industrial societies (Touraine, 2002). Touraine's work represented a shift in analytical focus, analysing "conflicts in terms of the actors and not to see the actor simply as the result of objective forces" (2002: 89). The effects of the current economic crisis in the lives of people all over the world seems to contradict Touraine's downplaying of material needs in contemporary societies. His theorisation does, however, play an important role throughout this thesis. Firstly, I was highly influenced by the context-specific nature of Touraine's concept of social movements. As the author puts it:

The notion of social movement, like most notions in the social sciences, does not describe part of "reality" but is an element of a specific mode of constructing social reality. (1985: 749)

Secondly, it helped to focus my attention on the Disabled People's Movement, rather than on the state or on disability politics or policies, and thirdly, it emphasised the role played by the movement as an actor on a conflictual stage. This perspective is pivotal in this research, which evaluates the impact of the Portuguese Disabled People's Movement on disability policies, exploring the influences and conflicts which are significant to Portuguese organisations of disabled people.

Alongside Touraine, within NSM theory the writings of Melucci also play a crucial role. Melucci was, in fact, responsible for introducing the term ‘new social movements’. In contrast to Touraine, for whom conflict plays a primary role within social relations, Melucci refuses to reduce social relations to conflict, even though he recognises its existence, especially in those areas of the system directly involved in the production of information. In line with Habermas’ thought, Melucci believes that contemporary societies are:

highly differentiated systems, which invest increasingly in the creation of individual autonomous centers of action, at the same time requiring closer integration and extending control over the motives for human action. (Della Porta and Diani, 2006: 9)

Like Habermas, Melucci advances the idea of a colonisation of the private sphere by the state and by the market. New social movements offer challenges to this intrusion, fighting against the system’s manipulation of individuals, as well as resisting “the expansion of political-administrative intervention in daily life and defend[ing] personal autonomy” (Della Porta and Diani, 2006: 9). Despite the fact that areas such as “self definition, emotional relationships, sexuality and “biological” needs” (Melucci, 1989: 45) can no longer escape the colonisation of the system, as Melucci recognises, societies now have the capacity to produce, and interfere with, the production of cultural codes and information. Social movements are the result of practices that do not obey the system’s rules; they inhabit what Melucci refers to as ‘social spaces’ (1989, 1996), i.e., an alternative space located outside the established political system. According to him, social movements are, as for Touraine (1985), “socially constructed collective realities” (1995: 110). Contrary to its North-American counterparts, NSM theory does not offer a static vision of collective action. Instead, multiple aspects are explored in the attempt to understand why social movements emerge and what struggles trigger action. As Melucci explains:

Collective action should thus be considered as the result of purposes, resources and limits: as a purposive orientation constructed by means of social relationships within a system of opportunities and constraints (1995: 111).

Capturing the multi-layered textures of collective action, such an understanding of social movements is of particular importance to my study, to the extent that it

encompasses both political and cultural constraints and possibilities, bridging the analytical gap between micro and macro levels of sociological analysis.

Other scholars, such as Diani, conceives social movements as networks “of social interactions, between a plurality of individuals, groups or associations, engaged in a political or cultural conflict” (1992b: 13), advancing the idea of a shared collective identity forming the ‘glue’ in a collective action. Despite the similarities between his notion of identity and Melucci’s solidarity dimension (1989), the concept of identity represents another possibility when considering the Disabled People’s Movement. As different analyses seem to suggest (Sutherland, 2006; Swain and French, 2000; Barnes and Mercer, 2010), the formation of a positive disabled identity has been a central element in the Disabled People’s Movement in the UK. As Barnes and Mercer state:

Instead of focusing on removing the stigma of being a disabled person or ending institutional segregation, disabled people have sought their own self-definition and an affirmation of their own culture.” (2010: 181)

For the purpose of this thesis, and drawing on these previous reviews, I suggest that there are four central elements that make social movements distinguishable from other forms of collective action: continuity, identity formation, ideologically-driven action and transformative intervention. A social movement emerges as a continuous conflict over time, differentiating it from a simple demonstration, riot or a crowd. This continuity is possible due to the existence of both an identity formation process, gluing the different elements together, and an ideologically defined agenda targeting the transformation of the system.

2.3.3. What’s new about New Social Movements?

Until the 1960s, social movements comprised mainly workers movements, which focused on class and economic issues, and which were organised by trade unions and political parties, and used strikes and demonstrations as their main tactic (Abercrombie *et al.*, 2000). The 1970s signaled the materialization of an increasing variety of social conflicts beyond the workforce in both Europe and North America – taking up civil rights, feminist, anti-war, peace, anti-nuclear, environmental, lesbian and gay, student, disability issues, to name but a few – and, consequently, the emergence of numerous

social movements around new 'post-material' issues (Lawrence and Turner, 1999; Melucci, 1989). These new social movements (NSMs) did not only push for a multitude of issues based on identity but also recognised civil society as its key location, organised in non-hierarchical structures and networks and embraced direct action, protest and lifestyle (Abercrombie *et al.*, 2000; Lawrence and Turner, 1999). According to Scott, the "New Social Movements are above all political phenomena" (1990: 10). Sociologically, this means that they can no longer be looked at as a coherent category: "they are, rather, manifestations of 'dysfunctions' in political decision-making processes" (1990: 10). Arguably, the key elements distinguishing NSMs from old social movements are their social support base (working-class versus middle-class), the values and issues feeding the struggle (material versus post-material – culture, identity, moral issues, lifestyle; distribution, 'grammar of forms of life' (Habermas, 1981)), their field of operation (state versus civil society), their action strategies (negotiation, lobbying versus direct action, lifestyle), their organisation (formal and hierarchical versus non-hierarchical, multi-headed, networks) and scope of intervention (revolutionary conflicts versus structural conflicts). Unsurprisingly, most of the debates about the Disabled People's Movement have led to discussions about whether it was a new social movement or not (Oliver, 1990, 1996; Shakespeare, 1993; Abberley, 1996; Campbell and Oliver, 1996; Lee, 2002; Barnes and Mercer, 2003, amongst others). I will return to this debate in Chapter 8.

The changing nature of social movements has been captured by the work of American political philosopher Iris Marion Young in her book *Justice and the Politics of Difference* (1990). Here, the author posits the idea that traditional understandings of oppression, as something that only happens in other parts of the world and which only involves tyrannical governments, have been challenged by "New left social movements of the 1960s and 1970s" (Young, 1990: 41). As she puts it:

In its new usage, oppression designates the disadvantage and injustice some people suffer not because a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society. [...] In this extended structural sense oppression refers to the vast and deep injustices some groups suffer as a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions, media and cultural stereotypes, and structural features of bureaucratic hierarchies and market mechanisms (Young, 1990: 41)

Oppression is, therefore, experienced by the whole community without there being a distinct aggressor – it is embedded in “the normal processes of everyday life.” (Young, 1990: 41). This oppression may, however, take different forms: exploitation, marginalisation, powerlessness, cultural imperialism and violence. The first three forms of oppression are a direct result of the division of labour and impact directly on the material lives of people. The last two forms of oppression refer to another category of oppression, which is frequently overlooked, and which is the result of the dominance of a particular group and the forms of coercion it uses to impose power.

The first form of oppression identified by Young is exploitation. Drawing on Marxist theory, she clarifies that:

The injustice of exploitation consists in social processes that bring about a transfer of energies from one group to another to produce unequal distributions, and in the way in which social institutions enable a few to accumulate while they constrain many more. (Young, 1990: 53)

The elimination of such forms of oppression requires an overhaul of decision making processes and of the division of labour, as well as requiring “institutional, structural and cultural change.” (Young, 1990: 53).

The most dangerous form of social oppression is, however, marginalisation. This refers to the segregation of people from “participation in social life and thus they are potentially subjected to severe material deprivation and even extermination.” (Young, 1990: 53). This has been the case for many disabled people, who have been forced into special institutions and subjected to patronising professionals.

As a result of the two former dimensions of oppression, there emerges what Young refers to as the ‘powerlessness’, a result of the current division of work into professionals and non-professionals. The powerless are non-professionals with little opportunity to take control of their lives:

The powerless are those who lack authority or power in this mediated sense, those over whom power is exercised without their exercising it; the powerless are situated so that they must take orders and rarely have the right to give them. (Young, 1990: 56)

Another form of social oppression is what Young calls ‘cultural imperialism’, meaning the process of being othered and simultaneously having one’s own culture rendered invisible by the dominant culture in a given society:

To experience cultural imperialism means to experience how the dominant meanings of a society render the particular perspective of one’s own group invisible at the same time as they stereotype one’s group and mark it out as the Other. (Young, 1990: 59)

The dominated culture is therefore represented as deviant, and people from these groups are stereotyped as different. This seems to describe the situation of disabled people in contemporary societies, whose bodies are contrasted with what is socially valued as ‘able bodied normalcy’ (Barnes and Mercer, 2010: 81).

The final form of oppression identified by Young (1990) is violence,

not only in direct victimization, but in the daily knowledge shared by all members of oppressed groups that they are liable to violation, solely on account of their group identity. (Young, 1990: 62)

Therefore, this is not random violence; it is a form of violence which is “directed at members of a group simply because they are members of that group.” (Young, 1990: 62). The systemic character of this form of violence is experienced by most oppressed groups including disabled people. In fact, disabled people, who are frequently portrayed as inferior and vulnerable, are often victims of abuse within society and within institutions, as the recent case of the abuse of disabled people in a Bristol care home exemplifies (Panorama, 2011).

Young’s theorisation may be regarded as a critique of a distributive or materialist model, and in so being exhibits several similarities with NSM scholarship. This idea that oppression is pervasive in contemporary societies, and that it assumes different forms in people’s lives, is in line with the idea proposed by NSM scholars of the colonization of the ‘life-world’ by the system, through which new forms of exclusion and oppression result. In addition, her multidimensional understanding of oppression expands materialist accounts of oppression, focused on exploitation, into new areas more in line with the post-materialist nature of new social movements. This framework represents, therefore, yet another possibility, not only for the theorisation of new social

movements, but above all, as Barnes and Mercer argue, for social movements' struggles, by making it possible "to include and compare the social oppression of all sections of the disabled population as well as other marginalized people." (2010: 80). I will return to this topic later on in this thesis.

Conclusion

This chapter has sought to provide a theoretical critical overview of the three major bodies of literature informing this thesis: disability studies, citizenship studies and social movement studies.

In relation to disability studies, I offered an analysis of the evolution of disability perspectives, signalling that, since the nineteenth century, there have been three main understandings, or models, of disability in the Western world: the medical or individual model, the social model and the relational model. As it was possible to conclude, the understanding of disability as a social construction is relatively new in science in general, only dating back to the 1970s and it was mostly a result of the emergence of the Disabled People's Movement. This perspective is, however, far from being the dominant one. As was also signaled earlier, the action of equating disability with oppression, which was suggested by UPIAS within the Disabled People's Movement and by social model thinkers, is even more problematic. In fact, a new body of feminist and postmodernist critics has developed within disability studies, questioning the separation between impairment and disability and between the social and the individual. I have situated myself as a social modelist, clearly understanding disability from a materialist and social oppression point of view. Two main reasons informed my decision: firstly, the explanatory potential of the social model, rendering visible the exclusion and oppression suffered by disabled people throughout history and, secondly, the emancipatory power offered by such an understanding, for both disabled and non-disabled people. As this section also demonstrated, disabled people's citizenship status has been hindered, or even denied, by charitable, medical and religious interpretations. Thus, the perspective used to understand disability drastically influences social policies, civil, political and social rights and, ultimately, the lives of disabled people. As Oliver states: "denial of inclusion into the political process constitutes a denial of citizenship for disabled people." (1996: 159).

The second body of literature analysed here was that of citizenship studies. As was demonstrated, contemporary debates on citizenship issues have been framed by two main perspectives: a republican stance and a liberal one. The first presents an understanding of citizenship as a process, where individuals play a key role in the construction and maintenance of citizenship, while the second understands citizenship as a status, presenting individuals as passive recipients of citizenship rights. Within this last perspective, attention was drawn to the influential work of Marshall, with his three generations of citizenship rights: civil, political and social. As was analysed, recent contributions to citizenship theory by feminist and post-modern thinkers have highlighted the limitations of this classical understanding, and of much of their current ramifications, signaling the limitations of a universalist and essentialist understanding of citizenship. As these authors showed, exclusion and discrimination have been hidden behind such universalistic and essentialist understandings of citizenship, and therefore they argue that the only way forward is through the construction of a radical view based on the recognition of differences, alongside the recognition of fragmentation as a reality of social life. I have positioned myself within this last group of thinkers, taking up the the nuances brought in by the reflexive understanding proposed by Ellison (1997). Ellison presents citizenship as a strategy of defensive engagement that, in contrast to postmodernist reasoning, emerges as a sign of unifying solidarity.

The third and final body of literature discussed in this chapter considered collective action, and, more specifically, social movement theories. As was signaled, the issue of the rise of collective action sits at the heart of disputes between competing theories of social movements. From the overarching analysis presented by NSM Theory, through to the more situated perspective presented by RMT, they all aim to explain how societal changes have enabled the emergence of organised collective action. For the first, the answer lay in the structural transformations that occurred in modern societies, such as: the increasing rationalisation of modern life (Habermas, 1979), the societal transition from industrial to non-industrial (Touraine, 1985), or from materialist to post-materialist values (Inglehart, 1977, 1990) or the cultural fragmentation of late capitalism (Jameson, 1984). For the second, the answer can be found in the social movement itself, in its organisational aspects, such as its infrastructural support and capacity to mobilise resources (McCarthy and Zald, 1973, 1977), or in the creation of solidarities and alliances (Tilly *et al.*, 1975, Tilly 1984). Consequently, from a new social movements perspective, the central questions to consider are: ‘Why did social movements emerge?’

and ‘Why did people mobilize?’, while for the resource mobilisation theorists the emphasis is on ‘how’ movements are established and survive. Despite at times engaging with different traditions, I positioned myself within the new social movements scholarship. In reality, this theoretical perspective seems to present the best anchorage for accounting for the multi-dimensional character of collective action, for paying close attention to culture and politics, as well as to structural and individual possibilities and constraints.

In sum, NSM theory attempts to capture the dynamism and diversity inherent in collective action, whereby “activism, even in its most serious form, is a method of performance that must be developed and improvised” (Wall, 1999: 96). Such a definition is far removed from RMT and PPA’s static and rational understanding of social movements, and is the reason why NSM theory has been chosen as the theoretical grounding of this research.

3. Designing the research: questions, data sources, methods and ethics

Introduction

To reiterate, disability is a social construction. As such, it must be understood in a (socially) contextualised way (Ghai, 2001). The previous analysis of the current theoretical debates within disability studies validates such a premise. However, in Portugal the theoretical debate involving the social model of disability is embryonic within the Portuguese Disabled People's Movement and almost non-existent in academia, with the exception of recent studies by Martins (2005a, 2005b, 2006) and Fontes (2006, 2008, 2009). Moreover, the theoretical debates on disability undertaken in Portuguese academia – particularly in the fields of psychology and education – have focused mainly on aspects of integration and, more recently, on the inclusion of disabled children in schools and in their communities.

Compared to what has been done so far in the Portuguese case, my research presents a different design and epistemological anchoring, as the following sections of this chapter will highlight. The first section presents the epistemological positioning of this study, which is influenced by the guiding principles of Emancipatory Disability Research. Then, the main research questions and aims will be discussed. The third section explains the sampling methods and strategies used. The fourth section presents the data sources, the data collection strategies and gives a glance at the way I conducted fieldwork and data analysis. Finally, the fifth section contains a self-reflexive account based on my ethical and political concerns.

3.1. Epistemological standpoints

In my study I am deeply committed to the emancipation of disabled people. This does not imply sacrificing scientific rigour or objectivity; it simply means that my work is politically committed to highlighting the social oppression of disabled people in order to contribute to their emancipation. Such commitment draws heavily on emancipatory disability research (Oliver, 1992; Mercer, 2002; Barnes, 2003), defined as “the empowerment of disabled people through the transformation of the material and social relations of research production” (Barnes, 2003: 6).

The term ‘emancipatory disability research’ was only coined in 1992 by Oliver (1992), at the end of a series of seminars that culminated in a national conference on disability research held in 1992 and funded by the Joseph Rowntree Foundation (Oliver, 1997a). This was, however, the result of an ongoing critique of mainstream disability research which can be traced back to the end of the 1960s and early 1970s (Barnes, 2003; Mercer, 2002), which stemmed from a growing politicisation of disability (Campbell and Oliver, 1996). A clear example of this critique can be found in the work of Hunt (1981). A dispute between the management of Le Court Cheshire Home, a residential institution, and its residents for greater control over their own lives, led them to invite the Tavistock Institute to conduct a research on the living conditions of disabled people within the institution in order to find support for their claims (Barnes, Mercer and Shakespeare, 2000; Mercer, 2002). This research (Miller and Gwynne, 1972) concluded, however, that the residents’ claims were unrealistic and “recommended a reworking of traditional professional practice” (Barnes, Mercer and Shakespeare, 2000: 214). The residents of Le Court felt betrayed by the researchers and accused them of being parasites (Hunt, 1981). This episode, again, represents the exhaustion of a positivist scientific paradigm based on allegedly value-neutral objectivity (Harding, 1991; Burawoy, 2004), and the dawn of a new epistemic and ethical approach in the area of disability studies. Emancipatory disability research was not an isolated phenomenon. In fact, discontent with conventional positivist research was shared by other social groups at the time, namely women and black people, creating space for the emergence of a critical social theory or research, which included emancipatory disability research (Oliver, 1992; Mercer, 2002; Barnes, 2003). Emancipatory disability research can be regarded as an academia’s answer to what Young (1990) refers to as cultural imperialism in the area of disability studies.

Several attempts have been made to summarise the key principles of emancipatory disability research (Stone and Priestley, 1996; Oliver, 1997a; Mercer, 2002; Barnes, 2003). Consensus seems to have been achieved in relation to four main principles: the adoption of the social model as the research lens; being politically committed to the struggles of disabled people – partisan research; being accountable to disabled people and to the organisations of disabled people; and opting for plurality in research methodologies and data analysis techniques.

The adoption of the social model approach is at the core of doing emancipatory disability research. This means that the social model forms “the ontological and

epistemological basis for research production” (Priestley, 1997b: 91), rejecting an individual approach, and one which sees disability as a tragedy. As was seen above (Chapter 2), the social model is basically a ‘heuristic device’ (Barnes, 2003) which allows social researchers to focus on the economic, cultural and physical barriers faced by disabled people in their daily lives. If this viewpoint became a ‘new orthodoxy’ in the UK, with traditional disability organisations incorporating it into their language (Barnes, 2003; Oliver and Barnes, 2006), in Portugal this is far from the reality and adopting this perspective still represents a radical standpoint. In the UK, this standpoint has generated intense theoretical debate and has received an array of criticisms from feminist through to postmodernist thought “for the incorporation of the diversity of disability experiences” (Mercer, 2002: 235) with important consequences for the way research is conducted. Social modelists like Barnes continue to argue, however, that:

within an emancipatory disability research framework, any discussions of disabled people’s experiences, narratives and stories are couched firmly within an environment and cultural setting that highlights the disabling consequences of a society organised around the needs of a mythical, affluent non-disabled majority. (2003: 10)

Embracing a partisan approach and rejecting the false objectivity of positivism epitomises the political standpoint of emancipatory disability research. Until recently, scientific research was dominated by a positivist paradigm that assumed the existence of a reality independent of our conceptions as individuals and as social scientists, which could be captured through objective research techniques (Harding, 1991; Burawoy, 2004). As a result, the followers of this scientific paradigm (Hammersley, 1995; Silverman, 2004) suggested that there is a neutral way of doing research and that any politically engaged research poses the threat of distorting reality. The formation of new social movements, like the feminist movement, the black movement or the Disabled People’s Movement, by “redefining social relations” (Stone and Priestley, 1996: 702) and bringing to light prior hidden sources of oppression, challenged such conceptions of science. As Touraine (1981) explicitly states, the ultimate role of social research is to “contribute to the development of social movements” (1981: 148). In a similar line of argument, Oliver states that:

Disability research should not be seen as a set of technical, objective procedures carried out by experts but part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives. (1992: 102)

Thus, emancipatory disability research clearly rejects this idea of objective research and sees the idea of the existence of a 'real' world based on natural laws as a myth, which is referred to by Oliver as 'investigatory foundationalism' (2002: 8). The only possible way ahead for social scientists in a world marked by the oppression and exclusion of some people based on their presupposed impairments is embracing partisanship (Oliver, 1997a) as their ontological standpoint. Again, this surrendering of objectivity is similarly suggested by Touraine in his notion of 'committed research' (1981: 198), i.e. research that, above all, is committed to political change and to the emancipation of socially oppressed and excluded people. This new ontological position asserts:

That there is a 'reality' out there, namely, the social oppression of disabled people that is historically, environmentally, culturally and contextually variable, that research is influenced by subjective values and interests, and is politically and socially influential. (Barnes, 2003: 11)

This is directly connected to the choice of research methods and techniques of data analysis. In contrast to positivist thinking, emancipatory disability research locates its strength in its logical and rigorous choice of research methods and data collection, and in analytical strategies that are open to scrutiny (Barnes, 2003).

Moreover, whilst emancipatory disability research has been connected to the use of qualitative data and qualitative research methodologies, there is a growing consensus about the value of using a plurality of data types, research methodologies and data analysis techniques. If authors like Morris (1991) have stressed the importance of oral tradition at the beginning of collective struggles and suggested the use of qualitative data in order to capture this oral richness, other authors, like Barnes (1991; 1992b, 2003) and Abberley (1992), advocate the use of multiple types of data and research methodologies in order to account for the oppression of disabled people and reveal disabling barriers. This is reiterated by Oliver who argues that:

Such techniques can only be part of an emancipatory project where, and only where, the social relations of research production have been changed. (Oliver, 1997a: 21)

The ultimate standpoint of emancipatory disability research is, thus, the need to change the social relations of research production, not only by making research accountable to disabled people and their representative organisations, but also by handing over ultimate control to the research subjects (Oliver, 1992). This crucial stance basically brings to the sphere of research the transformation it expects to produce in external society in the long term. If there is to be a radical social transformation, it has to start with the social relations of disability research production, through reversing the power relations between researcher and researched. This radical change within research production aims to give disabled people control over disability research so that it can be used to their best advantage (1992), in contrast to what happened in the past when disabled people were regarded as passive research objects (Abberley, 1987). As Mercer elucidates, “The aim of emancipatory research is to enable participants to take more control of their lives” (2002: 241) and to take control of what research should be done in order to facilitate the self empowerment of disabled people (Oliver, 1992). Moreover, reversing the social relations of research production allows disabled people to refocus disability research on to the issues defined by the social model as relevant for the emancipation of disabled people: society, disablism and disabling barriers. Despite the emancipatory potential of this principle, in the context of this study it was not possible to apply it thoroughly due to the academic constraints that characterise doctoral research. More specifically, a PhD thesis is designed to be accountable to the academy, not necessarily to the social movement with which it, nevertheless, engages. This thesis is, however, the result of a compromise between academia and the social world, and attempts to be accountable to both.

In sum, emancipatory research is about breaking with traditional and conservative ways of doing science research and embracing a radical perspective, which fosters real and immediate positive consequences in the lives of disabled people. These have been the principles guiding this research and the standpoint that informs the writing process in this thesis. In the next section an exploration of the research design will be provided.

3.2. Research questions

Collective action is an important catalyst for social change (McAdam, McCarthy and Zald, 1988; Tarrow, 1994). Research undertaken on the Disabled People’s Movement in

the UK and in the USA (DeJong, 1981; Campbell and Oliver, 1996; Fleischer and Zames, 2001) reveals how such collective action was crucial for changing the lives of disabled people. In this thesis I explore the way the Portuguese welfare-state has addressed the rights of disabled people, as well as the role played by the Portuguese Disabled People's Movement in shaping and influencing social policies. In order to do so, I consider the process by which disabled people construct social citizenship (Lister, 2003), alongside the creation of the democratic regime in Portugal. My main research question can be expressed as follows:

How and in what ways has the Portuguese Disabled People's Movement contributed to the struggle for social citizenship rights in Portugal since 1974?

This research question helped me in the double task of mapping and understanding the disability policies and politics that have developed in Portugal from the revolution for democracy (1974) until 2010, as well as identifying the role played by the Portuguese Disabled People's Movement in shaping and influencing politics, policies and law.

My research contains two main analytical dimensions, each including subsidiary questions with which this study engages.

The first analytical dimension explores the characteristics of the Portuguese Disabled People's Movement. Unlike the UK, in Portugal the Disabled People's Movement has not been very visible. Furthermore, disabled people have been repeatedly excluded from the public sphere, either by issues of mobility or by lack of measures for positive discrimination. Much of the political action of the movement in Portugal has been irregular and reactive, appearing only at specific moments, such as the discussion of a particular legal act that concerns disabled people, or the European Year of Disabled People. Considering the strategic role played by the Disabled People's Movement in both the USA and the UK in influencing and criticising the state's policies and disablist ideas (Driedger, 1989; Campbell and Oliver, 1996), I investigated the following subsidiary questions: how can we characterise the history and current state of the Portuguese Disabled People's Movement? What have been the major strategies of action and demands? What has been the significance of national and international alliances, both within and beyond the Disabled People's Movement?

The second analytical dimension addresses issues of political and cultural impact. Some of the questions considered under this dimension include issues around characteristics

of disability policies in Portugal, the way these have been applied in Portugal, the role of the Disabled People's Movement in defining and implementing relevant policies, the harmonisation between the Disabled People's Movement and the Government's agenda on disability issues and the influence of the international agenda (including the EU and the UN).

In one of the earliest, and most influential, works on the political consequences of social movements, Gamson (1975) identified two types of success: 'new advantages' and 'acceptance'. By the first, the author meant the benefits that result from the passage of new legislation and the implementation of new policies according to the movement's agenda and goals. 'Acceptance' refers to the claims of the challenger being recognised as legitimate by the challenged and to the implications this poses for their relationship. Other authors criticised Gamson's initial ideas and stressed other aspects of social movements' political consequences, namely the type of change produced (substantive, procedural and structural (Kitscheld, 1986)), the type of access gained to the state (representation and resources (Cress and Snow, 2000)), the duration of these consequences (short-term and long-term consequences (Andrews, 1997)) and the depth or level of consequences (Amenta and Caren, 2004). According to the latter perspective, a movement's political impact can span from the structural or systemic level to minor level impacts, such as "to win a specific state decision or legislation with no long-term implications for the flows of benefits to the group" (Amenta and Caren, 2004: 464). In contrast, a medium level impact would include "major changes in policy and in the bureaucratic enforcement and implementation of that policy" (2004: 464). The political consequences of the Disabled People's Movement can, thus, be established by assessing the change produced in legal and political terms in comparison with the movement's agendas and action, as well as the impact of those changes on disabled people's lives, and looking for "the historically contingent combinations of factors that shape the opportunities for social movements to contribute to social change" (Giugni, 1998: xxv).

Most studies about the consequences of social movements have focused on the impact they have had on policy and have largely ignored cultural outcomes (Giugni, 1999; Earl, 2000), what Melluci refers to as the 'myopia of the visible' (1988: 334). However, as Giugni (1999: xxxiii) argues, "collective action is hardly limited to its political aspects. [...] movements also have a range of potential effects in the social and cultural real". New social movement's scholars have taken precisely this direction, arguing that new social movements have been more concerned with non-material matters, namely

cultural values and beliefs and less with material and policy issues (Melluci, 1985, 1989, 1996; Offe, 1985; Touraine, 1985). In line with these arguments, in this study I am also considering the cultural consequences of the Portuguese Disabled People's Movement.

Culture has been variously understood across time and schools of thought (Hart, 1996; Earl, 2004). The establishment of the cultural consequences of a social movement is, thus, dependent on the particular vision of culture embraced. Within this thesis I tried to compound the three main visions of culture identified by Hart (1996) as dominant strands within sociology of culture. A first conceptualisation sees culture as a set of values, beliefs, social norms and meanings (Giddens, 1993) that can be captured in individuals' discourses. A second conceptualization considers culture as an artefact external to the individuals, but through which these individuals' values and beliefs coalesce (Hart, 1996). This can be captured, in the specific case of this thesis, in disability arts, music or literature. The final conceptualization examines culture at a macro level, as the culture of a particular community or group of people (Hart, 1996). This points to the existence of a disability collective identity, of a counter-culture, or a shared understanding of disability and of disabled people which differs from the dominant view within society. The extent of the cultural impact of the Disabled People's Movement can, thus, be determined by the change produced in these three cultural dimensions.

3.3. Data sources, data collection and data analysis strategies

Because the overall aim of this thesis is not descriptive, but rather analytical – gaining an understanding of the Portuguese Disabled People's Movement – this is a qualitative research project (Mason, 2002). I have used different data generation methods that I have applied to an array of data sources, which have been triangulated according to the requirements of my analysis (Mason, 2002; 2006).

Regarding data generation methods, I started by using documentary analysis (Prior, 2003; 2004). The documents collected and analysed included those produced by organisations of disabled people (annual activity reports, books of statutes; newsletters); media reports (press-releases; media coverage of issues relating to disabled people in Portugal in two daily newspapers: *Correio da Manhã* and *Público*); documents produced

by the Portuguese state (transcriptions of parliamentary debates on disability policies; legal documents; government manifestos; public statements of politicians; minutes of meetings of the National Council for Rehabilitation (CNR)); and documents produced by supranational bodies (EU legal acts and treaties; Council of Europe recommendations; UN Treaties). All of these documents were produced between 1974 and 2010. This documentary analysis was used to identify the main actors and events across time, providing an overview of the issues raised by the organisations and their action strategies and alliances. Simultaneously, I also conducted a literature review of the Disabled People's Movement in the UK. This was a necessary step to enable a comparison to be made between the Portuguese and the British Disabled People's Movement.

Then, I focused on gathering information about the history, activities and purposes of the selected organisations of disabled people. I started by collecting information that was available online (websites), and later complemented this with fieldwork in the selected organisations, in order to familiarise myself with past and ongoing activities, strategies of action and political standpoints. During this period I also undertook participant observation (Mason, 2002; Delamont, 2004; Ackerly and True, 2010) at events prepared by these organisations and other related events by other organisations between October 2007 and 2008 (see Appendix 1).

As “naturally or situationally occurring data” (Mason, 2002: 62), these events allowed me to generate important information concerning the direct actions of the movement, namely sound bytes, banners, speeches, the power of organisations to mobilise its members, action strategies and the power relations between activists (radicals and conformists). Additionally, it also gave me a broader picture of the members of the organisations studied, as well as a better understanding of dominant disability conceptions.

All observations and personal reflections and feelings were registered in my field notes. I remain aware that the data generated through participant observation might be criticised for being “subjective, unrepresentative and ungeneralizable” (Mason, 2002: 62). In addition, because my level of participation might impact upon the results achieved (Rocheleau and Slocum, 2001), I tried to adjust my role according to each specific situation (Gans, 1968). Therefore, on some occasions I was a total participant, helping and mucking in on what needed to be done; on others I was a researcher-

participant, observing events and participating in them simultaneously; and on others I was a total researcher, namely at national assemblies of ADFA, where my participation in events was negotiated and only accepted on that basis.

During the third phase of my fieldwork, I conducted semi-structured in-depth interviews with leaders and grassroots activists. These interviews were designed to recover part of the history of the Portuguese Disabled People's Movement. I sought to map out agendas during its different periods, as well as to identify any coalitions that were formed with other (national and international) organisations, to identify particular strategies, to discover views of governments' general disability policies as well as opinions about specific pieces of published legislation, which had great impact on disabled people. These in-depth interviews were digitally recorded, after first having received verbal consent from my interviewees, and were transcribed in their original language. In the case of deaf participants, the interviews were conducted with the assistance of an interpreter of Portuguese Sign Language, who was suggested by the Portuguese Organisation of Deaf People (APS). This fact added to the constructed nature of all research, including this thesis. As has been highlighted in the literature (Temple, 2002; Temple and Young, 2004), there is no correspondence between sign language and a sound/print language, meaning that any translation is always the result of a construction. As such, the translator is an active producer of the research as well. Overall, the 22 interviews generated almost 46 hours of interview and 369 pages of interview transcripts. These interviews were conducted in Portuguese and, after some consideration, it was considered more adequate to transcribe and analyse the interviews in Portuguese, only translating into English the statements chosen to be used within the thesis. My decision was informed not only by time efficiency concerns, but mostly by ontological, epistemological and ethical concerns, as I will elaborate on the last section of this chapter.

All interviews were explored according to a 'thematic analysis' (Attride-Stirling, 2001), which consists of considering "the themes salient in a text at different levels, and thematic networks aim to facilitate the structuring and depiction of these themes" (Attride-Stirling, 2001: 387). The identification of basic, organising and global themes was useful in organising my data and in facilitating the subsequent analysis.

Despite the fact that semi-structured interviews may be criticised for being too rigid in structure and potentially biased, thereby reinforcing preconceived ideas about the topic

under research (Oakley, 1982; Chamberlayne *et al*, 2000; Mason, 2002; Jones, 2004), this method proved to be an appropriate tool for achieving my aims within the context of a Social Model framework. This is particularly the case in a context in which the topic is understudied/underrepresented and where disabled people are often excluded, being rarely heard in academia. Moreover, besides being interested in people's perceptions and experiences, this study also aimed to explain complex processes of social change and, as such, qualitative interviews were the most efficient method (Mason, 2002).

3.4. Sampling and access

Bearing in mind the purpose of this study, alongside the time, and financial, constraints associated with a PhD thesis, I chose to use a non-representative sample (Mason, 2002; Ritchie *et al.*, 2003). A purposive or strategic sample (Mason, 2002) was used to select the documents, as well as the individual and collective participants in this study. This type of sampling, which is commonly used in qualitative research (Ritchie *et al.*, 2003),

means selecting groups or categories to study on the basis of their relevance to your research questions, your theoretical position and analytical framework, your analytical practice, and most importantly the explanation or account which you are developing (Mason, 2002: 94).

Being aware of the risks of purposive sampling (Mason, 2002), in this study I was particularly invested in selecting sampling units that presented an array of perspectives. This was achieved through the inclusion of 'contradictory cases' (Mason, 2002: 94), i.e., individuals or organisations who are critical of the movement (e.g. impaired war veterans and ADFA), and those who voluntarily keep a distance from disability issues and the Disabled People's Movement (e.g. deaf people and APS). In addition, I have also developed a sampling strategy, with specific criteria, that was designed to counter the risk of ending up with a random sample. The sampling strategy was designed specifically for each of the three different types of samples identified: organisations, individuals, and documents.

Sample of organisations

Considering the high number of disability organisations in Portugal and my expressed interests, I established four main criteria for selecting the organisations I intended to research. I decided to research only organisations *of* disabled people, with national scope, and with a broader issue approach to disability. By organisations *of* disabled people I mean “those organisations where at least 50 per cent of the management committee or controlling body must, themselves, be disabled.” (Oliver, 1990: 113). Six organisations fitted those criteria: two impairment specific (ACAPO, APS) and four broader-impairment (ADFA, ANDST, APD and CNOD). The study of these six organisations was facilitated by their concentration in Lisbon (except for the Oporto-based, ANDST), where my fieldwork was based.

The organisations selected were:

ACAPO – Portuguese Association of Blind and Low Vision People. ACAPO is an impairment specific organisation, which was formed in 1989. It is a national organisation based in Lisbon and has thirteen regional sections spread across the country, including on the islands of the Azores. ACAPO also represents Portugal in the World Blind Union, as well as in its European regional body European Blind Union. It has also been a member of the National Council for Rehabilitation (CNR) since 1990.

ADFA – Association of Impaired War Veterans. ADFA is a broader issue and impairment organisation that was formed by impaired war veterans in 1974 in order to fight for the rights of ex-service men who had been impaired in the colonial war between 1961 and 1974 (ADFA, 1994, 1999). It is a national organisation based in Lisbon with eleven regional sections, plus four local branches in the Lisbon area (ADFA, 1999). ADFA has been a member of the World Veterans Federation since 1982. The official voice of ADFA is its newspaper ‘ELO dos Deficientes das Forças Armadas’, which has been published uninterruptedly since November 1974. ADFA has organised five national congresses (1976, 1981, 1989, 2000, 2001) of impaired war veterans and has been a member of the National Council for Rehabilitation (CNR) since 1979.

ANDST – National Association of People Impaired at Work. ANDST is a multi-impairment organisation that was created in 1976. It is a national organisation based in Oporto, with two regional delegations: one in Coimbra and another one in Lisbon. ANDST is also the Portuguese representative for the International Federation of Persons

with Physical Disability. Having published a newsletter irregularly since 2006, called 'D'Olho no Trabalho', ANDST has also been a member of the National Council for Rehabilitation (CNR) since 1981.

APD – Portuguese Association of Disabled People. APD is a multi-impairment organisation that was formed in 1972. It has mainly focused its activities on fighting for the rights of disabled people and on framing disability as a human rights issue (APD, 2009). APD was responsible for organising the first Meeting of Disabled People in 1978 (Associação, 1978a, 1978b), as well as for the first National Congress of Disabled People in 1980 (APD, 1997). APD is a national organisation based in Lisbon with nine regional sections, twelve local sections including on the islands of the Azores and Madeira. APD is also a founding member of Disabled People's International (DPI). The official publication of APD is the newspaper, 'Associação,' which has been issued consistently since December 1977. APD has been a member of the National Council for Rehabilitation (CNR) since 1979.

APS – Portuguese Association of Deaf People. APS is an impairment specific organisation that formed in Lisbon in 1958. APS is the only organisation with national scope, including six regional sections (Carvalho, 2007: XXXV). APS was one of the members of the Commission for the Recognition of Portuguese Sign Language that formed in 1995 and which led to the official recognition of Portuguese Sign Language in 1997 (Surd' Universo, 2008). APS has been a member of the National Council for Rehabilitation (CNR) since 1982.

CNOD – Confederation of Organisations for and of Disabled People. CNOD is a national umbrella organisation in the area of disability, representing thirty-five organisations *of* and *for* disabled people (CNOD, 2009). It was formed in 1980, during the first National Congress of Disabled People organised by APD. CNOD has been responsible for organising the national congresses and national meetings of disabled people since its formation, having organised eight congresses by 2008 (1983, 1986, 1989, 1992, 1995, 1998, 2001 and 2007) and seventeen national meetings of disabled people. It has also been a member of the National Council for Rehabilitation (CNR) since 1987 but only as an observer.

Sample of individuals

In order to answer my research questions, I identified two main individual sources: leaders of movements and grassroots activists.

in Table 1, most of the interviewees headed organisations across several decades. This sample included people who were leaders from the 1970s onwards.

In the second case, I conducted 10 in-depth interviews with two grassroots activists from each selected organisation. Each participant was selected according to the following criteria: a) people who had never coordinated any organisation of disabled people; b) people who were active members, i.e. who participated in the events and/or meetings of their organisation; and c) people with at least 5 years of activism in the Portuguese Disabled People’s Movement, using the European Year of Disabled People (2003) as the landmark. Access to these interviewees was negotiated during fieldwork, on several occasions. Most of them were directly approached by me during events in which I was a participant-observer. In the case of deaf activists, due to the fact that I do not know Portuguese Sign Language, access was provided through the organisation, whose professionals suggested specific people to be interviewed. In these cases, interviews were conducted with the assistance of an interpreter of Portuguese Sign Language, who was provided by the Portuguese Organisation of Deaf People (APS).

This sample was intended to reflect the diversity of people participating in the Disabled People’s Movement in terms of gender, age and ethnic origin. However, during my fieldwork I noticed that the Portuguese Disabled People’s Movement is mainly white and is male dominated. In terms of the geographic spread, this sample includes participants across the country, namely from Lisbon, Oporto and the Algarve. The sample collected was distributed as follows:

Table 2 – Age and gender distribution of sample of grassroots activists

Age group					
Gender	20s	30s	40s	50s	60s
Female	1	0	1	0	0
Male	1	1	2	2	2

My interviewees were informed about the goals and nature of the research. Only after that, a time and place to conduct the interview were agreed. On the day, this information was repeated before starting the interview and permission was asked to record it. In order to safeguard both the interviewee and the interviewer, this information was repeated and confirmation of consent was recorded at the beginning of the interview. A set of guidelines was also shared with the interviewee, in order to reduce power asymmetries regarding the interview process and content. These included the power to

stop the interview at any point or to refuse to answer to any question without justification. In addition, anonymity was granted to the interviewee and to any person referred to during the interview. Finally, to give people control over their own words, no quote taken from the interview was used without previous consent from the interviewee. In order to accomplish this, all the interviews were anonymised, participants were given pseudonyms of their choice and names of people, places or organisations were omitted under the reference 'name', 'name of town' or 'name of organisation'. In a final stage of this thesis, all interviewees were contacted via e-mail or post in order to present them the statements intended to be used within this thesis, giving people one more opportunity to change or clarify, and to ask for permission for using those quotes in the thesis and any additional resulting publications.

Sample of documents

In my research I considered four main types of documents: legal documents (Portuguese legislation and European legal documents, originating from the Council of Europe and from the European Union, and focusing on the social rights of disabled people); Government manifestos (for references and the declaration of intentions in the area of disability); transcriptions of parliamentary debates addressing issues related to disability; and documents produced by the selected organisations (including book of statutes, manifestos, press-releases, annual activities reports, newsletters and other informational publications).

These documents cover a time range between 1974 and 2008 and were accessed via an array of sources, which included library and NGO archives, as well as online data bases. In the case of internal documents, access was granted after requesting permission from each NGO involved.

3.5. Ethical and political concerns – a self-reflexive account

As was stated above, this research is politically aligned to the social model of disability. It is, thus, my intention to disseminate the social model of disability in the Portuguese context and to contribute to highlighting the limitations of the individual and medical model as an explanation for social oppression and exclusion. Despite having been framed within a specific social, cultural, political and economic context – the British

reality –, the social model of disability is here understood as a tool to struggle against the oppression and discrimination felt by disabled people and as such its dissemination and use is highly valuable within the Portuguese context in order to highlight these phenomena and support disabled people's demands. Therefore, I hope to reveal the social and attitudinal barriers that are responsible for the oppression of disabled people in Portugal and, above all, to contribute to political change based on a social model perspective. Finkelstein has, however, warned us about the dangers of “accepting the model in principle while ignoring the problem of translating this into *material* changes to practice.” (1999: 859). Emancipatory disability research is not just about adopting a political standpoint, but is mainly about outlining the practical consequences of that ontological and epistemological positioning.

The major concern of this thesis was precisely how to reconcile changing the social relations of research production presupposed by the social model, i.e. giving disabled people control over research, with the purpose and practicalities of this study. In contrast to other projects, this thesis is the result of individual planning and solitary reasoning, where disabled people had no opportunity to participate in the research design, data analysis, or in drawing conclusions. Without rejecting the possibility of such intentions (see for example Priestley, 1997a, 1997b), I confess that my initial unfamiliarity with the principles of emancipatory research, the limited time to finish the research application for funding, the rules imposed by funding bodies and the academic bureaucratic constraints of doing a PhD including the need for the thesis to be the result of my own individual work and reasoning within a constrained limit of time, all impacted on the final research design. It limited the participation of disabled people from the beginning of the research process and, therefore, the development of a complete participatory research (Zarb, 1997; Oliver, 1992). In order to compensate for this, I have employed four main strategies:

- 1) An engagement in a dynamics of proximity with participants (both leaders and activists), i.e. the development of close relationships with participants and with the organisations of disabled people. This is crucial in order to reduce the risk of wrong interpretation, to avoid the feeling of detachment between researcher and participants, to develop a relationship of equality between the two and thus avoid falling into traditional power relations. This is what Barnes calls the construction of “a workable ‘dialogue’ between the research community [myself] and disabled people in order to facilitate the latter's empowerment” (1992b: 122).

In order to develop such a 'dialogue', I opted to disclose full details of my research from the first moment. The research design was presented to the organisations, initially by letter, which also contained a synopsis of the project, and then in a face-to-face meeting with all the leaders of the organisations. Plus, in my contact with other activists I always disclosed my identity and revealed my research goals. Against the traditional "rape model of research" (Reinharz, 1979), I suggest an engagement in a dynamics of proximity with disabled people and with the organisations of disabled people, which makes me accountable for all the consequences of this research and for any future contributions to the movement.

2) The recognition that all theory and knowledge is about situated interpretation. We are all situated subjects, as the facts and objects that we use in our research are constructed and maintained in ideological environments (Harding, 1991; Haraway, 2004). In practical terms, this meant that all the information gathered was considered relevant and valid in those terms and that the result of this research is simply my view of the events, based on one possible interpretation of the data, without claiming to be the 'true' perspective.

3) The adoption of a partisan approach, i.e. the adoption of disabled people's fights as mine without fear of 'going native' or of compromising the scientific validity of this research. According to most literature on research methodologies, participant observation is a critical moment of research due to the dangers associated with "abandoning the researcher perspective and adopting the views of the actors in the setting." (Delamont, 2004: 224). In order to avoid such an epistemological 'trap', researchers are advised to maintain high levels of self reflexivity. I do not question the importance of such reflexivity, but I dispute, however, this positivist vision of science, objectivity and truth, which implies that there is an inner truth that can be found in the research field, and that only we, as social scientists, may aim at achieving this. This is not only an arrogant way of thinking about science, but it also seems very problematic and totally inadequate when dealing with issues of discrimination and social oppression. In fact, there is no single truth, but rather different accounts constructed by different individuals or groups according to their experiences and interests (Harding, 1991; Haraway, 2004; Burawoy, 2004). As such, I contend that, particularly in cases of social oppression, researchers have a moral duty to support the struggles of the oppressed, to deconstruct and help to eliminate the factors causing such discrimination and to contribute to the emancipation of underprivileged actors.

4) To give participants in this research total control over their own words. In addition to the ethical issues related to undertaking interviews – namely providing thorough information about the purpose of the research and about the future use of the material collected, gaining informed consent before conducting the interviews and anonymising transcripts – all the excerpts included from interviews were first validated and authorised for reproduction in the thesis and future publications. This was intended to hand over to participants power over their own words, in an empowering process, so that they could change, withdraw or clarify ideas if they wished. In order to get authorization the interviewees were informed by e-mail or post about the statements I intended to use on this thesis and authorisation was requested. In the event of no reply by the interviewee within two weeks, people were informed that it was assumed that the authorisation given on the day of the interview was still valid. Again, I acknowledge that the analysis and conclusions drawn here are my own responsibility. Despite the initial intention of sharing and discussing the research results with my interviewees, and with the organisations of disabled people, the working language in which this thesis was produced created a barrier to participation. As I realised during fieldwork, language is a significant barrier, even when liaising with international counterparts. I have, for example, helped to translate documents from, and into, English for some of the organisations. In order to minimise these difficulties, at the end of my fieldwork I produced a paper based on preliminary findings that was circulated by the organisations and discussed in a specially organised seminar. More recently, I have also published an article based on my findings in a leading Portuguese sociology journal – *Revista Crítica de Ciências Sociais* – which was also sent to the organisations I have worked with, as well as to my interviewees. In addition, it is also my intention to publish this thesis in Portuguese, in order to make it available to, and a tool for, the Portuguese Disabled People's Movement.

During fieldwork and the process of data analysis other ethical difficulties emerged.

The first stemmed from my familiarity with the field. In my MA thesis I analysed disability policies concerning disabled children (0 to 5 years old). This was, undoubtedly, an advantage, in relation to the identification and collection of policy documents, but it also limited my creativity. Even if only unconsciously, I was nonetheless tempted to follow, and develop, previous analytical tracks and ideas, making new paths invisible. This forced me to be constantly self reflexive and to continuously question my data.

A second difficulty derived from the fact of this thesis being a cross-language and, therefore, a cross-cultural research. The language used within this thesis and the interface language of the research – used to present papers at international conferences and to discuss data at supervision meetings – is English. However, the language of the materials informing the study and the language of analysis of the materials collected is Portuguese. In other words, the thesis is the result of a Portuguese researcher working over materials in Portuguese which are presented in English. The complexities of translating from one language into another, widely acknowledged by other researchers (Venuti, 1998; Eco, 2003; Temple and Young, 2004; Temple, 2002, 2005, 2008, 2009; Pereira, Marhia and Scharff, 2009; Poblete, 2009), posed important methodological, epistemological, ontological and political questions from the outset. Umberto Eco recognized that a “word does not have the same evocative impact every time, in every culture or country” (2003: 107), and, indeed, after collecting the materials I faced the challenge of representing them in English without compromising its original meaning. Having in mind that in translating we are also constructing our data (Temple, 2002), I decided to transcribe and analyse my data in its original language (Portuguese), only translating the quotes intended to be used. The quotes were first translated by me and then, without compromising the anonymity of the interviewee, were double-checked, firstly by another Portuguese native speaker academic in order to check the accuracy of the translation and, secondly, by an English native speaker. In specific cases in order to clarify some contents I have added additional information inside the quote within square brackets. In cases in which translating the word could be misleading, I opted for the use of the Portuguese word highlighted in italics and explained briefly its meaning. I have, therefore, foreignised the words (Venuti, 1998). This all adds to the constructed nature of all research and to the denial of the neutrality of the researcher within the research project (Harding, 1991; Haraway, 2004). A third difficulty originated in the characteristics of the Portuguese Disabled People’s Movement. As I discuss in the thesis, one of the main features of this movement is the fact that the organisations of disabled people act mainly as independent bodies and not as clusters of organisations. This impacted deeply on the amount of data to be collected, plus it posed a further difficulty for analysis, which sought to move beyond the apparently individualistic approach portrayed by most documents and media reports to see the social movement as a collective body. In this process, new social movement’s scholars like Melluci, argue that:

events are the 'objectified' results of constructive social processes which comprise relationships and meanings, which form the basis of the publicly visible action. (1984: 44)

Collective action is not a 'fact' but a 'process', and, therefore, we cannot rely on the visible aspects of social movements. As Melluci (1984) states, it is crucial to concentrate on the production of collective action, i.e. on the creation of cultural models and symbolic challenges between the organisations. In order to do this, more data sources and data collection methods were needed, namely participant observation in meetings, direct actions and in the everyday happenings of the organisations.

A fourth difficulty arose as a result of the problems associated with determining social movements' outcomes (Giugni, 1999; Ear, 2000; Amenta and Caren, 2004; Della Porta and Diani, 2006), especially after the involvement of the EU in social issues, specifically its influence in determining disability social policies. Several difficulties may be highlighted. First, social movements are not homogeneous entities, but are instead composite action systems (Melluci, 1989) constituted by diverse "groups, organisations, and actions that may have different goals as well as different strategies for reaching their aims" (Giugni, 1999: xx) making it difficult to credit success or failure to the entire social movement. Second, perceptions of success or failure of a given action remain very subjective and often researchers and activists (Giugni, 1999), and sometimes different social movement's organisations, collide in their views. Third, social movements are only one amongst a range of social actors whose particular impact is sometimes difficult to single out (Della Porta and Diani, 2006). Assessing the consequences of social movements requires, therefore, an understanding of other social actors working on the same issue (Amenta and Caren, 2004). Fourth, establishing a chain of causality between a movement's action and change is very difficult (Giugni, 1999; Della Porta and Diani, 2006). Plus, consequences of social movements are often unintended and thus unconnected to their demands (Giugni, 1998; 1999; Tilly, 1999). As Touraine (2002) has argued, collective action is not based on, nor driven by, rational choices. Thus, to focus on the question of success/failure of a social movement is misleading as it overemphasizes activists' intentions in producing specific changes. Therefore four main strategies were used in order to overcome these methodological and analytical pitfalls: a) to focus on the consequences, impacts and outcomes; b) to consider the contribution of other social actors; c) to focus on the processes of change

and historical circumstances; and d) to compare the consequences of the Portuguese Movement with the impact of its British counterpart.

Overall, I do not believe that I have succeeded in producing a radical transformation of the social relations of disability research production. In fact, the specific academic context and practicalities of this research prevented it from achieving its aims. In practical terms, however, and despite recognising that I am the person, as the researcher, who obtained most from this research in terms of academic progression (Oliver, 1997a), I do believe that by exposing some of the disabling factors in Portuguese society and by disseminating the social model of disability in an arena where it has been almost absent in terms of practical consequences, this research has contributed to the process of emancipation of disabled people in Portugal.

In this chapter, I have explicated my epistemological and ontological position in this study, as well as outlining my research design. Issues relating to the sampling strategy and data collection and analysis were discussed, as well as my major ethical and political concerns. This was intended to familiarise the reader with my particular methodological choices, which have informed the study, the results of which will be presented and debated in the following analytical chapters.

4. Disability and disabled people in Portugal: a brief historical analysis

Introduction

Historically, impairment has been used as a source of oppression for those identified as disabled (Stiker, 1999). As analysed in Chapter 2, social model materialists (Finkelstein, 1980; Oliver, 1990; Gleeson, 1997) have suggested that the roots of that oppression reside in the establishment of the capitalist mode of production. Conversely, despite not denying this assumption, social model idealists (Morris, 1991; Shakespeare, 1997a; Garland, 1995; Garland-Thomson, 1996, 1997) argue that disability is culturally constructed on a daily basis by religion and traditional beliefs, and contend that its origins may be traced back to Greek and Roman times.

These ambiguities have permeated the politics of disability across time and they are still present in current cultures.

The analysis of the Portuguese case defies, however, Finkelstein (1980) and Oliver's (1990) arguments. In fact, Portugal did not experience industrialism on the same scale as the UK, where industrial production rapidly presented an alternative to agricultural employment. In Portugal that did not happen until the 1960s (Barreto, 2003). To illustrate this difference, in 1911, for example, 58% of the Portuguese economically active population worked in agriculture and only 25% worked in industry (Costa, 2003: 2). Nevertheless, in Portugal, as in the UK, disabled people's oppression goes back in time, meaning that it is not in industrialism or in capitalism that the roots of this oppression lie, but in older cultural conceptions, which have been sublimated, in the British case, by industrialism and capitalism and, in the Portuguese case, by the state's attitude.

Notwithstanding the chosen approach, the important point to raise here is that in both cases disabled people have been denied citizenship rights and their lives have carried the weight of stigma and oppression, in the multiple forms identified by Young (1990), across time. It is my argument that in the case of Portugal, due to the strong Catholic social background, in addition to the cultural heritage identified by Barnes (1997), an extra factor played a key role in the development of attitudes towards disability and

therefore curtailed the construction of a citizenship project for disabled people - Judeo-Christian morality. Plus, I also suggest that the Portuguese state's attitude to disability issues has been characterised by detachment, i.e. the state has maintained a secondary role here, only acting when pressured by civil society. As this analysis reveals, current and past laws and social policies regarding disabled people have been shaped by the combination of Judeo-Christian attitudes towards disability, the endemic economic crisis of the Portuguese state and the leading role played by the family in social provision.

This chapter is divided into three main sections. The first section will look at the factors which influenced disability policy and policies for people with impairments prior to the nineteenth century. The second section will focus on the nineteenth century, and on the institutionalisation of disabled people in Portugal. The final section will consider the twentieth century up until the 1974 revolution. By so doing, I intend to examine not only disability politics and policies, but also the forces that have shaped them and the prevailing ideas about disability that have informed their construction.

4.1. Before the nineteenth century: the charity system

As happened in Greek and Roman cultures, Judeo-Christian morality has been permeated with conflicting images of disability and disabled people. Again, the attitude of the Catholic Church towards disabled people was ambivalent. On one hand, it fostered the charitable status of disabled people, developing the spirit of Christian charity:

Then Jesus said to his host, [...] when you give a banquet, invite the poor, the crippled, the lame, the blind, and you will be blessed (Luke, 14: 12-14).

On the other, it maintained a latent connection between disability, sin, evil, witchcraft, impurity and God's punishment (see: *Leviticus*, 21: 16-23 and *Deuteronomy*, 28:28) (Haffter, 1968; Winzer, 1997; Barnes, 1997, 2000b; Barnes, Mercer and Shakespeare, 2000). In Judeo-Christian morality, disability emerges mainly as a question of spiritual and ethical conduct (Stiker, 1999). While it was the principle of Christian charity, developed in the New Testament, which mostly guided the approach of the Catholic Church, and moulded society's attitudes towards disabled people in the following

centuries, this ambivalence was maintained across time, surfacing at different moments to threaten, and even suspend, disabled people's citizenship rights. An example of this is the persecution of people with some type of illness and impairment by the Inquisition (established in 1183) (Stiker, 1999). Epilepsy and deafness were listed in the Inquisition Manuals as possible symptoms of possession by the devil, providing grounds for the practice of exorcism, or for accusations of witchcraft and subsequent murder (Winzer, 1997). The pervasiveness of this attitude towards disability is testified to by its presence in the minds of more progressive thinkers of the time, such as Martin Luther (1483-1546), who professed that children with mental impairments were a mass of flesh without soul and were born of the devil, and who suggested that they should be drowned in the closest river (Winzer, 1997; Barnes, 1990, 1992a, 1997, 2000b).

Such ambivalence is also traceable in the Church's attitude towards different impairments. The majority of the scarce institutions created by the Catholic Church were devoted to blindness and to acquired conditions. In medieval times, Oswin (1998) claims that:

Other groups of disabled children did not evoke the same interest and sympathy. They were called 'cripples' and depicted as ugly and evil in art and literature. (1998: 30)

Barnes (1990: 18) identifies this same reality in the British case:

In the England of the Middle Ages, the impaired were viewed with a number of attitudes ranging from, at worst, fear and degradation to, at best, paternalism and pity. They were excluded from the mainstream of economic and social activity and were dependent on the benevolence of others. [...] [and] on the haphazard, and often ineffectual, traditions of Christian charity and alms-giving for subsistence.

The impact of this disablist attitude also stemmed from the Catholic monopoly on service provision to disabled people over the centuries. In the UK, assistance to people with impairments was only secularised in 1601 – as part of a wider process of state reconfiguration – with the introduction of the Poor Laws (Scull, 1984; Barnes, 1990; Harris and Roulstone, 2011). In Portugal, this was only initiated in 1835, with the establishment of the General Board for Beneficence (Maia, 1985; Lopes, 1994). Before that, disabled people could only rely on their families and Church support (Maia, 1985;

Ferreira, 1990). Under such conditions, the dominant disabling attitude could easily be found beyond the religious sphere (Winzer, 1997).

In fact, since medieval times the history of assistance to disabled people has been closely connected with the political and religious history of Europe and of the Middle-East. Most charitable organisations addressing disability had a religious background and were designed to offer support to men impaired in the crusades, especially blind men. Examples of these institutions include the asylum created in Turkey in the fourth century AD, the cottages created in Syria in the fifth century and the asylum for blind people founded in the seventh century in France and the Hospice des Quinz-Vingts built in France in the thirteenth century (Winzer, 1997; Barasch, 2001).

In Portugal, despite the absence of such asylums, there is evidence of charities connected to the Catholic Church offering assistance to disabled people, even before Portugal became an independent kingdom in 1143 (Ferreira, 1990). These ancient charities were connected to monasteries, especially to those close to pilgrimage routes, and assumed the forms of ‘brotherhoods’, ‘confraternities’, ‘shelters’, ‘hospitals’, ‘leprosy houses’ and ‘shops’ (Ferreira, 1990). As happened in other countries (Scull, 1984), these institutions provided assistance to those in need under the same roof independent of their condition (Ferreira, 1990).

According to Maia (1985), by the end of the fifteenth century most charitable institutions in Portugal were inefficient, their actions were hampered by clashes between religious orders and there was a surfeit of small charities fighting for scarce resources. The combination of factors, which included social and demographic changes resulting from maritime expansion and new economic strategies (resulting in greater numbers of orphans, widows, people with impairments and with ill health and street beggars) and the general tendency in Europe towards the centralisation of political power (Scull, 1984; Mattoso, 1993; Barnes, 2000b), led to a reform of public assistance in Portugal (Maia, 1985). This reform, initiated by the state in the second half of the fifteenth century, disbanded old charities and incorporated others into a new type of charity – the *Misericórdias* or ‘Holy Saint Houses of Mercy’. The first *Misericórdia* was created in 1498 in Lisbon (Freire, 1995) and they rapidly spread all over the country and its colonies (Abreu, 2001). From the fifteenth century onwards the *Misericórdias* were made responsible for assisting most of the population in need in Portugal. This included

having a monopoly over the administration of numerous Portuguese hospitals, which only ceased in 1974 when the state took direct control.

What was new about these charities in relation to impairment was the introduction of specific services for disabled people within the community. These were home-based services, for those with incurable diseases (called the ‘visited’ or the ‘listed cripple’) (Lopes, 1994), what Barnes (1990), in the British case, refers to as ‘domestic relief’. These services provided by the *Misericórdias*, included free medicine, clothes, shelter, as well as offering some financial benefits too (Lopes, 1994). Disabled people continued, however, to be invisible within the broad category of those in need of assistance. As with the British case, they formed an indistinguishable group of people in need (Stone; 1984; Barnes, 1990, 2000b).

In Portugal, this new type of charity was, however, run and organised by the Catholic Church. This seems to be the first point of divergence in the history of assistance to disabled people in Portugal and in the UK. In fact, the Portuguese monarchs were reluctant to intervene directly in public assistance and opted for the maintenance of religious dominance, rather than assuming direct responsibility, whereas, in the UK, the crown was increasingly involved in the regulation and provision of public assistance (Scull, 1984; Barnes, 2000b). The establishment of the Poor Laws in the UK in 1601 symbolised the “official recognition of the need for state intervention in the affairs of the destitute and the disabled.” (Barnes, 1990: 19), introducing the principle of secular responsibility for the indigent (Scull, 1984), but also the need to separate abled and disabled populations (Roulstone, 2002; Harris and Roulstone, 2011). Although this Act established the need to create special facilities for those with different impairments, these specifications were not immediately implemented (Barnes, 1990; Stone, 1984). Up until the eighteenth century, disabled people remained indistinguishable within the large category of aged and infirm people (Stone; 1984; Barnes, 1990, 2000b). As has been argued in the Portuguese case, this category included not only impaired people, but also the sick, the aged, orphans, and poor people in general. In the UK the main concern was to distinguish between the ‘deserving’ and the ‘undeserving’ people, but “there was little attempt to separate them from the rest of the community” (Oliver and Barnes, 1998: 28).

I argue, therefore, that the histories of disabled people in Portugal and in the UK started to diverge in the fifteenth century. Whereas in the UK the secularisation of the state

initiated the disentanglement of disability from religious beliefs, in Portugal this connection was strengthened, first by the continuing dominance of the Catholic Church in charity provision and, second, by the role of the Inquisition in Portugal after 1536 (Saraiva, 1997). Both aspects impacted on diverse spheres and sectors of Portuguese society, namely on disabling attitudes and on the persecution of those with some types of impairments. With the advent of the Enlightenment, the gap between Portugal and the UK became even wider in terms of attitudes towards disabled people. If, in the UK, the Enlightenment enabled freedom from theological and supernatural beliefs and fostered trust in human reasoning, in Portugal the impact of the Enlightenment was limited. The presence of the Inquisition restrained the freedom of thought and scientific rationality, creating fear amongst the Portuguese population and Portuguese intellectuals (Saraiva, 1997), some of which left the country (Birmingham, 1993).

Despite this difference, from the eighteenth century onwards there were growing similarities in the Portuguese state's political approach to the population in need. As happened in the UK with the seventeenth century Poor Laws (Oliver and Barnes, 1998), the great increase in vagrancy after the Lisbon earthquake (1755) led to the introduction of policy measures to separate the 'deserving' from the 'undeserving' poor (i.e. the legitimate beggars from the 'non-impaired' unwilling to work) (Lopes, 1994). A decree published in 1755 established that vagrants considered able to work were to be sentenced to forced labour and those considered 'invalid' to work (namely the 'blind'), the 'real' poor, were licensed to go begging in an "orderly and virtuous way" (Lopes, 1994). In addition, in 1780 *Casa Pia*, a residential institution, was created in Lisbon, which aimed to collect and recuperate, vagrants and beggars through labour, as well as providing education to orphans (Lopes, 1994). The implementation of these measures targeting vagrants and beggars might be read in the light of the need to control the deviant behaviour of the time (Maia, 1997; Lopes, 1994).

It is possible to read these initiatives as the first step towards public assistance run by the state (Lopes, 1994: 501), in a similar vein to the public policies that created the workhouses and implemented the Poor Laws in the UK and the large institutions in France for the confinement of people with impairments (Stiker, 1999). I argue, however, that the initiatives taken in Portugal diverge considerably, not only in scale, but also in philosophy, from those undertaken in the UK and in France. First, as will be analysed in the next section, the tendency to segregate disabled people into residential institutions in Portugal only began in the mid-nineteenth century and never reached a dimension

similar to those other countries. Second, in contrast to the UK and France, where such institutions were meant to segregate disabled people from the general population, in Portugal, again, up until the second half of the nineteenth century these initiatives were mainly meant to control vagrancy in general and did not target people with impairments specifically.

In the French case, the emergence of specialised hospitals, such as the *Hôpital Général* and the *Hôtel des Invalides* created in Paris, dating to 1656 and 1674 respectively, marked the beginning of the segregation and confinement of disabled people (Stiker, 1999). In the British case, the segregation seems to stem from the changes introduced by the industrial revolution (Finkelstein, 1980; Oliver, 1990). Due to the inflexibility of the industrial mode of production towards individual specificities and difference, disabled people were rendered inadequate to the production process (Finkelstein, 1980). These changes, in combination with other social processes (urbanisation, mercantilism and the changes in the family structure, etc.), were responsible for the emergence of numerous institutions for disabled people and for their institutionalisation (Ryan and Thomas, 1987; Barnes, Mercer and Shakespeare, 2000). Barnes (1990) goes even further, suggesting that the key to understanding the movement towards institutionalisation is individual wage labour. According to him, the spread of individual wage labour impacted upon the organisation of families in two different ways. Firstly, by making them “dependent on wage earnings [which meant that they] could not provide for its [their] members in times of economic depression,” (Barnes, 1990: 21). And, secondly, individual wage labour “made the distinction between the able-bodied and non-able-bodied poor crucially important,” (1990: 21). Following Ingelby (1983), Barnes concludes that:

Segregating the poor into institutions had several advantages over domestic relief: it was efficient, it acted as a deterrent to the able-bodied malingerer, and it could actually create labour by instilling good work habits into the inmates. (Barnes, 1990: 21)

In a similar line of argument, Stiker states that, “the Great Confinement [...] inaugurates a new phase of administrative repression in the treatment of the poor” (1999: 98). The logic of this new phase was to establish public order through the physical concentration of, and circumscribing the presence of, disabled people.

The differences, in both the scale and philosophy of the initiatives taken in the area of disability, between Portugal and France and the UK were also the result of the limited impact of the Enlightenment and the consequent delay in scientific development in Portugal. Whereas in the UK the emergence of medicine as a scientific profession and its success in the medicalisation of impairment made it legitimate to introduce new radical changes in the treatment of disability which, then, resulted in the expansion of segregating institutions (Barnes, Mercer, Shakespeare, 2000). Furthermore, this new medical science introduced novel means of social vigilance and punishment of people with impairments. Medicine transformed disability into incapacity and limitation, leading social policies towards seclusion, imprisonment, social exclusion and encouraged the dependence of disabled people, and ultimately, led to the individualization of disability and the construction of disability as tragedy (Oliver, 1990). A huge array of new techniques, to identify, classify and regulate the lives of infirm and disabled people, were created, contributing to the construction of a “therapeutic state” (Foucault, 1989) and to new conceptions of normal/abnormal, sane/insane and healthy/unhealthy. In Portugal this scientific development in general and in medicine in particular only became evident in the nineteenth century and only then did disability start to be defined as a problem of the body, with disabled people being transformed into a focus for medical attention and control, as had happened in the UK in the previous century (Hughes, 2002).

4.2. The nineteenth century and the creation of the category ‘disability’

To reiterate, notwithstanding the drive towards the institutionalisation of disabled people in France and in the UK, which dates back to the seventeenth and eighteenth centuries, in Portugal this transition only began in the mid nineteenth century. Several reasons may account for this time lag. First, as has already been mentioned, the dominance of religion and the control exercised by the Inquisition, which prevented the development of Enlightenment thinking and of a new attitude towards disabled people based on rational scientific reasoning, dominated before 1820, the year in which the Inquisition was extinguished, and when several religious orders were expelled from Portugal (Neto, 1993). Second, the fact that all of the economic and social processes described for the British case – urbanisation, industrialisation, mercantilisation, individual wage labour settlement and the change in familial structures (Finkelstein,

1980; Ryan and Thomas, 1987; Barnes, 1990; Barnes, Mercer and Shakespeare, 2000) – only occurred in Portugal in the second half of the nineteenth century (Mónica, 1987; Vaquinhas and Cascão, 1994; Martins, 1997). Despite the similarities in terms of targeted groups ('lunatics' and people with sensory impairments), the analysis reveals that in Portugal this movement was less comprehensive than in the UK. The reality was that Portugal's economic situation, the lack of political consensus within its liberal thinkers in relation to public assistance at the time and the late development of industrialism and capitalism deferred the transformation of disability, making it into a problem of management (Mendes, 1993; Lopes, 1994). In fact, the emergence of residential institutions in Portugal was more a result of the need to control and repress vagrants, rather, than, as Stone (1984) describes, an attempt to create an alternative distributive system based on need, which can be regarded as an embryonic form of citizenship rights.

This analysis suggests that in the case of Portugal there is a clear distinction between the first and second halves of the nineteenth century. If, in the first half, disabled people were not distinguishable from others in need of public support, in the second half of the century disabled people were not only isolated from the rest of those in need, but were also institutionalised according to categories of impairment.

The first half of the nineteenth century in Portugal was disastrous. The French invasions and the political upheavals contributed greatly to the deterioration of the living conditions of the Portuguese population, with an increase in the number of beggars and people demanding public assistance (Lopes, 1994). In addition to the spread of the new liberal ideology and its faith in work and combating idleness (Lopes, 1994), these facts pushed the Portuguese state, for the first time, to intervene directly, and in an organised way, in the provision of public assistance. An example was the publication in 1835 of a Decree establishing the General Board for Beneficence (*Conselho Geral de Beneficência*). As Lopes (1994: 502) notes:

The constitutional monarchy developed a noticeable role in the suppression of Portuguese society in terms of: vagrancy, reverie and indolence (playing a large effort in its regeneration), in combating diseases and their causes, in assisting aged, ill health, disabled, orphans and abandoned children, imprisoned and lunatic people... An insane effort, since there were multiple combat fronts, uncountable needs and generalised poverty.

This law created the Portuguese equivalent of the British workhouses: the ‘mendicancy asylums’, the ‘infancy asylums’ and the ‘asylums for the old and invalid’ (Maia, 1985). The first ‘mendicancy asylum’ was created in Lisbon in 1836 and several others followed in major cities (Lopes, 1994). The goals of these asylums were, as happened with the workhouses in the UK, twofold: to repress and to support vagrants. It is interesting to note that, in contrast to the British workhouses, where confinement was compulsory, in the Lisbon asylum, due to the huge number of ‘invalid’ beggars, which exceeded the capacity of the asylum, vagrants were authorised to beg in the streets (Lopes, 1994). This case illustrates, not only the correlation between disability and poverty, but also the indistinguishableness between disabled people and other populations in need of public support in the first half of the nineteenth century. Contrary to the Portuguese case, in the UK the 1834 Poor Law reform, and, later, the 1845 Lunacy Legislation and the 1871 legislation (that abolished the Poor Law Board and transferred its authority to a Board of Local Government), were designed to reduce help to the impoverished, limiting its provision to indoor relief (inside the workhouse), to the classification and categorisation of those in need, making institutionalisation in the workhouse compulsory for the provision of support, and making poor-relief unattractive by its rigidity and associated stigma (Stone, 1984).

Due to the fact that public assistance was a highly contentious issue amongst the liberal thinkers of the time, the successive reforms only added to its controlling character. The state only acted in cases of need, and public assistance was not an individual right; instead, it was an expression of the moral duty of the state (Lopes, 1994). Again, this conception of public assistance was one of the reasons for the lack of public institutions for disabled people in Portugal during the nineteenth century. As was the case in the UK, despite the shift towards the categorisation and institutionalisation of disabled people having begun in the first half of the nineteenth century, the ‘great confinement’ only started in the second half (Ryan and Thomas, 1987; Borsay, 2005; Harris and Roulstone, 2011). In Portugal’s case it is also only possible to single out the emergence of one specialised institute incorporating the spirit of this movement – the Institute for Deaf-Blind Children (1823) – before the middle of the century (Costa, 1981). This Institute was formed within the existing structure of *Casa Pia* of Lisbon, and combined the large institution’s typical goal of confinement with a new medical spirit (Costa, 1981), which echoed what was happening abroad. Despite the fact that the first specialised institution created for disabled people was public, in the second half of the

nineteenth century public initiatives focused mainly on the creation of hospitals for 'lunatics', leaving it to the private sector to develop disability institutions.

In the UK, the changes described above in the arena of medicine and the revolution produced by new writing and reading techniques created by Louis Braille for the education of blind people, had an immediate impact on the creation of schools and on new teaching techniques. As has been argued, this specialised institutions had no parallel in Portugal at the time. These transformations had, in the British case, perverse effects on the lives of disabled people, transforming them into objects for medical study. As Barnes, Mercer and Shakespeare argue:

disabled people came increasingly to the attention of new medical specialisms and professionals. A whole new field of rehabilitative medicine and allied professional intervention was gradually established 'for' disabled people. (2000: 20)

Consequently, the old segregationist institutions were transformed into new specialised institutions for different types of impairment. The first to be created were the asylums for 'lunatics' (*sic*), followed by residential institutions for blind people and institutions for deaf people, people with physical impairments and people cognitively impaired (Stone, 1984; Barnes, 1990; Hendrick, 2003). In Portugal this categorical approach (Harris and Roulstone, 2011) only came into use in the second half of the nineteenth century, with examples of such institutions including: the Asylum for the Blind Nossa Senhora da Esperança created in Castelo de Vide in 1863 and the Asylum for People Impaired from Work, which was set up in Alcobaça in 1864 (Goodolphim, 1900).

However, the most obvious characteristic of disability policies developed in the second half of the nineteenth in Portugal was the emergence of a new concern with the education and professional training of sensory impaired people, specifically of deaf and blind people. This was the case with the Lisbon Municipal Institute for 'Deaf-Mutes' created in 1887 and with the School for the Blind of Oporto set up in 1903. Most of these institutions resulted from the philanthropy of privileged families (Pereira, 1894; Lourenço, 1956; Oliva, 2001; Ribeiro, 2003). The state only intervened where private initiative was absent, which is in accordance with the terms of public assistance at the time. International influences also played a significant role. A magazine article dating from 1907, entitled "The Deaf-mutes speaks!" (*Ilustração Portuguesa*, 1907: 547) explained that the teaching method used in the 'Institute for the Deaf,' José Rodrigues

Araújo in Oporto, was based on “pure oral intuition”, a method used by the most developed countries and introduced to the institute by professors who studied at the National Institute for the Deaf-mutes of Paris.

One area absent in private initiative was the provision for ‘lunatics’. As happened in the UK in the second half of the nineteenth century, the Portuguese state focused on the creation of several specialised psychiatric hospitals (Graça, 1996; Ferreira, 1990). Most of the hospitals, however, were created to receive people who had previously lived in specially designated areas in large hospitals in Lisbon and Oporto, revealing that the incarceration of this population was already in place. This was the case with the Hospital for the Lunatics of Rilhafoles, founded in Lisbon in 1848, and with the Hospital of Conde Ferreira, created in 1883 by the *Misericórdia* of Oporto (Graça, 1996; Ferreira, 1990).

Again the ‘differing bodies’, those with congenital impairments, had to rely on public assistance, that is, on the support of the ‘Mendicancy Asylums’ and on begging. This situation seems to have been the same in the UK:

A fundamental nineteenth century response to people with physical or cognitive impairments was either to ignore them or to incarcerate them in prisons, asylums and workhouses. (Drake, 1999: 46)

This movement towards confining disabled people parallels an increase in the repression and imprisonment of beggars, in order to distinguish between those considered able and unable to work (Roulstone, 2002). In Portugal, for example, the 1852 Penal Code established that beggars and rovers would be punished with correctional imprisonment, and that only the ‘real poor’ would be licensed by the ‘asylums of mendicancy’ to beg on the streets, (Lopes, 1994). In the UK, this retrenchment was also a reality. The disappearance of the Poor Law Board in 1871 and the transference of its authority to a Board of Local Government (Stone, 1984), caused a more stringent application of the workhouse confinement and a further tightening of the access criteria in order to identify the indolent (Barnes, 1990):

Even after 1885 when the initial fervour of the new regime died down and a more humanitarian approach was adopted, local officials were still instructed to scrutinize carefully those seeking aid, so that help should only be given to those of

'good character'. The net result of these policies was to further separate the impaired from the rest of the community (Barnes, 1990: 24).

This situation of disabled people remained unchanged until "the advent of the community care movement" (Barnes, 1990: 25) in the twentieth century. This is confirmed by Drake, who states that "the twentieth century began much as the Victorian age left off" (1999: 49).

In sum, and despite the differences in scale and aim that were referred to above, by the second half of the nineteenth century the long standing gap between the disability policies of Portugal and the UK had begun to narrow. In fact, the medicalisation of disability and the institutionalisation of disabled people according to impairment categories became a reality in Portugal. The institutionalisation of disabled people in the second half of the nineteenth century signifies a denial of their citizenship rights. This fact challenges Marshall's evolutionary understanding of citizenship, which equates historical change with civil, political and social rights (Marshall, 1950). In fact, disabled people were totally absent from the citizenship project and from the struggle for citizenship rights in the UK and Portugal in the nineteenth and early twentieth centuries, which focused much more on the abolition of slavery and on women's right to vote (Giddens, 1993; Vicente, 2007; Purvis, 2009).

4.3. The twentieth century

The twentieth century in Portugal was marked by three main political and social events. The first was the end of the monarchy in 1910 and the inauguration of a Republican regime. The second was the establishment of a political dictatorship in 1933, which lasted for 48 years, the longest dictatorship in Western Europe. Finally, there was the Democratic Revolution of 1974, which ended the dictatorship and re-established a Republican Democratic regime. The lives of disabled people were, as we will see, also effected by these changes, which impacted greatly on ensuing social policies. If, in the first period, there was a growing similarity between the disability policies of Portugal and the UK, in the second period, the dictatorship generated further differences between the realities of disabled people in these countries.

4.3.1. The period from 1910 to 1933

The period comprising the Portuguese First Republic (1910-1926) and military dictatorship (1926-1933) was marked by a sweeping political instability and an acute economic crisis aggravated by the outbreak of the First World War (Maia, 1985; Rosas, 1994). This political and economic crisis led to a military dictatorship that lasted from 1926 to 1933, and was followed by a right-wing political dictatorship. It is my contention that, in this period, despite the improvement to the social welfare of the general population, with the establishment of social assistance, this was not extended to disabled people. Disabled people's citizenship rights continued to be denied at the same time as the political regime prevented them from taking an active role in the construction of their citizenship project.

During the First Republic (1910-1926) several initiatives were taken to solve the question of public assistance. Perhaps the most important of these was the 1911 Constitution of the Portuguese Republic, which defined the right to public assistance under the section concerning individual rights and warranties (article 29). In 1913 another important measure made employers accountable for any job-related injuries. In 1916 the Ministry of Work and Social Providence was created and in 1919 social insurance (for protection against illness, accidents at work, incapacity and old age) was made compulsory, alongside the creation of the Institute for Obligatory Social Insurance and General Providence (Maia, 1985; Pimentel, 1999). Some of these initiatives, such as compulsory social insurance, were never fully applied, due to the economic difficulties of the time (Maia, 1985; Pimentel, 1999). However, what is interesting to note is the change in the underlying philosophy of these measures. The introductory chapter of the Law Decree of 25 of May 1911 offers a clear example. In its preamble it stated that poverty could not be changed through public assistance and that mendicancy could not be extinguished by laws or by taking repressive measures, but through an increase in, and redistribution of, health provision, alongside adequate public assistance to true 'indigents' (Carreira, 1996a). This seemed to denote a change from the nineteenth century way of thinking and acting, and reflected the move towards a more egalitarian and humanitarian perspective.

As was argued above, these improvements did not translate into any improvement in disabled people's lives. In fact, as the analysis indicates, any support offered to disabled people continued to be mainly provided by the specialised institutions developed in the

nineteenth century, some of which lacked specific goals besides the incarceration of and separation of disabled people from the mass of vagrants and, above all, from the rest of society (e.g. asylums and hospitals). Others, as has already been stated, were concerned with the education and professional training of disabled people (e.g. new institutions). Even in these, however, the education provided was often very basic and the training was dominated by the pre-conceptions of the time. This was the case with the School Asylum for the Blind, António Feliciano de Castilho, set up in Lisbon in 1888 by the Association for Promoting the Education of the Blind (APEC), which, after a brief period dedicated to training for work, focused only on the musical education of 'blind' people (Oliva, 2001). Moreover, most of these institutions continued to rely financially on private funding and charity (Goodolphim, 1900).

This analysis also evidences the growing medicalisation of disabled people's lives in Portugal – in line with what happened in the UK (Oliver, 1990) – revealing the prevailing role of the medical model of disability in the Portuguese context at this time. This is indicated by the creation in 1916 of a Medico-Pedagogic Institute within the *Casa Pia de Lisboa*, and by the medical labels and classifications it employed when defining its aims – to study the 'physically and mentally abnormal' children of the *Casa Pia* of Lisbon (Fontes, 1940; Costa, 1981). In 1929, this institute was reorganised, becoming directly dependent upon the Ministry of Education (decree n. 16:662) and was renamed *Institute António Aurélio da Costa Ferreira*, after its first director. This change also meant its transformation into a national institute and, thus, a concomitant increase in its responsibilities. The institute played a key role in the training of professionals and in the definition of everything related to the education and support of disabled children in Portugal throughout most of the twentieth century (Costa and Rodrigues, 1999).

The period of the Portuguese First Republic was also marked by the First World War, which, according to Drake (1999), was the turning point in the area of disability in the UK. The huge number of dead, injured and impaired British soldiers, and the need to offer compensation for their patriotic efforts, fostered a new sympathy towards disabled people (Bourke, 1996; cited in Drake, 1999). Several legal documents were subsequently published in order to provide war pensions to people with impairments, to those with injuries, to widows and to orphans, as well as to regulate charities, etc. (Drake, 1999). In the Portuguese case, the impact of the First World War was not so extensive. Portugal did not join the war until 1917 and thus the number of dead, injured

or impaired soldiers was much less than in the UK. However, the impact of the First World War, in general, should not be overlooked. By the end of the War, the notion of disability came to be mediated by the idea of rehabilitation. Arguably, this event had a great impact on disability policies and politics worldwide, to which Portugal was not immune (ELO, 1979).

The economic crises of the 1920s and 1930s brought, however, this sympathetic period towards disabled people to an end. In the UK there was a return to the segregation of disabled people, with the persistence of ‘lunatic’ asylums, the creation of new orthopaedic hospitals in major cities, “the provision of ‘special education’ in certified schools for disabled children [...] and for disabled adults in the continuance of the Poor Law.” (Drake, 1999: 51). In a similar turn, Portugal also evidenced a retrenchment in the disability benefits that had been created for impaired war veterans and in the emergence of new segregationist institutions for disabled people with no pedagogic purpose. Examples include the Medico-Pedagogic Institute, Condessa de Rilvas, founded in Lisbon in 1927 (Pimentel, 2001) and the Institute Adolfo Coelho (Fontes, 2006).

Alongside these segregationist institutions for disabled people, this period also witnessed the formation of the first organisation *of* disabled people in Portugal - the Louis Braille Association formed in 1927 (Oliva, 2001). As was the case in the UK, with the formation of the British Deaf Association (1890) and of the National League of the Blind (1899) (Campbell and Oliver, 1996), the Louis Braille Association was a single-impairment and single issue organisation formed by ‘blind’ people as a ‘trade union’ of ‘blind’ musicians. The roots of this organisation were laid by the institutes for blind people, which had been created since the 1920s in Portugal, with their educational focus on music (Garcia, 1995). This transformed most blind people in Portugal at the time into musicians, whose labour consisted in playing at private parties, for radio stations, in cafés and night clubs (Oliva, 2001). As will be highlighted in the next section, the establishment of the political dictatorship in 1933 had a great impact on the existing organisations, emphasising their charitable status and eradicating their collective spirit.

The Portuguese society of the time was illiterate, rural and largely employed in agriculture (Barreto and Preto, 1996). In 1920, for example, 70.8% of the Portuguese population was unable to read or write, a situation that persisted throughout the

following decades (67.8% in 1930, 59.3% in 1940, 48.7% in 1950, 40.3% in 1960 and 33.6% in 1970) (Carreira, 1996b: 11; Barreto and Preto, 1996: 79). The period of the First Republic was also marked by an acute economic crisis, leading to a military dictatorship in 1926. The need to solve the economic problem led António Salazar to be selected to the Ministry of the Treasury in 1928. The apparent economic miracle performed by the new Minister, granted Salazar the nomination for Prime Minister in 1932 (Rosas, 1994), opening a new page in Portuguese history with direct consequences in the area of disability. It was the beginning of the 'New State'.

4.3.2. The period from 1933 to 1974: disability politics under dictatorship

In 1933 the approval of the new Portuguese Constitution replaced the previous military dictatorship by a right-wing political dictatorship headed by António Salazar. Salazar's regime was extremely conservative, especially in relation to familial structures and moral values (Pimentel, 1999; 2001). The control and repression of ideas opposed to the regime was one of its main traits (Bastos, 1997), which was undertaken by the political police and by the ideological engines of the regime. The area of public assistance and disability was also constrained by the ideology of the regime. In 1933 the new Constitution denied citizenship rights to disabled people by withdrawing the right to public assistance, which had been recognized by the 1911 Constitution, and which stipulated that the only duty of the state was to coordinate, stimulate and rule all social activities in order to improve the life conditions of those belonging to the lower economic classes (Pimentel, 1999; 2001). In 1934 this idea was developed at the First Congress of the National Union (the single political party of the regime) and the secondary role of the state in the provision of public assistance was adopted fully. The primary role was left to private initiative, which is to say to the Catholic Church (Pimentel, 1999).

The end of fascist regimes after the Second World War and the publication of the Beveridge Report in the UK in 1942 (which led to the development of the welfare state) influenced the Portuguese state to take a more active role regarding public assistance. One major result was the publication in 1944 of the Statute of Social Assistance (Law n. 1998, of 15/05/1944), which organised public assistance in Portugal and confirmed that the dictatorial state had abandoned the citizenship project. As is evident, under the new

designation of 'social assistance', 'public assistance' disappeared and became less far-reaching in accordance with the ideology of the regime. According to this document, the state would only provide help to people with ill health and 'disabilities', i.e., those considered the 'good poor,' and thus worthy of assistance, while the support provided would not foster idleness or reliance on the state or charity (Pimentel, 2001). The impact of this social assistance policy was, however, minimal (Maia, 1997). Social assistance was only meant to supplement private initiative, and the state's action need only be directed towards coordinating and facilitating private assistance (Carreira, 1996a; Pimentel, 2001). The level of protection offered to people by social assistance remained low and was not universal in application. The initiatives and activities were disorganised and the services provided were randomly dispersed (Maia, 1997). These benefits were rarely used and this was always only a transient and sporadic strategy. All initiatives targeted the family and not the individual, and even when they addressed the individual, this was done in order to promote the recovery of the family and of its morality (Pimentel, 2001). The publication of a new Law defining the politics of health and social assistance (Law n. 2120, 19 July) in 1963 did not change much. The idea of social assistance as a private issue persisted (Carreira, 1996c).

This ideological structure created by the regime and applied to social assistance shaped the policies towards disabled people in Portugal, widening the gap between the reality of disabled people in Portugal and those in the UK. In contrast to other European countries, where the social citizenship project had been a reality since the end of the Second World War with the establishment of welfare-states (Esping-Andersen, 1990; Ferrera, 1996), in Portugal the state had opted out and had taken a secondary role, that of coordination and supervision. The construction of the welfare-state in the UK provided new financial means, which were previously unavailable, established disabled people's rights to education and employment, and encouraged the development of health and rehabilitation services and the creation of numerous medical institutions and therapy services. This resulted in a sharp increase in the number of disabled people living in institutions (Oswin, 1998). In 1929 the number of people living in asylums for 'mental' impairment in England and Wales was 25,000; the figure rose to 60,000 people in 1952 (Oswin, 1998: 34). Disabled people were forced to live outside of society and, as Stiker states: "nothing that could make a strong contribution toward the presence of the impaired among the others is ever a budget line item" (Stiker, 1999: 161).

In contrast, the solutions developed by the Portuguese state were mainly directed towards the maintenance of disabled people within the family or towards the coordination and promotion of private initiatives. This was the result of the lack of a welfare-state in Portugal and of the delegation of social responsibility to the family and civil society. This seems to confirm Esping-Anderson's (1990) idea that the development of the welfare-state is not the result of macro phenomena, like the creation of wage-labour (Manning, 2003) or a shift from a "monarch-subject relationship to a state-citizenship relationship" (Heater, 1999: 4), but of the specificities of each country, such as the type of state intervention in society, the characteristics of the social structure and the 'generosity' of state redistribution.

As has previously been acknowledged, contrary to what happened in most of Europe, Portugal did not develop a welfare-state until the collapse of the dictatorship in 1974 (Santos, 1999). Until 1974 a system of compulsory social insurance excluded a considerable number of citizens (Pimentel, 1999), including disabled people. In 1960, for example, only 13.3% of the resident population and 35.6% of workers were protected by this system of social insurance (Carreira, 1996a: 38). In 1970, due to the major reforms undertaken towards the end of the dictatorship in the sector of *Previdência Social* (Guibentif, 1996), these figures rose to 27.8% and 78.9% respectively (Carreira, 1996a: 38). In the health sector the situation was similar, with only 56% of the population being protected by a health system in 1970 (Mozzicafreddo, 1992: 66). Since its beginnings, the dictatorial state had played only a supplementary role in the sector of social assistance. Those who fell outside of the protection schemes relied mainly on kinship and friendship networks and on the few existing charities.

Under the dictatorship, social policies were structured around private initiatives, namely charitable organisations dependent on the Catholic Church (Pimentel, 1999, 2001). However, during the first half of the twentieth century, this lack of a public system of social security was barely supplemented by a private charity system due to the state's control over all grass-roots organisations, including existing private charitable ones (Hespanha *et al.*, 2000). This is confirmed by the publication of the Statute of Social Assistance in 1944, through which the state created the Institute for the Assistance of the Invalid, among other public institutes, in order to coordinate the activity of local private initiatives (Maia, 1985; Pimentel, 1999). Moreover, despite the regime's tolerance of the organisations *for* and *of* disabled people that had emerged in Portugal since the 1930s, these organisations had to be based on charity. An example of

this is the revision undertaken by the Association Louis Braille in 1935 to its book of statutes. As a result, the association changed its name to Association of Beneficence Louis Braille and, thus, emphasised its charitable status (Oliva, 2001). During this period other organisations and groups of disabled people emerged, such as the Group of Deaf People of Oporto (1934), the Group “The Mute” created in Lisbon (1936), the Sports Group of Deaf-Mutes of Lisbon (1945), the Sports Group of Deaf-Mute of Porto (1951), the League of Blind People João de Deus, created in Lisbon (1952), the Blind Association of Northern Portugal (1958) and the Portuguese Association of Deaf People (APS) formed in Lisbon (1958) (ELO, 1986; Oliva, 2001; Carvalho, 2007). The only reason these organisations were tolerated by the political regime was because these collectives remained as peer meetings and/or sports groups, reinforcing the social isolation of disabled people. Moreover, none of them developed any political understanding of disability or undertook any type of public-political intervention, and their approach reinforced the charitable perspective of disability.

Moreover, as with the British case, where, by the mid-twentieth century, a new volunteer run, specific-impairment organisations sector, fostered by parents of disabled children, emerged (Campbell and Oliver, 1996), a new disability sector, focusing on pedagogic and social issues, was formed by families and professionals in Portugal from the 1950s onwards (Costa, 1981). Like the former case, these new organisations were single-impairment. Examples in the UK include MENCAP and the Spastic Society (Campbell and Oliver, 1996). In Portugal the emergence of this sector is exemplified by the creation of the Portuguese League of Motor Impaired (1956), the Portuguese Association of Cerebral Palsy (1960) and the Association of Parents and Friends of Mongolic Children (1962) (Costa, 1981).

The attention of the state was, however, drawn to the creation of psychiatric hospitals. During the twentieth century there was a great increase in the number of psychiatric hospitals in Portugal. Examples are the Hospital of Sobral Cid, created in Coimbra (1945), and the Hospital Magalhães Lemos in Oporto (1960). The creation of institutions for the incarceration of ‘lunatics’ can be interpreted as an example of the incorporation of eugenic ideas within the ideology of the regime, which were also widespread in Europe and the United States of America (USA) at the time (Ryan and Thomas, 1987; Davis, 1997; Hubbard; 1997; Drake, 1999), and of social controls that drew a direct link between ‘mental’ impairment, delinquency and vagrancy (Reis, 1940). A propaganda document produced by the regime, dating from the end of the

Second World War, located the causes of poverty in 'mental disorders' caused by inherited 'degeneracy', syphilis and alcoholism; social situations, such as lack of support for big families; and individual 'defects' caused by industrialisation (Pimentel, 1999). At that time, vagrancy was prohibited and vagrants, and those who helped them, faced legal punishment (Bastos, 1997). Drawing upon the dominant political ideas, the creation of these institutions was a strategy used to incarcerate people with mental impairments, to control their actions, prevent them from procreating and facilitate the moral rehabilitation of families, as happened in the UK and the USA (Scull, 1984).

By the time these institutions were being introduced in Portugal, the British government was shifting its policies towards community-based services (Barnes, 2000b). This change in government policy, which led to the closure of most institutions, was not due to the inhumane conditions, which had been revealed by several studies and surveys conducted in long-stay hospitals and institutions at the end of the 1950s and the beginning of the 1960s (Scull, 1984). As Scull stresses, the humanitarian concerns were already present at the end of the nineteenth century when most of these institutions were formed. The only difference was that at the time there was no financial pressure to rebuild hospitals, which had only just been built, plus the scientific development of control mechanisms was not as advanced as it was in the 1960s.

In 1968, due to health problems, Salazar was replaced by a new dictator - Marcelo Caetano, a former law professor at the University of Lisbon, who ruled until the revolution of 1974 and the consequential re-establishment of a democratic republican regime. This change in the regime also signified a change in the government's attitude towards disabled people. This shift, clearly depicted in an OECD report, was marked by the state's intervention in the education of disabled children (Presidência do Conselho de Ministros, 1984). This was facilitated by the creation of the 'Services for Education of the Disabled' within the Institute for the Assistance of Minors (Costa, 1981). Through this service, a Centre for Medical-Pedagogic Observation, a Braille Commission and a Home based Orientation Service were created to support parents of blind children in early years in the Lisbon region, as well as several educational institutions for children with visual impairments, hearing impairments and mental impairments (Costa, 1981).

Notwithstanding the changes introduced, it was not until the end of the dictatorship that impairment specific assistance benefits for disabled people were introduced, meaning

that disabled people had to rely mostly on their families. In other countries, like the UK, where a welfare-state was instituted, disabled people were already experiencing problems. The failure of the welfare state to adequately protect disabled people (Oliver, 1990) prompted activism during the 1960s in a global context. This was particularly true for the UK and the USA (Shakespeare, 1993), where disabled people struggled “for equality and participation on an equal footing with other citizens” (Driedger, 1989: 1). This was made possible through the creation of the Disabled People’s Movement, which comprised diverse organisations of disabled people. In the UK, the first organisations of disabled people emerged in the 1960s as a reaction to the fact that disabled people were not sharing in the wealth of post-war British society, and were unhappy with the traditional medicalised response to their needs (Campbell and Oliver, 1996; Fagan and Lee, 2001; Oliver, 1990). The seeds of the Disabled People’s Movement in the UK, however, can be traced back to the end of the nineteenth century and the emergence of new organisations linked to the workers’ movement and the trade union struggles and other single-issue organisations, like the Disability Drivers’ Association (DDA) (Barnes, 1992a; Oliver, 1990). As happened in the Portuguese case, with the organisations that emerged during dictatorship, these organisations cannot be considered as a Disabled People’s Movement, because they were not politicised (Campbell and Oliver, 1996).

The first organisations to emerge in the UK were single-issue organisations, like the Disability Income Group (DIG), in 1965, which focused on the economic and social disadvantages of being disabled in a disabling society (Barnes, 2005; Oliver, 1990). DIG introduced some important features into the organisational scenario – it was an organisation run exclusively by disabled people and it was not specific to one type of impairment (Barnes, 2005). This organisation soon attracted attention from more traditional organisations for disabled people, leading to changes in strategies and to the formation, in 1975, of a larger umbrella organisation – the Disability Alliance (DA) – which included organisations *of* and *for* disabled people (Barnes, 2005; Campbell and Oliver, 1996; Oliver, 1990). Disappointment with DIG led a group of former DIG members, including Paul Hunt and Vic Finkelstein, to form the Union of the Physically Impaired Against Segregation (UPIAS) in 1972. Criticisms addressed to DIG included its focus on symptoms, rather than on the underlying causes of poverty faced by disabled people, and the economic technical jargon used in many of its meetings

(Campbell and Oliver, 1996; Oliver, 1990). This new organisation focused on what was thought, by this group, to be the biggest problem faced by disabled people – oppression.

In Portugal, control over civil society during the Portuguese dictatorship prevented disabled people from being politically active before 1974 (APD, 1997). Several changes, however, introduced during the 1960s, facilitated the emergence of a Disabled People's Movement in Portugal in the second half of the 1970s. First, there was the experience of activism acquired by some disabled people, especially blind and deaf people, during the twentieth century. Second, the development of a group identity, and the conscious awareness that experience enabled. Third, the echoes of the development operated in the disability sector after the 1950s. Fourth, the changes in the state's attitude towards the education of disabled children. Finally, I would single out the importance of the colonial war developed by Portugal in the African colonies after 1961. As happened in the USA, where disabled Vietnam war veterans stirred up disability protest in the USA (Barnes, Mercer and Shakespeare, 2000), the mass of disabled war veterans returning to Portugal paved the way to a new understanding of disability. The upsurge of political consciousness by disabled people is described by an interviewee:

the ladies from the National Female Movement and from the Portuguese Red Cross [...] used to visit us and bring old cookies and old magazines [...]. Once there was one, or a couple of them, [...] who asked us not to leave the hospital in military clothes, because it wouldn't be good for public opinion to see us without legs, without arms or with plaster casts, because that would call attention to our injuries. [...] That afternoon we had a meeting [...] and we went, in our military clothes, for a snack to *Pastelaria Suiça* [a famous café downtown in Lisbon], some of us without legs, others without arms. At the time I had plaster casts, others were using sticks, others were in wheelchairs [...] it wasn't a demonstration, well, for us it really was, but for the people who saw us it wasn't. [...] And I believe that we caused an impact on people who saw us, dozens of people in military clothes occupying the available tables at the *Pastelaria Suiça* and other standing because there were no tables left. [...] And it was these small actions that created a union, wasn't it? Because to create an organisation at the time was impossible. (Armando, interview)

As has been evidenced, these internal factors impacted not only on disabled people, but also on the Portuguese state. This is evident in the publication in 1971 of the first law for the rehabilitation of disabled people (Law nº 6/71 of 8/11/1971). Discussion of this new law also allowed for the emergence of a new group of activists, led by impaired war veterans, to create the first non-single-impairment and non-single-issue organisation of disabled people in Portugal – the Portuguese Association of Disabled People (APD) (APD, 1997). Similarly to UPIAS in the UK, the main idea was to establish a different perspective towards disability and disabled people (Campbell and Oliver, 1996; Oliver, 1990), an image unrelated to the charitable perspectives taken by its predecessor organisations. Its first book of statutes elected the fostering of rehabilitation, the provision of technical support, the representation of disabled people and their interests and the creation of a publication concerning disability politics as the main goals of APD (Vieira, 1973). The difficulties associated with the political regime prevented APD, however, from being immediately active in Portuguese society, which only happened after 1974 (APD, 2007).

Conclusion

Disability policies and politics in Portugal have been moulded by a combination of three main factors: the strong Catholic social background of Portuguese society, the economic situation of the Portuguese state and the leading role of the family in social provision. This analysis also evidences that the Portuguese state has maintained an attitude of detachment in relation to disability issues, i.e. the state took a secondary role, only acting when pressured by civil society. It was also suggested that disabled people in Portugal have experienced a different reality than those disabled people living in countries such as the UK. In fact, historical, economic, political and cultural factors, such as the Inquisition, the low redistributive ethos of the Portuguese state, the dictatorship and Catholicism have dictated different trajectories in disability policies and politics and, above all, in citizenship rights.

The analysis allowed me, however, to identify some general common trends, namely that of disability and disabled people as a specific category, which is a modern creation, which is as recent as the nineteenth century. Several explanations for this were provided for the Portuguese case, including: the lack of specialised institutions for the assistance

of disabled people in Portugal before the nineteenth century; the fact that disabled people were included amongst other groups of people as entitled to assistance by generic institutions; the prevailing connection between disability and poverty; and the fact that disabled people as a defined category for state support emerged only in the nineteenth century. As has been suggested, this was the result of the increasing involvement of the state in the mitigation of the necessities of the population and the need to distinguish the 'good poor' from the 'bad poor', i.e., the deserving from the non-deserving of public support, rather than the need to create and legitimise an alternative redistributive systems based on need.

Throughout this chapter I have also traced the roots of the medicalisation and institutionalisation of disability and disabled people in Portugal. As has been argued, most of the impairment-specific institutions emerged in the nineteenth century and had no other purpose apart from the incarceration and separation of disabled people from the rest of society. This started to change at the end of the nineteenth century, with the emergence of a new attitude towards disabled people expressed through education. This was, however, a very biased form of education based on stereotypes and preconceived ideas about what a blind or a deaf person could do.

Despite this improvement in the education of disabled people in the first quarter of the twentieth century, the implementation of the dictatorship would tear down previous gains and introduce further differences between disabled people in Portugal and those in other countries. In Portugal, the elimination of the idea of public assistance and the assumption of a secondary role by the state in the provision of social assistance, at a time when other states were developing comprehensive welfare-states, resituated disability as a charitable concern and maintained its connection to exclusion and poverty.

I have also outlined the origins of the Portuguese Disabled People's Movement. As has been argued, the seeds of the Portuguese Disabled People's Movement were laid down in the first half of the twentieth century. These organisations, however, lacked a political character, which is the reason why they were not considered as part of the Disabled People's Movement. I also suggested that due to the secondary role adopted by the state the lives of disabled people in Portugal have been marked, not only by the traditional system of Catholic charity, but by the emergence in the second half of the twentieth century of the disability movement, with the creation of several organisations for

disabled people. The development of the disability movement was extremely important in raising the state's awareness of disability issues, and its effects became evident towards the end of the 1960s with the publication of widespread legislation in the areas of education and social assistance. The start of the colonial war in the 1960s and the subsequent return of thousands of injured military people, alongside their concentration in special military hospitals, led to the creation of a new consciousness of disabled people's situation within Portuguese society. This led to the creation of APD in 1972, the first non-single-impairment and non-single-issue Portuguese organisation of disabled people, which was followed by the Association of Impaired War Veterans in 1974, as I will address in Chapter 6.

The beginnings of a disability movement in Portugal in the 1950s did not, however, mean a change in, a challenge to, or questioning of most disabled people's living conditions or prevent the exclusion and oppression imposed upon disabled people. As has been seen throughout this chapter, the political regime imposed a rule of silence, which prohibited the questioning of policies or their absence, and the main criteria for the existence of these charities and other disability specific organisations was their silence. Again, the end of the 1960s and the new wind from abroad, plus the fractures opened up by the colonial war and the dire social and welfare situation of the Portuguese population in general, and of disabled people in particular, created the climate to overcome the political regime. The re-establishment of democracy in Portugal in 1974 thus inaugurated a new period of disability politics and policies and the beginning of a citizenship project for disabled people. It has been demonstrated that up until 1974, and in contrast to the UK, disabled people saw their citizenship rights denied by a state which sacrificed civil and political rights to the political stability of the regime. The reestablishment of democracy in 1974 thus represented a shift in the citizenship project of disabled people in general and of social citizenship in particular, opening up the possibility for disabled people, as a collective, to participate in its construction, as will be analysed in the following chapters.

In the next chapter I provide a critical analytical account of these changes and achievements in disabled people's social citizenship.

5. Defining the disabled people's social citizenship project in Portugal since 1974

Introduction

Unlike most other European countries, the Portuguese Welfare State only developed after 1974, following the Revolution. In fact, improving living conditions was one of the main priorities of the new democratic regime (Guibentif, 1996), which developed an array of measures that allowed for the emergence of an embryonic welfare-state (Gough, 1996; Santos, 1999). As Mozzicafreddo (1992: 71) states, "Social Policies have been an important element in the creation of the political consensus and legitimacy for the democratic regime". However, the Portuguese 'welfare-state' has developed unevenly across different social sectors, which are protected by different welfare regimes and have experienced contrasting levels of generosity (Ferrera, 1996; Santos, 1999; Hespanha, 2001).

In this chapter I suggest that the lengthy Portuguese dictatorship, alongside the country's isolation and separation from its European counterparts, as was seen in Chapter 4, are of particular importance in understanding the Portuguese welfare-state and, consequently, the disability policies it developed after 1974, which are analysed here as part of the construction of the disabled people's social citizenship project. This may be summarised as the development of a disorganised, piecemeal, unplanned and mostly inconsequential system of disability policies. I will also argue that until very recently these policies were conceptually and ideologically based on medicalised and individualised understandings of disability that prevented any challenge to the discrimination and exclusion of disabled people in Portuguese society. Notwithstanding the low level of redistribution enabled by these policies, such failures, alongside the maintenance of psychological, social and physical barriers to the integration and inclusion of disabled people in the different spheres of society, led to disabled people's dependency on benefits, which has had a great impact, not only on disabled people's lives and expectations, but also on the Portuguese Disabled People's Movement, as I will argue in Chapter 6. Only in recent times, as will be shown in this chapter, has there been an upsurge of a new type of disability policy, which is concerned with the civil rights of disabled people as well as social aspects of disability – a turn to what Drake

(1999, 2001a) would call the citizenship paradigm. However, as I suggest, this movement is still only embryonic and therefore unlikely to generate any long-term impact and to revolutionise current disability policies by unifying the different policies and philosophies currently in place. Moreover, the current economic crisis represents a serious threat to the welfare state, and its consolidation in Portugal.

This chapter considers the main features of the Portuguese welfare-state as part of the Portuguese citizenship project of developing a minimum level of social welfare, as well as comparing and contrasting it with other welfare regimes. Then it focuses specifically on disability policies, identifying and discussing their main traits. The last section examines how these policies have been implemented, i.e. the politics behind disability policies in Portugal.

5.1. The Portuguese welfare-state

In one of the most influential comparative works on welfare states, Esping-Andersen (1990) suggests that welfare-states cluster into three types of welfare regimes: the liberal, the social democratic and the conservative. The liberal regime, characteristic of countries like the USA, the UK, Ireland, Canada, Australia and New Zealand, is distinguishable by its low level of de-commodification, i.e. limited individual access to social benefits, the investment of the state in the regulation of the market rather than in welfare provision or in the finances of social welfare and by the maintenance of a high level of stratification in terms of income inequality. At the other side of the spectrum is the social democratic regime, which is typical of the Scandinavian countries, and which is characterised by a high level of de-commodification, a high level of state intervention in the provision and finances of social welfare and a low level of stratification. In between these two poles, Esping-Anderson (1990) identifies a conservative or corporatist regime. This regime is typical of countries like France, Germany, Austria, Belgium and Italy, and is distinguishable by its moderate level of de-commodification, the reliance of the state on other spheres of social support – namely the family – for welfare provision and by the low impact of the state in the redistribution of wealth and, consequently, on existing social stratification. Instead, the state is greatly concerned with the regulation of the market by non-profit providers.

Esping-Anderson's work has been subject to several criticisms (Arts and Gelissen, 2002). An important series of criticisms comes from feminist scholars, and focuses on his lack of attention to the role of the family in any given welfare regime (Borchorst, 1996; Daly, 1996) and for his disregard of female working patterns (Lewis, 1992). Another body of criticism, and one particularly important for this thesis, derives from the absence of Mediterranean countries, like Portugal, Spain and Greece in this typology. For Esping-Andersen (1997) these countries share noticeable common characteristics, namely their Catholic backgrounds and the strong role played by the family in welfare production. Nevertheless, they do not form a distinct welfare regime, but represent an underdeveloped version of the conservative regime. This has steered the investigation into Southern European welfare-states and led several authors to argue for the existence of a specific model for the social policies of Latin Rim countries (Leibfried, 1992) and, more recently, of a Southern model of welfare policy (Ferrera, 1996, 2005; Bonoli, 1997; Trifiletti, 1999). According to Ferrera (1996), the 'Southern European Model' is characterised by having:

(1) a highly fragmented and 'corporatist' income maintenance system, displaying a marked internal polarization: peaks of generosity (e.g. as regards pensions) accompanied by macroscopic gaps of protection; (2) the departure from corporatist traditions in the field of health care and the establishment (at least partially) of National Health Services based on universalistic principles; (3) a low degree of state penetration of the welfare sphere and a highly collusive mix between public and non public actors and institutions; (4) the persistence of clientelism and the formation – in some cases – of fairly elaborated 'patronage machines' for the selective distribution of cash subsidies. (1996: 17)

Combining an analysis of how the state spends its money on welfare, with an examination of how much the state is spending as a whole, Bonoli (1997) draws the same conclusion. He suggests a grouping of European countries based on their welfare-systems, as follows: Nordic countries, continental European countries; Britain and Ireland; and Southern European Countries and Switzerland.

Trifiletti (1999) offers another analytical perspective by incorporating issues of gender into Esping-Andersen's (1990) model. She re-focuses the analysis on whether the welfare-state treats women as mothers/wives or as workers. She then suggests a new typology of welfare regimes which, again, highlights the specificities of a

Mediterranean welfare-state. This is characterised by a low level of state protection from the market, combined with a regime that treats women mostly as mothers and wives, in opposition to the Universalist welfare regimes of the Nordic countries. With high levels of welfare protection teamed with a similar understanding of the role of women as that seen in Mediterranean countries, Trifiletti identifies the Breadwinner welfare regime of countries like Germany, Britain (pre-Thatcher) and Ireland, in opposition to the Liberal welfare regime typified by the USA (Trifiletti, 1999). An interesting fact emerging from her analysis is the peculiar place occupied by Portugal. Unable to position it in one of these four groups, the author opted for an in-between position. Thus, Portugal is positioned within the group of countries which offers its citizens a low level of protection from the market (like Mediterranean welfare regimes and Liberal welfare regimes), but in-between those countries with high levels of discrimination based on gender (Breadwinner welfare regimes and Mediterranean welfare regimes) and those with low levels of discrimination based on gender (Universalist welfare regimes and Liberal welfare regimes). This shows that Portugal, despite sharing some common features with its Mediterranean counterparts, also presents peculiarities which are worth analyzing before focusing specifically on the disability policies pursued in the Portuguese context.

The Portuguese welfare-state results from the universal system of social protection (Law-decree 513-L/79, 26/12/79) created in 1979, which put an end to the previous system that only protected those covered by the contributory system, and the changes introduced during the 1980s.

The 1980s brought about new arrangements in social policies, mostly in preparation for Portugal's integration into the European Economic Community, which happened in 1986. The process of integration required economic stability, which led to a change in the social protection scheme – from universality to selectivity, which was already in place in other European countries (Hespanha *et al.*, 2000). Thus, in 1980 new legislation (Law-Decree 160/80, 27/05/80) introduced two distinct welfare regimes in Portugal: a contributory and a non-contributory regime. Again, access to state social protection resumed the logic of social assistance for the poor. This had a great impact on disabled people's lives and hindered their prospects of social citizenship. Disabled people became trapped in a system that limited their autonomy and any possibility of constructing an autonomous life without the risk of losing benefits. In the area of

employment, for example, stepping into paid work meant the loss of all disability benefits. As one of my interviewees explains:

In this country people think like this: well, I'm retired, if I don't work, I've got €325 which is mine for sure. [...] If I decide to work, I've got to go to the job centre and to Social Security [...] because I've got a lifelong invalidity pension, [and] if I work I can't receive the pension at the same time, [so] I've got to go to Social Security and tell them to stop it. I can re-establish it again later on if I become unemployed. But the problem is: if I ask them to stop it, they do it immediately, but in order to re-start it, it takes 3 to 4 months. The question is how would I live during that time? (António, interview)

The current welfare system results from the dual system established in 1980, in parallel with another welfare-system created exclusively for public servants.

Therefore, one of the most distinctive characteristics of the Portuguese welfare-state is its late development. As was the case with the UK, at this time, most European welfare-states were already decaying due to neo-liberal economics (Trifiletti, 1999). Additionally, the development of the Portuguese welfare-state occurred during a period of profound international economic crises in the 1970s. The result was what Santos (1999) calls a *quasi-welfare-state*, i.e., a welfare-state that was never a real welfare-state. This Portuguese *quasi-welfare-state* is characterised by low levels of social protection, a comparatively low redistributive scheme based on low benefits, by its non-universal character and the existence of a diverse series of welfare-regimes (Santos, 1999; Andreotti *et al.*, 2001; Hespanha, 2001). Compared to other European countries, the level of protection achieved by the Portuguese welfare-state is well below average (Gough, 1996), pushing those groups who are already economically deprived, namely old, and unemployed, people, below the poverty line (Hespanha, 2001). In relation to the previous period of dictatorship, the number of people protected by the new system increased (Carreira, 1996a). However, as Hespanha (2001) acknowledges, the resulting system was never a universal one, since it continued to exclude large sectors of the Portuguese population, namely those relegated to the informal labour-market.

Unsurprisingly, Portugal also presents a low level of investment in the social protection of its citizens in proportion to *gross domestic product* (GDP), and is well below the European Union (EU) average and below its Mediterranean counterparts (Flaquer,

2000: 3). Besides this, in 1997 the expenditure on social protection per capita in Portugal represented only 53.77% of the EU average (Guillén *et al.*, 2003: 237-238). This, again, mirrors the previous situation of social protection in Portugal.

Similarly to other Southern European countries, this lack of state protection is balanced by a strong civil society, based on relations of kinship, friendship and neighbourhoods. Nevertheless, such a ‘welfare-society’ (Santos, 1999, 2011) – which provides financial help, psychological support and unpaid care services – is showing signs of exhaustion (Wall *et al.*, 2001; Damas *et al.*, 2002). Plus, it is replicating and reinforcing existing social inequalities (Wall *et al.*, 2001) and fostering the state’s low level of responsibility in the provision of social services (Hespanha *et al.*, 1997; Ferreira, 2005). These responsibilities have been relegated mostly to the welfare-society, particularly to families and to women (Portugal, 1996, 1998, 1999; Fontes, 2006) and to social/familial services run by non-governmental organisations (Ferreira, 2005; Portugal, 2008) producing an unusual welfare mix intrinsically connected to the semi-peripheral position of Portugal in the world system (Santos, 1990).

These particular characteristics of the Portuguese welfare-state have had a direct impact on the disability policies developed over the last three decades and, indirectly, on the lives and demands of disabled people, as well as on their citizenship status. In the next section, I analyse the trends within disability policies and the way social policies have addressed disabled people in Portugal.

5.2. What’s in the law – disability policies in Portugal

The 1974 revolution inaugurated a new phase in Portuguese history that brought with it a new spirit and a commitment to resolving the country’s various social problems, which translated into the 1976 Constitution of the Portuguese Republic (see article 66, N. 4). Moreover, after decades of being disregarded, the new Constitution, in article 71, stated:

1. Citizens with physical or mental disabilities shall fully enjoy the rights and shall be subject to the duties enshrined in this Constitution, save the exercise or fulfilment of those for which their condition renders them unfit.

2. The state shall undertake a national policy for the prevention of disability and the treatment, rehabilitation and integration of disabled citizens and the provision of support to their families, shall educate society and make it aware of the duties of respect and solidarity towards such citizens, and shall ensure that they effectively enjoy their rights, without prejudice to the rights and duties of their parents or guardians. (1976 Constitution of the Portuguese Republic, translated in Tribunal Constitucional, 2005)

Following revision of the Constitution in 1982, a third point was added to this article, stating that: “The state shall support disabled citizens’ organisations” while the Constitutional revision of 1997 introduced changes to the language used in the document, replacing the term ‘disabled’ with ‘citizens with disabilities’.

Therefore, this document represented a turning point for disabled people in Portugal, as citizens, and the beginning of the state’s acceptance of its responsibility for all its citizens, including disabled people. However, in light of the absence of any specific legislation, in practice this article was unable to overcome a disabling ideology that had built up across decades, a fact which reduced the impact of forthcoming policies.

Disability policies put forward after 1974 stem from a complex process that involved balancing various competing factors. These included financial contingencies and the country’s position in the global economic system; Portugal’s socialist ethos and its focus on employment and workers’ rights; the various negotiations between political forces following the revolution; the dominant role of the Catholic Church in welfare provision and policy making (Ferreira, 2005; Portugal, 2008); and the late development of Portugal’s welfare system in a period of welfare-state retrenchment in most European countries. Nevertheless, the importance of these social protection measures in the post-revolutionary period is unquestionable for the Portuguese population, disabled people included. Some of the most significant measures were the creation of a benefit for all young disabled people up to 14 years old, the introduction of a social pension and a supplement to the pension for severely impaired people, which were all implemented in 1979 (Hespanha *et al.*, 2000) with the formation of the Portuguese welfare-state.

Ferrera argues that:

The Southern European safety net evolved slowly, through a sequence of fragmented and mainly categorical additions (orphans, widows, disabled, poor

elderly, etc.) with disparate rules and differentiated benefit amounts, with a low (if not altogether lacking) degree of integration between cash benefits and services and with wide holes in the overall fabric of public provision. (2005: 6)

This can be seen in Portugal in the fragmentation of the welfare system into diverse regimes, as was analysed above; in the categorisation of disabled people into separate groups based on impairment (blind, deaf, motor impairment and a multitude of other medical conditions) and the way it was acquired (congenital, acquired, work accident, war impairment acquired during service, war impairment acquired during a military campaign). The incorporation of these filters into the disability policies system had a great impact on the benefits claimed by and social rights of disabled people, creating different rules, benefits and benefit amounts for those in similar situations, as is exemplified by a summary produced by the Association of Impaired War Veterans (ADFA) (1994: 18). In 1993, in relation to ADFA's members, 39.5% received their benefits through Law-Decree 43/76 (20/1/1976), 37.9% through a former legal document approved during the dictatorship (Law-Decree 498, 2/12/1972), 4.8% through Law-Decree 404/82 (24/9/1982) and 2.8% were not able to access any benefits according to these documents (for the remaining 15% ADFA had no information).

I suggest that the differentiation and fragmentation of disabled people into categories of worth stems from two distinct but interconnected factors: a political and a strategic factor. Politically, as I will explore in Chapter 6, this enabled the state to control the emergent Disabled People's Movement, as well as disabled people's social demands. One of my interviewees recalls this fact in relation to the Disabled People's Movement:

I believe that this [joint initiatives which gathered different organisations of disabled people together] should be the way forward in order to improve the living condition of disabled people, but this won't happen anytime soon because there are huge powers opposing it. There is an old saying that is 'divide and rule' [...] and here I believe we've been faced with the abusive interference of these powers in order to inhibit the understanding and connections between the organisations. (Daniel, interview)

This absence of connections between organisations with regard to making common demands was also exploited by the state in order to keep down its expenditure on social

benefits. According to Drake (1999), one of the characteristics of this piecemeal approach in disability policies is precisely the fact that the state:

makes some response to disablement but only in a reluctant and haphazard way, perhaps being provoked to action as a result of pressure and circumstance rather than through any desire to construct and implement a cogent and carefully planned strategy. (Drake, 1999: 36)

Thus, the analysis of the Portuguese case reveals the presence of a piecemeal approach to social policies concerning disabled people, as suggested by Drake (1999). However, as was argued above, in the Portuguese case the shortage of economic resources and the long-established role of the family in social provision has transformed this accidental way of action into a political and economic ‘resource’ exploited by the state. In fact, if this piecemeal approach was initially unintended, it soon became apparent that the state exploited this situation in order to pull back from responsibilities in the field of social citizenship, particularly in relation to disability. This can be seen in the following analysis of four key areas for the development of the disabled people’s social citizenship project: benefits and social rights; education; work and employment; and accessibility.

5.2.1. Benefits and social rights

The first piece of social policy legislation specifically directed at disabled people dates from 1976 – Law-Decree 43/76 (20/1/1976). In fact, from 1974, disabled people had access to a social pension (Law-Decree 217/74, 27/05/1974), but this legislation was not disability specific, it targeted people over 65 years old and ‘invalid’ [*sic*] people. This new legal document, which is still the main tool of disabled war veterans’ rights, provides a collection of social, economic, medical, rehabilitative and educational rights to impaired war veterans, namely social benefits, tax exemptions and benefits, priority in accessing employment in the public sector, concessions in public transport, medical rehabilitation and treatment, provision of prostheses, etc. The publication of this legal document was, however, the result of a long campaign undertaken by ADFA in 1975 (ADFA, 1994). The extension of some of these rights to other civilian disabled people occurred only later and only gradually, first with tax exemption for the acquisition of wheelchairs and other personal transport vehicles (Law 11/78, 20/3/1978), next with

exemption from car tax (Law-Decree 143/78, 12/6/1978), then income tax reductions (Law-Decree 138/78, 12/6/1978) and, four years later, with mortgage privileges (Law-Decree 230/80, 10/07/1980) and disability specific social benefits. This package of social benefits for disabled people included: a supplement to the social pensions of 'severely disabled' people (Law-Decree 139/80, 20/5/1980) and Disability Additional Benefit of the Children and Youth Family Allowance, Special Education Attendance Benefit, Third Person Assistance Benefit and Lifelong Monthly Disability Benefit (Law-Decree 160/80, 27/5/1980). This, again, was the result of pressure from the Disabled People's Movement, which started to organise itself in the late 1970s, as I explore in Chapter 6.

The demands of other groups of disabled people had been largely ignored by the state. This is the case of people impaired at work. This particular group, which, from 1976, was structured around the National Association of People Impaired at Work (ANDST), is another piece of a fragmented system that has struggled to influence the government. In contrast to other groups of disabled people, people impaired at work are protected by private insurance companies and their impairments are evaluated by a specific national table (Law-Decree 341/93, 30/09/1993; Law-Decree 352/2007, 23/10/2007). The rationale is that the state considers the liability for any accidents at work to be a private responsibility, between the worker and the employer, and this responsibility is transferred to the insurance companies through work insurance (Ribeiro, 1992). Notwithstanding the demands for the incorporation of criteria dealing with accidents at work into the national welfare system by ANDST (Bastos, 1992), and the inclusion of legislation dealing with accidents at work into the General Laws of Social Security (see for example article 71 of Law 28/84, dated 14/08/1984), this was never regulated by specific legislation. This meant that the guidelines established by the law were never put into practice and the insurance companies retained a monopoly over people impaired at work. This situation has been exploited by the state to further fragment the Disabled People's Movement and also to reduce the state's spending and withdraw from service and income provision. The action of the state at this level has been mostly regulatory through the publication of legal documents decreeing an increase in pensions (e.g. Law-Decree 668/75, 24/11/1975) and stipulating the guiding principles in reparations for work accidents (e.g. Law 100/97, 13/9/1997, Law-Decree 143/99, 30/4/1999 and Law-Decree 382-A/99, 22/9/1999).

In sum, notwithstanding the establishment of category-like benefits for disabled people, the disability policy system has evolved unevenly for different sections of the population, depending on specific social insurance schemes, origins of impairment and sectors of activity (with greater generosity for public servants (Ferrera, 1996; Santos, 1999; Hespanha, 2001)). An example of this is the fact that impaired war veterans rely on different legal documents in order to access benefits, as was mentioned earlier. Another example is the reliance on insurance companies by people impaired at work, as was also discussed above.

As a result, there has been what I have identified as a differentiation and fragmentation of disabled people into categories of worth. However, the disability policies implemented since 1974 have not been limited to the creation of disability benefits typical of what Drake (1999, 2001a) labels as a compensation approach to disability. In fact, as I have argued, the initial development of a disorganised, piecemeal, unplanned and mostly inconsequential system of disability policies, in combination with the lack of a political will to change this situation, resulted in, in the Portuguese context, the presence of various competing policies. Paralleling this tendency towards compensation, from the 1980s there has also been an investment in policies of care (Drake, 1999; 2001a), first in the area of employment and retirement, and then from the 1990s on, in the field of education and, following that, in the 2000s an investment in policies of citizenship.

5.2.2. Education

Education policies in Portugal display two major tendencies: until 1990, the perpetuation of segregation or containment policies; after 1990, the use of a combination of policies of segregation and policies of 'care.

Notwithstanding the first examples of the integration of disabled children (blind children) into regular classes, which dates back to the 1960s (Costa, 1981), most disabled children lived a separate reality. Oliveira (1979), in his analysis of the Portuguese reality of disabled children in the 1960s, refers to the existence of a large number of children who were totally dependent on a system of assistance or who were submitted to other marginalizing education systems. This situation resulted from the lack of public provision for the education of disabled children and the development of a

strong private and co-operative sector for the education of disabled children. This reality led the state to develop a policy of action by inaction (Fontes, 2006), i.e., acting by keeping quiet and remaining absent. This is visible in the fact that, regardless of the pressure put on it by professionals in the area of education, the state never saw the education of disabled children as its responsibility. In fact, despite the introduction of several laws enforcing compulsory education for Portuguese children (Law-Decree 538/79, 31/12/1979 and Law-Decree 301/84, 7/09/1984), each of them contained an article excusing disabled children from this obligation, hence presenting disabled children as different and uneducable. The unwillingness of the state to implement any measures regarding the education of disabled children can also be testified to by the parliamentary approval in 1979 of Law 66/79 (4/10/1979), which provided a definition of special education and a structure for its implementation and organisation. This law, however, was never implemented and subsequent legislation published by the government in the same area even contradicted this document.

The blatant lack of a political project in the arena of the education of disabled children, the huge development of the private and co-operative education sector and the unwillingness or inability of the state to take responsibility in this area, directed the state's attention to the regulation and structuring of a third sector. Third sector can be understood as "non-governmental organisations which are value-driven and which principally reinvest their surpluses to further social, environmental or cultural objectives; it includes voluntary and community organisations, charities and social enterprises, cooperatives and mutuals" (NAO 2009: 5). The Portuguese third sector developed an enormous amount of Special Education Schools throughout the country. This strategy impacted greatly on the future of the disabled children schooled, as well on the success of future policies.

Only in 1990 did the state take full responsibility through the publication of Law-Decree 35/90 (23/09/1990) and the enforcement of compulsory education for all children including disabled children, paving the way for their integration into regular schools. This was achieved in the next three years with the publication of Law-Decree 319/91 (23/08/1991), which regulates the integration of disabled children into regular schools and *Portaria* 611/93 (26/06/1993), which applies the same principles to kindergartens. As Costa and Rodrigues (1999) highlight, this political change did not eliminate the special educational schools that were maintained by the private and co-operative sector. It merely established that all children should be educated, meaning

parents could choose between registering their children at a regular school or at a special school.

The approval of the Salamanca Declaration in 1994 and the affirmation of the principle of inclusion in the education of disabled children brought about more changes to the Portuguese system. In 1997 a new piece of legislation (Shared Dispatch 105/97, 1/07/1997) was published, enabling the introduction of this principle into the education system. This document created a system of Educational Support which was to be provided by specialised professors and educators.

The 1990s inaugurated, thus, a transformation in the schooling of disabled children in Portugal, first towards their integration into the regular system, without, however, questioning the need to change this same system and, after 1997, through the creation of an inclusive system of education for all children. The former move relied on the existence of teams of special educators, external to and separate from the regular school; the latter was based on the responsibility of the school and on the existence of internal support services to address the individual needs of each student. Another change introduced by this legislation made schools accountable to all their students and for the accommodation of their needs (Costa and Rodrigues, 1999), in contrast to the previous system in which this task was the responsibility of local education authorities.

This new tendency for the establishment of a policy of rights for disabled children in education has, however, been undermined by structural problems in the Portuguese Educational System. Notwithstanding the flexibility introduced into the system and the autonomy conferred to the schools, the lack of financial and professional resources partially compromised the implementation of this inclusive philosophy. The gap between the number of professionals needed and the ones actually available is even wider if we consider the low numbers of specialized professionals. Most educators and teachers in the education support services have no specialisation, as it is dictated by law, which means that they also need support from the local educational authorities and other specialised services (Breia, Santos and Colôa, 2002). Moreover, the publication of the Shared Dispatch 105/97 did not preclude the maintenance of segregated educational solutions. In fact, two legal documents published after this document and which apply it to the special educational schools of the private and co-operative organisations (*Portaria* 1102/97 and 1103/97, both from 3/11/1997) maintained the possibility of segregated solutions.

In 2008 a new structuring document in the area of the inclusion of disabled children at school was published (Law-Decree 3/2008, 7/01/2008). This document can be criticised for its focus on individuals' needs, the central character played by medical classifications and for its support of non-inclusive solutions in the schooling of disabled children.

To summarise, despite the drawbacks of this new legislation, there was a structural change in education policies in relation to disabled children. From a system of segregation and special schools, there was a move towards the accountability of the state and the integration of disabled children into regular schools, supported by teams of special educators, in the early 1990s. Later on in the 1990s there was another structural change, this time towards the creation of an inclusive system of education for all children, which, however, remains unfinished. Therefore, there was a movement from segregation to care and from care to citizenship. However, as in other areas, changes are never completed and often coexist with older tendencies.

5.2.3. Work and employment

Work and employment are two key areas in disabled people's demands from the state. My analysis of government policies in relation to this revealed two main governmental strategies: a strategy of inducement (Barnes, 2000b) and a strategy of 'care' (Drake, 1999; 2001a).

The primary strategy adopted by the Portuguese government in its policies concerning the employment of disabled people is inducement, which is based on the creation of subsidies that provide financial rewards to employers who hire disabled people. This strategy, as Barnes (2000b) notes in relation to the UK, is focused on disabled people, rather than on the employers and workplaces. Similarly to the situation in the UK since the 1960s, in Portugal this has been achieved through the creation of subsidies for employers who integrate disabled people into the workplace, for the adaptation and elimination of physical barriers in the workplace, to compensate for hiring disabled people (Normative Dispatch 218/80, 24/07/1980; Normative Dispatch 52/82, 26/04/1982; Law-Decree 247/89, 5/08/1989). This strategy was also achieved by a Job Introduction Scheme through which the state gives an initial 2 year exemption and then a 50% reduction in social security payments to employers who hire disabled people

(Law-Decree 299/86, 19/09/1986); and, finally, through the creation of awards for employers who hire disabled people (Dispatch 12008/99, 23/06/1999). In sum, and in line with the situation in the UK, disability employment policy has been based on a “deficit approach to understanding disabled peoples’ inferior employment position” (Roulstone, 2004: 18). Such inducement strategies have been highly inefficient, as the 2001 Census revealed: only 29% of disabled people over 15 years old were economically active (Gonçalves, 2003: 80). As is the case in the UK this focus is deemed inefficient:

Because individual disabled people are packaged and sold as different from other members of the labour force the traditional divisions between them and non-disabled workers are underlined and, indeed, deepened. (Barnes, 2000b: 97)

The way ahead is to focus on demand, “creating a barrier-free work environment and requiring employers to use production processes accessible to the entire workforce.” (Barnes, 2000b: 97), or to redefine work, as not all disabled people may ‘work’ in a capitalist system (Roulstone, 2002; Barnes, 2003).

The second major strategy was mainly employed after 1983 with the publication of Law-Decree 40/83 (25/1/1983) and the creation of sheltered employment for disabled people. This legal document defined three main types of sheltered employment: Centres of Sheltered Employment, in cases where the labour activity or training of disabled people is done in a centre created specifically for that use; Enclave, when the labour is done by a group of disabled people within a regular workplace; and Sheltered Home Work, in cases where the paid work activity is done from home. Within this same strategy, in 1989 the state created a regime of occupational activities for disabled people (Law-Decree 18/89, 11/01/1989), i.e. non-paid social activities (mostly traditional crafts) done in specific Centres of Occupational Activity or in any other community venue. This document also advanced the possibility of financial compensation for people developing activities in Centres of Occupational Activity. However, this remained without effect for 17 years until the publication in 2006 of a legal document regulating this section of the law (*Portaria* 432/2006, 3/05/2006).

In contrast to countries like the UK, where, despite its limited results, a quota scheme was used from 1944 until 1995 (Barnes, 2000b; Roulstone, 2004; Roulstone and Barnes, 2005), in Portugal the existing quota scheme has not been implemented.

Notwithstanding the establishment of a work quota scheme for disabled people during the dictatorship, in the first General Law for the Rehabilitation in Portugal (Law 6/71, 8/11/1971), and later too in the General Law for the Prevention, Rehabilitation and Integration of disabled people (Law 9/89, 2/05/1989), it was not until 2001 that this quota scheme was finally established (Law-Decree 29/2001, 3/02/2001). Still, the application of this law has been almost nil, firstly because it does not apply to the existing labour market, but only to future job adverts; secondly, because the quota of 5% in future job adverts was limited to those that advertised ten or more working places; thirdly, because it was limited to the public sector; and, finally, because the state has ignored its own rules (*Associação*, 2002). Again this scenario is similar to the British case, and the reason why this quota scheme was abolished in 1995 (Roulstone, 2004; Barnes and Roulstone, 2005).

5.2.4. Accessibility

Since 1974, the state has resisted implementing what Drake (1999) calls a social or rights-based policy model. This can be seen in all areas described above and most clearly in relation to the issue of accessibility to the built environment. The analysis of the legislation revealed how this major area, as it was defined by the Derbyshire Coalition of Disabled People within the 'seven needs' to enhance community provision and the independence of disabled people, which encompasses: information, peer support, housing, equipment, personal assistants, transport and access (DCODP, 1986; Davis and Mullender, 1993), has been disregarded by the state. The first key piece of legislation in Portugal dates back to 1982, immediately after the International Year of Disabled Persons, with the publication of Law-Decree 43/82 (08/02/1982). This document introduced changes into the General Rules for Urban Construction making the elimination of disabling physical architectural barriers in new buildings compulsory. The unwillingness of the state to enforce this law and to monitor its application, and the impact of other external pressures made this document inconsequential. In fact this piece of legislation was initially postponed for one year (Law-Decree 204/82, 22/05/1982), then for six months (Law-Decree 185/83, 09/05/1983) and in 1986 it was revoked (Law-Decree 172-H/86, 30/06/1986) with the argument that a new piece of legislation would be published in its place, which only happened eleven years after with Law-Decree 123/97 (22/05/1997). This legislation only covered public buildings and

public spaces, and allowed owners a period of seven years to eradicate physical barriers in old buildings after which penalties would be applied. As one of my interviewees reflects:

Curiously, 1986 coincides with the year that we got into the EU and this document [Law-Decree 43/82] was replaced by some technical rules [Dispatch 28/86 17/05/1986] that were mere recommendations. These recommendations ruled for eleven years, from '86 to '97, and that was the bad period, because people were relying on something which wasn't law, but that was there, and people were still fighting without achieving anything, until the increasing pressure brought about [Law-Decree] 123/97. So, Law-Decree 123/97 was the first that functioned and applied until 2006. (Matias, interview)

Seven years after its publication, this piece of legislation was, however, scarcely implemented (Carretas, 2000, 2002, 2004; Associação, 2004a), which led organisations of disabled people to initiate a new strategy: bringing charges against those not abiding by the law and encouraging disabled people who felt their rights had been violated to come forward and present their cases (Associação, 2004b). As a result of this pressure and of the possibility of charges being brought against the state, in 2006 a new piece of legislation was published, revoking the previous one (Law-Decree 163/2006 (08/08/2006), and which is still the most current legislation in this area. Again, the implementation of this legal document has been fairly poor as can be seen in the National Congresses of Disabled People and activities organised by the Portuguese Association of Disabled People (APD) (Associação, 2007a, 2007b). The fact that legal change has been largely inefficient is also evident in the creation of the National Plan Promoting Accessibility 2007- 2015 (PNPA) (Resolution of the Council of Ministers 9/2007, 17/01/2007), which attempts to provide specific guidelines and deadlines for the implementation of previously agreed targets regarding accessibility.

These different events and documents continue to press for access to the public built environment on behalf of disabled people, as well as for respect for the existing law.

5.2.5. Main traits of disability policies in Portugal

As this analysis of these key areas of Portuguese disabled people's social citizenship project reveals, progress in the establishment of social citizenship rights has been limited while most of the policies implemented across the different areas are doomed to failure due to their partial or faulty implementation. This fact stems from several major traits of these policies.

Several distinguishable characteristics emerge from taking a glance at disability policies developed in the Portuguese welfare-state. The first, and most obvious is the historical reliance of disability policies on a needs-based approach, rather than on a rights-based approach (Clarke and Langan, 1998; Borsay, 2005). This has meant that disability welfare services and benefits were not constructed as rights, as an entitlement of disabled people. Instead, they worked as a safety net catching disabled people according to a needs-based criteria. This was visible after 1980 with its selective logic in relation to social policies and the creation of two distinct welfare regimes in the Portuguese welfare-state. By doing this the state limited citizens' access to disability, and other social, services and benefits. This was done through a two-pronged access system which was simultaneously means tested and dependent on needs assessment. This was similar to the changes introduced in the UK by the Thatcher government, which transformed a 'citizenship of entitlement', that had prevailed since World War II, into a 'citizenship of contribution' (Borsay, 2005).

This needs-based approach was based on the premise of passive recipients, instead of active citizens, with a reliance on professionals. As can be established by the analysis of published legal documents, the identification of these needs was not left to individuals to decide; rather, the state delegated that role to a class of professionals who were responsible for evaluating individual needs. These figures acted as gate-keepers in the access to welfare services and benefits. In Portugal, as in many other countries (Clarke and Langan, 1998), medical professionals have been the main gate-keepers. In order to access to the majority of welfare benefits and services, disabled people had, and still have, to submit themselves to a medical assessment. An example of this is the procedure used to define disability and impairment specific benefits. As it is defined in Law-Decree 291/2009 (12/10/2009), this is done through a medical evaluation which is based on the respective National Chart of Impairments, defined by Law-Decree 352/2007 (23/10/2007), at the end of which people should receive a medical certificate

of impairment. This is supported by the typology of disability assessment processes covering European countries that has been produced by the European Commission (2002), and which locates Portugal amongst countries where medical evidence in disability assessment is paramount (group D – which shows high medical evidence and low levels of discretion), even for the purpose of granting benefits.

The second main characteristic of Portuguese disability policies is the low level of support provided to disabled people, in terms of cash benefits and the services provided. The benefits created to support disabled people have always been subject to medical and means tested criteria, and have also been extremely modest. This is apparent in the fact that in 1987 the government had to increase by 50% and 64%, correspondingly, two of the most important disability benefits – the disability supplement benefit for children and young disabled people under 24 years old and the disability benefit for life for those older than 24 years old, which was established in 1980 (Law-Decree 170/80, 29/05/80) – due to their low amounts and the drop in their economic value (Regulatory Decree 24/87 from 3/4/87). This has also been confirmed by recent research which reported that disabled people's lives in Portugal have an additional cost estimated between €4.103,00 and €25.307,00 per year when compared to the non-disabled population (Portugal *et al.*, 2010).

The impact of the current economic crisis and the prioritisation of capitalist imperatives of financial markets over people's needs has taken its toll on disabled people's social citizenship rights in Portugal. In addition to the meagre social benefits granted to disabled people – illustrated by the value of the Invalidity Social Pension for the Non Contributory Regime in 2010 (€189,52) – Law-Decree 70/2010 (16/06/2010) introduced new rules and criteria for calculating the amount of social benefits. This new law, by including in the definition of 'family' any person who shares a household and by changing the 'individual value' previously ascribed to each family member, made it more difficult to access benefits and reduced the amount available. Furthermore, another new law was introduced – Law 55A/2010 (31/12/2010) – preventing social benefits from being updated according to the rate of inflation.

The amount of services made available by the Portuguese state has also been extremely scarce. As was the case in the UK after 1980, when the Thatcher government transformed a Beveridgean welfare-state into a mixed welfare-system that enhanced the role of the voluntary and private sectors (Borsay, 2005), in Portugal a similar strategy of

low state involvement was used and a mixed welfare-system was adopted. In fact, third sector organisations have always played a crucial role in the provision of social and family services in Portugal. In 2005, 73% of social services belonged to the third sector and only 1.9% was the responsibility of the local or central government (DGEEP/MSST, 2007: 8). Therefore, the Portuguese state has transferred its responsibilities in the provision of social and family services onto the third sector, which absorbs much of the social security 'Social Action' subsector budget in Portugal. In 1998 the money transferred from the subsector 'Social Action' of the Social Security System to third sector organisations represented 67% of the total budget (Ferreira, 2005: 8). This process has been achieved through cooperation agreements between the state and third sector organisations.

The low level of generosity shown by the Portuguese welfare system, when compared to other Central and Northern countries (Eardley *et al.*, 1996; Gough, 1996), is not specific to disabled people – it has been characterised as one of its most distinctive traits, making it typical of most Southern European countries. In 1997, for example, Portugal's expenditure on disability as a percentage of both its total social expenditure and its Gross Domestic Product (GDP) was higher than the EU average (Guillén, Álvarez and Silva, 2003). As Ferrera (1996) underlines, a distinguishing characteristic of Southern European welfare-states is the dualistic nature of the protection they offer: a high level of generosity (mainly through pensions) to those within the core sectors of the regular labour market and poor protection for those outside it, which is where most disabled people fit in. According to the Portuguese 2001 Census, only 29% of disabled people over 15 years were economically active (Gonçalves, 2003: 80). The insufficient protection of disabled people, alongside their lack of access to an adequate education, to the job market, to the public sphere and to economic resources, makes them one of the most economically and socially deprived groups in Portugal. Therefore, this distribution of social expenditure needs to be contextualised. The lack of investment in this area over a long period and the high level of prejudice in Portugal towards disabled people has created barriers to their integration into the regular labour market, making them more dependent on the welfare-state (Gonçalves, 2003).

The third characteristic of Portuguese disability policies is the presence of diverse and contradictory approaches, with a focus on compensation and care. In his general overview of the policies directed towards disabled people and welfare-state services, Drake (2001a) identifies four main approaches: containment, compensation, care and

citizenship. The first refers to the segregation of disabled people into prisons, hospitals, working farms, etc. The second concerns the need to compensate those who were impaired during a war or at work, via war pensions, disability benefits, tax exemptions and the provision of health and rehabilitation services. The third is linked to the development and dissemination of direct state support programmes, including day centres, special education, sheltered employment, occupational training, healthcare, community based personal social services, assistance programmes, social security and direct financial support. All of these systems, needless to say, are based on the individual model of disability and aim to adjust the individual to the existing physical and social environment. And, finally, the latter refers to the idea of citizenship, which emerged during the 1990s within social policies, and which produced a change in disability policies.

Based on the reality of core countries like the UK and USA, which inhabit central positions within the world economy and evidence high levels of industrialisation (Giddens, 1993), Drake's model is of little application to Portugal's semi-peripheral situation, characterised by not being fully industrialised, having a rather supportive role of core economies by providing labour force and raw materials (Giddens, 1993), where different approaches, as previously discussed, coexist in different policies at the same time. If the propensity to segregate disabled people from their communities began to change from the 1960s onwards in core countries (Barnes, 1991), in Portugal this remained a central approach throughout the first three quarters of the twentieth century and is still a reality today. For example, the deinstitutionalisation of disabled people with a mental health condition only happened after the publication of the 1998 Mental Health Law (Law 36/98, 24/7/1998). As was analysed earlier in this chapter, most disabled children were segregated from mainstream schooling until the 1990s. In other areas the existence of residential institutions for disabled people is still a reality, and one funded by the state through the Social Action subsystem of Portuguese Social Security, namely the Support Residential Unit ('lar de apoio') for disabled people from 6-16 years and the residential Home ('lar residencial') for disabled people over 16 years (Portaria 1102/97 and 1103/97, both from 3/11/1997; Costa and Rodrigues, 1999; Breia et al., 2002).

The reestablishment of the Portuguese Democracy in 1974 and the incorporation of welfare policies into the 'mechanisms' of the state brought about the three last approaches identified by Drake.

The use of compensation emerged as a direct result of the campaigns carried out during the 1970s by impaired war veterans. The various demonstrations, sit-ins, road and bridge blocks and lobbying actions they undertook forced the government to publish the Law-Decree 43/76 (20/01/1976), which conferred upon impaired war veterans most of their current rights. The compensation approach is also visible in the panoply of disability benefits created by the Portuguese government, namely the additional disability benefit added to the Children and Youth family allowance, the Special Education Attendance benefit, the lifelong monthly disability benefit (for those in the contributory subsystem), the additional disability benefit for the Invalidity Pension, and the third person assistance benefit. For example, Law-Decree 133-B/97 (30/05/1997), which defines most of the existing social benefits (originally defined by Law-Decree 160/80, 27/05/1980), clearly states that the Additional Disability Benefit for the Children and Youth Family Allowance, the Special Education Attendance Benefit, Lifelong Monthly Disability Benefit and the Third Person Assistance Benefit (articles 7, 8, 9 and 10 respectively) all aim to compensate for the increase in family expenditure due to having an impaired family member.

The tendency for 'care' is less obvious in Portuguese Disability Policies. As Drake (2001a) stresses, at this level, the action taken by states differs immensely. He identifies three main groups of countries according to the services, and their organisation, provided to disabled people: a first group of countries (the Scandinavian ones) with a vast programme of services intended to support disabled people; a second group (which includes the UK) that is characterised by the development of a less organised system, with a range of different types of services, dependent on different state departments; and a third group (USA, Canada and Australia) based on juridical measures, which confer civil rights to disabled people in a system of rights based claims by disabled people. The Portuguese state does not fit into any of these three groups. As was described above, and as is typical of a Southern European Model of welfare (Ferrera, 1996), the Portuguese case demonstrates a low level of state penetration in the service provision sector and, instead, a high degree of involvement by non-public actors.

The citizenship approach only emerged in the 2000s, with documents such as disability anti-discrimination legislation (Law 46/2006, 28/08/2006), the '1st National Plan for the Integration of People with Disabilities or Impairments' (PAIPDI) (Resolution of the Council of Ministers 120/2006, 21/09/2006) and, more recently, the National Strategy for Disability, 2011-2013 (ENDEF) (Resolution of the Council of Ministers, 97/2010,

14/12/2010). The first document is a landmark in disability issues in Portugal, because it finally acknowledged a longstanding demand of the Disabled People's Movement regarding protection from discrimination which, until then, was only covered by a general rule of the Portuguese Constitution. The other two documents (PAIPDI and ENDEF) represent a departure from the state's piecemeal approach to disability to an integrated perspective (MTSS, 2006).

The creation and implementation of PAIPDI has, however, caused controversy. Firstly, because the document states that it was approved after the government listened to contributions from organisations of disabled people, which is contested by organisations like APD which claims that the government did not take into account any of the suggestions offered by organisations of disabled people (APD, 2006; Associação, 2006). Secondly, because this document draws upon the International Classification of Functioning, Disability and Health (ICF) and uses a terminology that locates the problem in the person (Associação, 2006). Thirdly, because its implementation has been limited and it has had little impact on the lives of disabled people (Associação, 2008a). According to APD (2008a), the implementation of this strategic document has been restricted to the approval or revision of legislation, to the issuing of recommendations and to the establishment of protocols or Commissions. But, regardless of its results, this document signals the government's recognition of the need to create a coherent and transferable disability policy in Portugal. Yet, organisations of disabled people continue to question and criticise the state's action, pinpointing discrepancies between what is written in these documents and the real practice of the government. Bearing in mind that Portugal is criticised for a discrepancy between law-in-books and law-in-action (Santos, 1990; 1993), this raises the issue of the application and consequences of disability policies in Portugal.

Despite this recent change, the general tendency of the state regarding disability policies in Portugal has been to hand over its social responsibilities to civil society, namely the family and third sector organisations (Portugal, 1996, 1998, 1999, 2008; Wall *et al.*, 2001; Ferreira, 2005; Fontes, 2006). Therefore, the state has redirected its responsibility for provision to families, through the creation of compensatory benefits, as was previously identified, and to third sector organisations, through cooperation agreements. The agreements signed between local Centres of Social Security and local non-governmental organisations (NGOs), involve, in most cases, money being transferred through the subsector 'Social Action' of the Social Security System. Through these

cooperation agreements the state has funded the creation and maintenance of day centres, rehabilitation centres, professional rehabilitation centres, residential units, centres for occupational activities (CAO), early intervention services and other local services managed by NGOs, like organisations for and of disabled people, private foundations and Holy Houses of Mercy (DGEEP/MSST, 2007).

Finally, the most striking characteristic of the disability policies developed in Portugal since 1974 is the lack of a unified disability policy. I argue that the piecemeal nature of Portuguese disability policy is not the result of a deliberate coordinated strategy but rather the result of developments which have been in response to particular difficulties. As one of my interviewee states:

except for the PAIPDI [Action Plan for the Integration of People with Disabilities or Impairments] or the PNPA [National Plan for the Promotion of Accessibilities] several years passed when things were scarce and without connection to each other [...] the links were not created due to ineptitude or the interests of those in power, because several in-depth studies were made by the universities, plans for the organisation of rehabilitation that ended up having no effect, because it was not convenient, because the process was not accepted. (Matias, interview)

In fact, disability policies in Portugal have focused mostly on particular aspects of disability and not until very recently did they form a comprehensive and integrated perspective. Consequently, these policies have led to highly specific and particularised pieces of legislation, which focus on single issues. Examples of this piecemeal approach to disability policy are the multitude of specific benefits that apply only to specific people in specific circumstances (see Appendix 2) and that have changed over time, as well as the various and widely dispersed tax benefits credited to disabled people, as was identified earlier. Another clear example of this patchwork of disability policies concerns legal documents regarding access to the built environment. Several pieces of legislation have been published addressing this issue in respect to public services (Resolution of the Council of Ministers 34/88, 28/07/1988; Law-Decree 123/97, 22/5/1997), working environments (Normative Dispatch 99/90, 06/09/1990), access of guide dogs to public transport (Law-Decree 118/99, 14/04/1999), and the Houses of Parliament (Parliamentary Resolution 82/2003, 09/12/2003). As the diversity of these areas might suggest, there has been a multitude of concurrent disability policies deriving from different political bodies (visible in the different types of legal documents

involved) with no connection to each other, creating gaps and duplications, and sometimes without any clear cut definition of their particular attributes or of any general, or global, outcomes. An example is the creation of a working group with governmental representatives to discuss rehabilitation issues (Shared Statement of 14/11/1980), which duplicates the National Rehabilitation Council, which already brings together representatives from the government and from organisations of disabled people (formed in 1977, Law-Decree 346/77, 20/08/1977). Another, more recent, example is the publication in 2005 of two official documents (Shared Statement 28/2005, 11/1/2005 and Shared Statement 55/2005, 17/1/2005), which created two different working groups to evaluate the implementation of the early intervention system. These two disputing documents were issued by different governmental bodies, which established two divergent working groups, chaired by two separate governmental bodies.

This evaluation is in line with what Drake (1999, 2001a) describes as ‘the piecemeal approach to policy making’, i.e. which offers neither a forceful nor planned strategy of state action in relation to disabled people. The outcome has been a duplication of services and the formation of policies with different goals and sometimes based on contradictory principles. This is particularly true in the support given to disabled children and their families, who are offered a multitude of different services from a range of public sectors (Education, Social Security and Health), which are often difficult to coordinate and have divergent philosophies (Fontes, 2006).

This piecemeal approach to policy making in relation to disability issues in Portugal sits at the root of another phenomenon, the maintenance of a high level of discretionary power in the hands of governmental agents. As one of my interviewees signals:

Nowadays [...] disabled people have many benefits [available to them] but it is very hard to access them. I mean, there is no equality. A Paralympics’ disabled athlete should have the same rights as the others. But no. It is the state that draws the distinction. This is a matter of mentality. [...] It all depends on the people in charge of institutions, of governments, and some are more sensible than others.
(Armando, interview)

A similar situation exists in relation to the financing of organisations of disabled people by the state. The lack of a coherent policy and of criteria gives those in decision-making

positions high levels of discretionary power, which may be used to favour one organisation over another that is more demanding or more of a political inconvenience.

These are the main characteristics of the disability policies developed by the Portuguese state since 1974. In the next section, I examine the development of these policies and approaches since 1974.

5.3. What's not in the law – the politics of disability in Portugal

As has been argued, the major feature of disability policies in Portugal is the lack of an overarching national disability policy, which is able to gather together and guide the different sectors dealing with disability, and which is essential to the development of disabled people's social citizenship project. Instead, disability policies have been dispersed across different sectors, which, most of the time, have no communication between them, while only recently have a few documents emerged signalling a change in the state's practices. The main features of the state's actions will become apparent following my analysis of the politics of disability in Portugal.

First, there is what I name a 'politics of management and evaluation of possible damages'. By this I mean the fact that the government acts only when pressured from the outside and it acts in order to prevent any damage to its image. This pressure is exercised by the Disabled People's Movement by creating public awareness through the use of the media, especially public television, and through public demonstrations. As one of my interviewees puts it:

The state, following its own initiative, without anyone to instigate action, [...] will not do anything [...] This is the reality, it was always like [...] the more you demand, the more you get. (Armando, interview)

This pressure initially came from the Disabled People's Movement and as a result of public opinion and, after 1986, from the European Union and the Council of Europe as well. A clear example was the publication of Law-Decree 43/76 which followed a long period of contestation by disabled war veterans during the extremely sensitive post-revolutionary period (Reis, 1996). Due to the public outcry created by the disabled war veterans, the government was pushed to legislate. As one of my interviewees explains:

After that fight, by the end of September [1975], it was a fight that had consequences, it had political consequences in the country, this was said here in this house by *Marshal XXXX* [name], ‘You almost caused a civil war!’, he said. It had political effects on the country. (José, interview)

However, for the majority of the time the pressure exerted on the government to act did not create a will to act, which therefore compromised the application of these legal gains. There are several examples across time showing that sometimes the state legislates without planning to implement its own legal documents, making them redundant. This leads me to argue that the government not only acts when pushed, but also that it only acts to mitigate any damage and to reduce criticism against it. Examples include the legislation in the area of accessibility and the creation of employment quotas for disabled people in the public sector.

Secondly, it is possible to identify a ‘politics of absence or of invisibility’, meaning that the state also acts by inaction, by deliberately remaining silent or by making itself invisible. By doing this, the state manages to push civil society to act, as happened with service provision for disabled people, and manages to boycott or block some processes that would lead to decision-making. An example is the creation of the working group for the revision of Law-Decree 43/76. This group, formed by members of ADFA and the Defence Ministry, met only once, after which the Minister of Defence declared that it was over, stating that the work would continue at the government level, which never happened (*ELO*, 1980b). The existence of long gaps between the publication of legislation and its application, due to the lack of any regulation, is another feature of this politics of absence or of invisibility. In relation to education, examples include the publication of Law 66/79 (special education), which was never implemented or the sixteen year gap between the beginning of the Special Education Teams and the legal definition of their activities (1974-1988) (see Fontes, 2006). In the area of employment, some parts of Law-Decree 18/89 (establishing the regime of occupational activities for disabled people) were only regulated in 2006, seventeen years after its original publication. This trait can also be seen in the delays imposed on some commissions and areas due to the absence of government representatives, which happened with the Parliamentary Commission for the International Year of Disabled People (*ELO*, 1981b; 1981c). This also happened with the National Council for Rehabilitation, which remained inactive for one year (26/6/1979 – 11/7/1980) due to the non-nomination of government representatives. And it is also obvious in the history of the National

Council for Rehabilitation and its substitute from 1997, the National Council for the Rehabilitation and Integration of disabled people (CNRIPD). In fact, this Council, which promotes the conversation between the government and disability NGOs, should meet at least once every trimester (Number 2, article 6, Law-Decree 225/97, 27/08/1997), but it has never achieved this target, as one of my interviewees stressed:

The organisations do not reflect themselves on the Council [CNRIPD] [...]. But the responsibility is also that of the management of the council. If the management had defined a plan of activities, with a plan and a minimum level of organisation, the meetings would happen. [...] In 2007 I'm not sure if they met, and in 2008 there is no evidence that they did. (Matias, interview)

Thirdly, my analysis identified two contradictory but interconnected types of politics: a 'politics of self-subversion' and a 'politics of control'. By using the first the state manages to undermine the mechanisms of participation without abandoning or cancelling these mechanisms and, by using the second, the state manages to impose the government's ideas and/or strategies.

Such 'politics of self-subversion' have been identified by Santos (1990, 1993) as a strategy of action of the Portuguese state across history, encapsulated in his concepts of the 'Parallel State' and of the 'Heterogeneous State'. In the first instance, which corresponds to the existence of a 'Parallel State', there is a clear discrepancy between the social practices of the state and its legal and institutional framework, it acts against its own laws and institutions: "the state seems to shrink in its official area of action and to lose its strength and motivation to mobilise the formal means it has available" (Santos, 1990: 135). In the second instance, after its integration into the EU, the state transformed itself into what Santos refers to as the 'Heterogeneous State'. This new type of action refers to strategies deployed by the state to maintain the 'Parallel State' effects but in a covert way. There are numerous examples of these two types of action in the area of disability. The first can be seen in the publication of legislation without any practical effect, because it was never regulated or was contradicted by new legislation; it is also seen in the dilution of the state's responsibilities over different areas of the state or over civil society; and in the duplication of existent structures by the state, subverting its own institutions. The second emerges clearly in the creation and implementation of services of special education, educational support and, more recently, in the process of inclusion of disabled children into the education system. It is visible in the development

of measures without the creation of conditions for their implementation, namely financial and technical resources and technical training. This new type of state subverting action is also evident in the selective application of laws. Again in relation to education, this has allowed the maintenance of and public funding for schools of special education when the law defines the implementation of an inclusive education system. Finally, and most recently, there has been a dilution and duplication of the state's structures in the area of disability, signalled by the creation of a Shadow-Minister of State and Rehabilitation, whose role surmounts that of the President of the National Institute for Rehabilitation (former SNRIPD and SNR).

The 'politics of control' refers to strategies of action by which the state removes power from its institutions and from the organisations of disabled people to empower itself. This is particularly evident in the lack of power of institutions and commissions created by the state in the area of integration and rehabilitation of disabled people and also in relation to the participation of disabled people's organisations. In so doing, the state allows the Disabled People's Movement to participate in the discussion of disability issues but blocks its power in the decision-making process. Several examples include the initial blocking of legislation which has discussed, voted in and approved by the National Council for Rehabilitation (CNR) with the participation of both governmental representatives and representatives of disabled people's NGOs and the current exclusive use of the National Council for Rehabilitation and Integration of Disabled People (CNRIPD, formerly CNR) to inform the organisations about the government's plans. As one interviewee summarises:

Today what do we have in reality? An organ of sacred functioning, that works only when 'God' wants and whose goals, invariably, are almost the same, that is, to keep us informed [...]. This is very little, very little, and it is not what we need. What we need is a consultation organ that can help in the construction of instruments and policies [...], that can assess the application of these policies and, possibly, help in the execution of those policies as well. (Daniel, interview)

In fact, bodies like the National Secretariat for Rehabilitation (SNR) and the National Council for Rehabilitation (CNR), which were designed to plan, execute and coordinate all governmental policies in the area of disability and to promote the rights of disabled people in Portugal with the participation of disabled people's NGOs, lost their power to

influence the government shortly after their creation and the disabled people's NGOs also lost their influence within these institutions. As another interviewee explains:

The Secretariat [SNR] was really an advanced structure, it worked democratically, it had a National Council [CNR] with enormous powers, the government could not decide anything on disability without listening to the CNR, the decisions of the CNR were supreme, the ministries had to obey these decisions [...]. Well, the AD government [Democratic Alliance – centre-right wing government elected in 1980] drained almost completely its contents, destroyed the CNR, changed the supporting legislation [...]. After that, the Secretariat almost died, never managing to be what it was in the past. (José, interview)

As my interviewee highlights, in 1980 the government decided to replace the Secretary of the SNR without consulting the organisations of disabled people as established by law (see *ELO*, 1980c; *Associação*, 1980a) and in 1982 it restructured the SNR (Law-Decree 355/82, 6/09/1982) transforming it into a consultative, rather than, a deliberative body (*Associação*, 1982).

Another example of this 'politics of control' is the state's overlapping of the role of the organisations of disabled people through its use of the SNR. In fact, the state represented Portuguese disabled people at several international organisations and events, undermining the role of the organisations of disabled people and, in doing so, controlled the organisations and their international contacts. As one of my interviewees reported:

The SNR, [...] was the one representing the organisations [of blind people] in the World Blind Union, which was an aberration, wasn't it? Because the person who was there [at the SNR] was also blind, [...], and was not interested in giving that [the representative status] to the organisations because they did not get along well. (André, interview)

These are some of the most evident traits of Portuguese disability politics in the last 35 years. A micro-analysis would, however, reveal some of the specificities of the different governments and political backgrounds, which was not the intention of this section.

Conclusion

The efficiency of a rights-based approach in disability policies in the Portuguese welfare state since 1974 has been limited and most legislation approved within this spirit seems to be doomed to failure. Arguably, this has compromised the development of disabled people's social citizenship project, which has impacted on the current situation of disabled people as will be analysed in the following chapter. I would say that despite the promulgation of transformative laws in the area of disability, partially influenced by the internationalisation of disability issues (see Chapter 7), most of them have turned out to be captured laws, to use Krieger's term (Krieger, 2003), i.e. captured by the dominant social norms. Several reasons may account for this, some of which have already been analysed in this chapter, namely political and financial reasons. A closer analysis of the policies and the different legal documents reveals, however, a more structural reason for this, which is the dominance of a medical understanding of disability. As Drake puts it:

Governments formulate and implement policies, in part, to give concrete expression to their ideologies, values and beliefs, and each administration creates and promotes policies that resonate with its own particular understanding of 'disability'. [...] the way in which a government conceives of disability has a profound effect on the eventual shape that a country's laws and institutions will take, as well as on the quality of life that disabled people can enjoy. (1999: 35)

This medical understanding of disability inaugurated by modernity (Hughes, 2002) suggests an understanding of disabled people's lives in terms of incapacity and inadequacy. As Barnes, Mercer and Shakespeare (2000: 20) argue:

This medicalisation of disability represented the establishment of an 'individual' model of disability that became the professional, policy and lay orthodoxy through the twentieth century.

This individualised model represents the needs and problems faced by disabled people as a direct consequence of their impairment. It is a model centred on difference, on bodily impairment and on the way this impairment limits disabled people's lives, transforming disabled people into non-valid, non-active and dependent people.

This ideology is evident in most Portuguese legal documents in the area of disability, particularly those conferring rights, special status or disability specific benefits to disabled people. The presence of this medical ideology is obvious in the area of social

security in which most benefits granted to disabled people require a thorough medical assessment first. Furthermore, most benefits are based on the principles of assistance rather than on the recognition of the rights of disabled people. This individualistic ideology is also manifest in the areas of employment and education. As was indicated above, in the arena of employment, policies have been implemented which focus on the supply side of labour and not on demand, as well as being invested in the creation of subsidies for the integration of disabled people into work spaces instead of the creation of generally accessible workspaces. In respect to education, notwithstanding the current focus on inclusion, the system is overloaded with an individualised and medicalised ideology and by the use of jargon in plans for intervention.

In sum, as was the case in the UK (Barnes and Mercer, 2010), the political system only recognises disabled people through a medical lens, which leads to a mismatch between disabled people's citizenship aspirations and social policies. As such, disabled people can only find the means to demand and be represented through collective action. Such a mismatch is even more pervasive today, in the current context of the global economic crisis. As was analysed above, the recent cuts in the area of social security have widened this gap. Thus, the disabled people's social citizenship project has been compromised not only by the main features of the Portuguese welfare system, but also by the ideology behind the disability policies and politics that have been implemented.

As Sainsbury argues: "A regime policy logic involves a set of constraints and opportunities affecting future politics" (2003: 272). Therefore, an analysis of disability policies and politics in Portugal would necessarily be incomplete without considering the role of the disabled people's organisations and their collective action in shaping social policy, introducing variation in welfare-state models and lobbying politicians. The next chapter will deal specifically with the Disabled People's Movement as a political agent in shaping and restructuring the Portuguese welfare-state in relation to disability issues.

6. The struggle for social citizenship rights: characteristics and strategies of the Portuguese Disabled People's Movement

Introduction

Informed by the events discussed in Chapter 4, this chapter will turn to the development of the Portuguese Disabled People's Movement following the 1974 revolution. The military coup that initiated this forms the cornerstone of the transition to democracy and of the emergence of the Disabled People's Movement in Portugal. During the dictatorship the state repressed most forms of collective action and subordinated individual claims to a so called common or natural good (Hamann and Manuel, 1999), which the state itself obviously represented. As was seen in Chapter 4, this same reason thwarted the focus and activity of most disability organisations that emerged in Portugal in the first three quarters of the twentieth century. The revolutionary period following the military coup created the opportunities for a participatory civil society and for the expression of dissent by socially excluded groups. This new social climate favoured the emergence of "a plethora of social movements and citizen initiatives [and] gave rise to the invention of new forms of participatory democracy." (Santos and Nunes, 2004: 11). One of the 'new' social movements emerging during this revolutionary period was the Portuguese Disabled People's Movement.

In this chapter, I offer a critical analysis of the movement's development and main features. Thus, first I will consider the development of the Portuguese Disabled People's Movement, pinpointing its main features, alongside comparing and contrasting it with the development of the Disabled People's Movement in the UK. Then, I will examine the politics, action strategies and resources mobilised by the movement, in an attempt to identify patterns of action and underlying ideas. This will be followed by an analysis of collective identity and unity within the movement. Both sections offer a critical comparative engagement with the British case.

6.1. The development of the Disabled People's Movement in Portugal after 1974

The collapse of the Portuguese dictatorship in 1974 enabled the transformation of disability into a field of protest within existing organisations and the emergence of new voices. The first organisation of disabled people to emerge after the revolution was the Association of Impaired War Veterans (ADFA) (ELO, 1974a, 1974b), shortly followed by the Movement of the Mutilated in Work Accidents which was soon renamed the National Association of People Impaired in Work (ANDST) (CNST, 1974, 1975). These organisations shared the space already inhabited by some impairment-specific organisations, particularly the blind and deaf organizations that had first formed in the 1920s, and the Portuguese Association of Disabled People (APD) formed in 1972. The movement would, however, continue to grow in the following decades. The first sign of growth came with the formation of the National Coordinating Commission of Disability Organisations (CCNOD, later CNOD) in 1980 (APD, 1997), the first national umbrella organisation *of* and *for* disabled people. Secondly, with the unification of the blind organisations into a single organisation in 1989, the Portuguese Association of Blind and Low Vision People (ACAPO) was formed (ACAPO, 2009). Thirdly, came the development of a range of organisations of deaf people during the 1990s as well as the formation of the Portuguese Federation of the Organizations of Deaf People in 1993.

6.1.1. The rise of collective action

Based on my data, I suggest that there was no Disabled People's Movement in Portugal before 1974. Despite earlier initiatives for collective action, the nature, characteristics, focus and the absence of disabled leaders in previous organisations (see Chapter 4) led me to disregard them as a disabled people's movement. Even organisations like APD, formed in 1972, and which was led by disabled people, were completely neutralised by the political regime of the time. As one of the founding members of APD illustrates:

[Former war veterans appeared] on TV [...] publicising that they were going to create an organisation of disabled people [...] And I enrolled myself. The next day I returned to help enrol more people. We enrolled roughly 200 people. [...] In sum, that didn't work! [...] The two hundred members we had when I left [...] were the same as we had in 1975, in 1974... Nothing happened. (Rui, interview)

In addition, as was seen in Chapter 4, the dominance of a charitable framework and the constraints imposed on organisations of disabled people by the political regime, made disabled people almost invisible in Portuguese society before 1974.

I argue, therefore, that the 1974 revolution also signifies the moment when disability was transformed from a charitable and private issue into a political one. The question that remains is: What accounts for the emergence of disabled people's collective action in Portugal in this period?

From a structural point of view, the Portuguese Disabled People's Movement is the product of three political phenomena: firstly, the re-establishment of a democratic regime in 1974; secondly, a situation of political, social and economic exclusion experienced by disabled people and, thirdly, the return to Portugal of a huge number of young military people impaired in the colonial war in Africa (1961-1974). This confirms Scott's (1990) assertion about the political nature of new social movements, i.e., that their roots lie in dysfunctional decision-making processes that oppress some elements of society (Young, 1990).

Following the revolution, and up until the introduction of the 1976 Portuguese Constitution, the country vibrated with popular movements and countless citizens' initiatives. This revolutionary climate, in conjunction with the lifting of legal constraints to collective action, encouraged the creation of vibrant grassroots initiatives, which enabled the appearance of politically-engaged disability organisations and which gave voice to disabled people in Portuguese society.

At the same time, however, as was analysed in Chapter 5, the lack of existence of a welfare-state in Portugal until 1974, allied with a disabling society, made disabled people dependent on their families and excluded them from participating in Portuguese society and benefiting from the improvements and the wealth generated by the Portuguese economy, during the 1960s and early 1970s (Pinto, 2003). For instance, between 1960 and 1973 Portugal registered a significant increase in the Gross Domestic Product (GDP), which stimulated the growth of the Portuguese middle-classes. This situation resembles the British case, where disabled people remained marginal to the affluence enjoyed by most of British society during the 1960s and were not able "to secure a reasonable standard of life" (Campbell and Oliver, 1996: 60). This situation pushed disabled people in the UK to organise collectively from the 1960s onwards in

order to fight against their social and economic exclusion and to demand sufficient resources and services from the welfare-state in order to become part of the community. The difference between the UK and Portugal is that, in the first case, there was already a welfare state (UPIAS, 1976; Barnes, 1991), whereas in the second case, no welfare-state existed. As one of my interviewees reported, this absence of a welfare-state, in combination with the state's attitude towards disability, left most disabled people to their own luck and reinforced their dependency on family support and care:

Obviously, this impairment caused great embarrassment in the beginning. [...] I wasn't prepared to deal with this situation [...] due to the difficulties associated with this impairment, particularly at a functional level, because [...] I saw myself as almost totally dependent [...] with terrible personal psychological consequences, that resulted from my impairment, which was aggravated by the lack of information concerning possible solutions for the future. [...] There was the initial accident that impaired me and there was a second 'accident' [the lack of information and support] that made my situation worse. (José, interview)

Finally, the thirteen years of colonial warfare had produced over 25,000 impaired Portuguese soldiers (Rodrigues, undated). As in other contexts, war was a catalyst for change. This was also the case in the USA with the return of impaired war veterans from the Vietnam War and the growing politicisation of disability issues, which led to the development of the Independent Living Movement (ILM) (DeJong, 1981). The return of these people to Portugal, where they were confronted by a disabling society and by a lack of opportunities and of public answers to their needs, became a catalyst for change in the area of disability. In addition, the communal experience of serving in the colonial war and the long stays in military hospitals gave impaired war veterans a sense of solidarity and collective identity, creating the conditions for the development of critical thought about their position in Portuguese society. These elements have been highlighted in the literature as central to the formation of any social movement (Melluci, 1989; Diani, 1992a). My analysis shows that this collective spirit started to develop in the mid-1960s but that it only took a consistent shape in the post-revolutionary period. Some people locate the beginnings of this spirit in Lisbon:

My involvement started in the Military Hospital. And it was here that the big difference was made. That doesn't exist anymore, but it existed after the 25th of April... We, the Association of the Armed Forces... and we, if you want, the

Movement of the Impaired Military, we emerged very strong, strong as an organisation. Why? Because we were all together, we were all together in the military hospitals. And that's why in [19]73 / [19]74 we were doing... we tried to organise... [...] ADFA was formed by the Movement of the Impaired Military that was created in the Military Hospital. (Armando, interview)

Others disagree and locate its origins in the military hospitals in Germany:

I would say that the spirit of all this, of a kind of solidarity between us [...] developed largely in Germany. [...] At first, here in the military hospital it didn't develop that much [...] We didn't have a great environment in the military hospital for the emergence of this collective spirit. In Germany it really had to develop because we were stuck in the same room from dawn to dusk, many of us severely impaired people, and we were all mixed together in terms of military hierarchy. [...] It was there that I learned to develop this spirit of solidarity. (José, interview)

Based on my data, I suggest that it was through this Movement of the Impaired Military, which was created in military hospitals, that the Disabled People's Movement really took hold. The ADFA was established in May 1974, a month after the revolution, and focused on changing the situation of impaired war veterans. As will be analysed in Chapter 7, ADFA's direct action and radicalism rapidly attracted the attention of the Portuguese population as a whole.

This is very similar to the British case, where the experience of living in institutional settings gave disabled people a political consciousness and created a collective identity that has spurred the movement on since the 1960s (Campbell and Oliver, 1996; Barnes, Mercer and Shakespeare, 2000). An example of this critical thinking can be found in *Stigma: The Experience of Disability*, a collection edited by disability activist Paul Hunt in 1966, but can also be found in the commissioning of a research study (Miller and Gwynne, 1972) by the residents of a charity-run residential institution in Hampshire in the late 1960s (Barnes, Mercer and Shakespeare, 2000). Despite the results of this research (see Hunt, 1981), it represented the rebellious attitude of disabled people living within such residential institutions.

I argue, therefore, that despite the different patterns of disabled people's institutionalisation in Portugal and the UK a crucial factor for the development of both

movements was the formation of a collective ethos between disabled people. Although this collective ethos and critical thinking only developed amongst impaired war veterans in military hospital settings, I suggest that the extension of this collective spirit has been critical for the formation of alliances and for the movement's vitality.

Several other contextual factors may also have contributed to the organisation of disabled people into a social movement and to their demand for the same citizenship rights as non-disabled citizens. I would single out the international contacts established by Portuguese disabled people in the 1960s. In fact, due to an existing agreement between Portugal and Germany, since the 1960s a number of impaired Portuguese military people have travelled to German military hospitals to receive rehabilitation. Such contact with different realities and ways of thinking was very important for consciousness-raising amongst Portuguese impaired war veterans in relation to disability issues. José states:

I went to Germany in [the late 1960s]. [...] That was the moment when things started to change in my mind, which made me realise that I was still valid. [...]. In Germany they knew how to deal with disability, it was an open and developed society, completely different from ours, and I realised that they dealt with disabled people as people in the process of reconstruction, contrary to Portugal where disabled people were held in a non-dynamic and static position. [...] When I returned from Germany I was very excited [...] and I started to draw up plans for my life, 'I'm going to work, I'm going to study, I'm going to write'. [...] Well, I came back full of expectations and tried to do things in order to change my situation. (José, interview)

These contacts abroad were also central to the creation of the ADFA, as one interviewee suggests:

I stopped by the Heidelberg hospital. I was there after having visited Germany for several times, I was there at the service of the organisation. We had a German language course at the German Institute [...] [We] went to Germany to visit all their [rehabilitation] centres. (Interview)

This was, thus, the start of the Disabled People's Movement in Portugal. It was the impaired war veterans who challenged the older, more established organisations of disabled people. Unlike the British case, ADFA never managed to lead the movement as

happened with UPIAS, which formed in 1972 (Campbell and Oliver, 1996). Moreover, its political project was much less ambitious and revolutionary, as will be discussed in the next section.

6.1.2. The political within

A central aim of the Disabled People's Movement in the UK since its beginnings in the 1970s has been to expose the roots of oppression of disabled people as a way of changing society. This is visible in the writings of disabled activists like Vic Finkelstein (1980) and Mike Oliver (1978, 1983), as well as in the documents produced by UPIAS (1976). In these writings, disability is represented as a construction of society that is imposed on the top of people's impairments, which discriminates against, excludes and oppresses disabled people. As was analysed in Chapter 2, this contention has been the backbone of the Disabled People's Movement in the UK and the central argument of collective claims and demands. This transformative argument was later transposed into the heart of Disabled Peoples' International (DPI) through pressure exerted by its British and Irish representatives (Campbell and Oliver, 1996).

In Portugal, the above described political transformation operated within British organisations and DPI is still ongoing, as can be appreciated from the definition of 'disabled person' in the proposal for anti-discrimination legislation, which was approved in 1996 during the second National Parliament of Disabled People. It states that a disabled person is:

A person in his/her own right, placed in a disadvantaged position due to physical/environmental, economic and social barriers that the person, due to his/her specificities, cannot overcome as other citizens would. These barriers are frequently strengthened by society's marginalising attitudes. It is a duty of society to eliminate/reduce or compensate these barriers so that everyone can benefit from a full citizenship. (Associação, 1997a: 2)

As can be concluded from this definition, the barriers are not created specifically by society to oppress disabled people. Instead, barriers affect everyone including non-disabled people. Disabled people are more affected by these barriers due to the limitations imposed by their impairments and because these barriers are strengthened by

disabling attitudes. The final line encapsulates the political positioning of the Portuguese movement, which is not aiming for a complete overhaul of society. It seeks instead the possibility of simply reducing these barriers or even compensating disabled people for the maintenance of these barriers and the maintenance of their position as ‘second class citizens’. Notwithstanding the use of social model jargon, the way it is worded directs me towards a different conclusion. The way the movement has framed disability in the Portuguese context seems to illustrate the pervasiveness of one form of oppression denominated by Young (1990) as ‘cultural imperialism’. In this case, dominant disabling conceptions and imagery have permeated disabled people’s own discourses, preventing the politicisation of disability, promoting the internalisation of disablism and perpetuating disabled people’s subordination.

I argue, therefore, that the social model of disability has not been central to the Portuguese Disabled People’s Movement. This is visible, for example, in the use made of the notion of rehabilitation. My analysis reveals that this notion is used to refer to medical rehabilitation and to every single aspect necessary for the inclusion of disabled people in Portuguese society, including: accessibility, disability benefits, work training, education and daily living activities. This is blatant too in my interviewees’ discourse:

Currently rehabilitation policy includes everything. [...] Basically, it is a politics of the adaptation of disabled people to life. (Matias, interview)

What we want [...] is a policy that gathers together all social dimensions – accessibility, transport, health – that defines [...] a strategic plan of action that includes all social dimensions. (Daniel, interview)

Within the six organisations analysed for the purpose of this thesis, only APD and CNOD revealed some engagement with the social model of disability. The presence of the social model within the demands and claims of these two organisations does not signify, however, a shift in their understanding of disability. In fact, a closer look at the internal materials and discourses of APD and CNOD reveals the coexistence of both philosophies, with the demand for anti-discrimination legislation being used in parallel with demands for disability-specific benefits or for medical rehabilitation. Several reasons may account for this. The main reason advanced by my interviewees is the lack of internal discussion and shared collective reflection in these organisations:

A couple of years ago I read a text [...] from Latin America which was a manifesto, an appeal for us not to let our own agendas be defined by those in power, i.e., for us, as a Disabled People's Movement, to have our own agenda. This is something impossible in Portugal. Our social movement doesn't have such richness, this internal culture of self-reflection, because most of the organisations are financially dependent [...] which subordinates them to the will of the government [...]. People only think about, only deal with those questions that are offered to them, most of the time [...] without questioning if that's the best way. (Daniel, interview)

My research does not discard this argument, despite directing me towards other structural causes. Arguably, the main reasons for the lack of political and theoretical engagement shown by the Portuguese Disabled People's Movement in this form of oppression stems from its lack of an academic arm and from the absence of a specific agenda created by the movement. In contrast to the British case, where the movement has always had a particularly articulate academic dimension (Barnes, Oliver and Barton, 2002), Portuguese disability activists have had no connection with academia. Therefore, the academic production emphasising disability as a social oppression (Finkelstein, 1980; Oliver, 1983) which played an important role in changing public attitudes in the UK has had no parallel in Portugal. The data also reveals that after the emergence of the movement and subsequent state acknowledgement, the movement's agenda has drifted towards the state's agenda. An analysis of the claims of the movement during the National Meetings and Congresses of Disabled People, as well as claims from other organisations, shows a focus on specific rights or special status, stemming from an ongoing dialogue with the state's actions and/or its legal framework. The movement is indeed more reactive than pro-active and this is the reason why its agenda is too narrowly focused. As Barnes and Oliver rightly warned regarding the Disabled People's Movement in the UK:

To get too close to the government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise. To collaborate too eagerly with the organizations for disabled people risks having our agendas taken over by them, and having them presented both to us and to politicians as theirs. (1995: 115)

This lack of a political and theoretical anchorage left the Portuguese movement adrift and compromised its struggle for citizenship rights. In contrast to the UK, where the social model of disability functioned as a hub for the movement from which major principles and guidelines were generated, in Portugal its absence meant not only a lack of unifying principles, but also the assimilation of the movement's agenda by the government. The absence of a set of ideas and principles to guide decision-making processes, individually, as organisations of disabled people and, collectively, as a movement also meant that the movement opportunistically seized any given chance without thinking about its political consequences. For instance, despite being an umbrella organisation, CNOD incorporated organisations *of* and *for* disabled people, in an attempt to compound the different perspectives and interests of members, as a strategy by which to control organisations *for* disabled people for the benefit of organisations *of* disabled people, as was revealed by one of my interviewees. In contrast, what BCOOP, CNOD's equivalent in the UK, did, for the sake of political unity, was to encourage not the incorporation of organisations *for* disabled people, as CNOD did – in fact they were banned from membership – but instead the election of disabled people as leaders (Campbell and Oliver, 1996).

An example of such absence of guiding principles in the Portuguese movement is the changes implemented by the government within the CNR (National Council for Rehabilitation, later CNRIPD). Until 1982 this public body, which was created in 1979 by the government as a direct result of the demands put forward by the Disabled People's Movement, only incorporated organisations *of* disabled people (APD, ADFA and ANDST since 1981). In 1982 the publication of Law-Decree 355/82 introduced drastic internal changes into the SNR and the CNR, which aimed to reduce the power of the organisations *of* disabled people within the Council. This was achieved, directly, by removing rights previously granted to the organisations, namely that the government would listen to the organisations of disabled people before appointing a new director for the SNR and, indirectly, by the incorporation of organisations *for* disabled people into the Council, thereby reducing the voice of the organisations *of* disabled people. An analysis of the minutes of the Council meetings and of the publications of major organisations *of* disabled people at the time (APD and ADFA) reveals that, despite these changes being highly contested, the decision to incorporate organisations *for* disabled people into the council was never mentioned or questioned. In fact, the movement

seemed to have embraced the government's decision or, at least, distanced itself from such discussions, as may be concluded from the statement of one of my interviewees:

We tried to discuss, within CNOD, what is this thing of being an organisation *for* disabled people and an organisation *of* disabled people. We [...] questioned that and why should there be organisations for and of disabled people, but it was, say, very superficial. We didn't get to the bottom of the issue [...] and we didn't manage to reach a conclusion. (Jorge, interview)

This issue emerged much later on in Portugal and it was never as prominent a concern as it was in the UK. In fact, except for the early reactions of the impaired veterans towards the female volunteers of the Portuguese Red Cross before 1974, which was reported in Chapter 4, the movement was sympathetic towards organisations *for* disabled people. In the conclusion of the 2nd National Congress of ADFA held in 1981, ADFA demanded the restructuring of the CNR and the inclusion of representatives from the organisations of 'mentally impaired children' (sic), of the cooperative movement (education cooperatives created by parents after the revolution for the education of disabled children) and of the 'visually impaired' (ELO, 1981d: 6). Arguably, the lack of politicisation of disability, the prevalence of a disablist ideology and the economic difficulties which pushed organisations of disabled people to replace the state in the provision of services to their associates, made organisations *of* and *for* disabled people almost indistinguishable from each other in terms of their aims and strategies. The first reference regarding the need to distinguish between organisations *for* and *of* disabled people only emerges in 1995, in the summary of a meeting between APD and the Shadow Minister for Social Integration. As it states in the minutes of this meeting:

We also discussed the urgent need to separate organisations *of* disabled people from organisations *for* disabled people, in order to clarify any doubts or confusion. The aim is to achieve more gains for disabled people, [to overcome] the excessive bureaucracy of public services and the lack of information concerning disability issues (Associação, 1996: 2).

Apart from this episode, the movement kept silent about this issue.

In the UK several attempts were made to create a national disability council, similar to the post-1982 CNR, comprising organisations *of* and *for* disabled people. All of them failed. In fact, BCOOP's adoption of the social model led to the repeated rejection of

these attempts because disabled people were clear about not wanting professionals to speak on their behalf (Campbell and Oliver, 1996). The loss of steam of the British Disabled People's Movement by the mid-1990s is attributed to the increasing closeness of organisations *of* and *for* disabled people. This is a result of the approval of anti-discrimination legislation in 1995 and the adoption by "the big charities [...] [of] the big ideas of the Disabled People's Movement, [which] usurped its language" (Oliver and Barnes, 2006: 10), as well as being due to the redirection of available funding and the government's enforcement of partnerships between organisations *of* disabled people and those *for* disabled people (Oliver and Barnes, 2006; Barnes and Mercer, 2010: 163).

Nevertheless, this does not mean that the Portuguese Disabled People's Movement did not develop an alternative understanding of disability. On the contrary, the movement was able to offer a counter-narrative of disability, but in contrast to the UK, the Portuguese movement did not opt to shift attention from the body to society. In fact, the embodied nature of impairments is central to the construction of disability and to a positive disabled identity and, therefore, to the arguments used by the movement. This counter-narrative of disability uses the body as its core. However, contrary to the dominant narrative which uses the disabled body to justify disabled people's societal position and the need for rehabilitation, medical intervention and even charity, the body is here portrayed, as a locus of discrimination by society and by politicians, and also as a locus of emancipation, rather than dependence and charity. Disabled people experience through their 'flesh' the lack of public support, the lack of benefits, of public services and the maintenance of physical barriers, but it is in their bodies that the potential also resides for emancipation through rehabilitation and employment. Thus, public policies should focus on the promotion of rehabilitation services *and* on providing disability benefits to promote the (re)integration of disabled people into mainstream society.

Despite the emphasis on rehabilitation, the counter-narrative offered by the Portuguese Disabled People's Movement, which focuses on individuals' experiences, a positive identity and on emancipation, seems to partially confirm Swain and French's (2000) argument about the development of a new model of disability by disabled people – the affirmative model. As they summarise:

The affirmative model directly challenges presumptions of personal tragedy and the determination of identity through the value-laden presumptions of non-

disabled people. It signifies the rejection of presumptions of tragedy, alongside rejections of presumptions of dependency and abnormality. [...] the affirmative model is borne of disabled people's experiences as valid individuals, as determining their own lifestyles, culture and identity. (Swain and French, 2000: 578)

In fact, this counter-narrative presents disabled people as active and autonomous individuals, able to overcome their corporality and opposes the traditional narrative which portrays disabled people as useless and as charity cases. Many of the arguments put forward, especially in the early days of the movement, focused on the ability of impaired bodies, their ability to work and their validity in society. The spirit of this counter-narrative is captured in some of the slogans for banners used by ADFA during the 1970s: 'Right to work', 're-integration through work', 'the disabled worker can produce the same as the normal worker', 'charity impoverishes, work dignifies' (ELO, 1978, n. 56).

Despite emerging around the same moment in time, there was a philosophical and political gap between the Portuguese and the British Disabled People's Movements. In contrast to the Portuguese Disabled People's Movement, which centred its demands and its counter-narrative of disability on the notion of rehabilitation, the British Disabled People's Movement focused its struggle on controlling services (Barnes and Mercer, 2010). This aim was pursued through initiatives promoting disabled people's control of their own lives and services. Early initiatives included the formation of the Spinal Injuries Association (SIA) in 1974, a user-led organisation; the creation of user-led services for disabled people allowed disabled people to move out of residential schemes into the community, as was the case with the innovative housing scheme created by the Derbyshire Coalition of Disabled People (DCODP) in 1972 or the alternative scheme of payments to disabled people set up in 1979, commonly known as "Project 81-Consumer Directed Housing & Care", which allowed disabled people who had previously been institutionalised to live in their communities. Other initiatives included telephone advice services such as the Disablement Information and Advice Line (DIAL) established in 1976 by the Derbyshire activists (Project 81, 1981; Campbell and Oliver, 1996; Barnes and Mercer, 2010). From the 1980s onwards there has been a focus on establishing independent living. Examples include the formation of Centres for Independent Living (CILs) and lobbying the government for [establishing] direct payments and individualised budgets (Morris, 1993, 2005; Barnes and Mercer, 2006).

I argue, however, that this gap does not stem from the different maturity levels of the movements, but that it derives instead from the different political, economical and social contexts in which they emerged. In the UK the beginning of the movement was inspired by the rise of black people's and women's movements in the USA, by the approval of anti-discrimination legislation and by the impact of Thatcher's neo-liberal government on the rights and services previously granted (Oliver, 1990). In Portugal the reality was different: social movements were almost inexpressive/silent or had only very recently been formed, there was no anti-discrimination legislation and no welfare-state. Instead, people were moving from a situation of a total absence of social rights to a new situation characterised by the emergence of a welfare-state. The long tradition of medical rehabilitation in the UK also made disabled people more aware of its implications for their lives and for the policies developed by the government. Plus, in the UK the movement took shape at the hands of disabled people, some of whom lived in large residential units detached from mainstream society, whose bodies dictated their fate. Having almost no tradition in the institutionalisation of disabled people, the Portuguese movement developed from the impaired war veterans, whose bodies were living proof of society's historical debt and from the centre of their individual and collective identities. If, in the first case, the focus on the body represented a problem for *disabled people's integration into mainstream society*, in the second case the body offered a solution, as it was only through the body that emancipation could take place.

The Portuguese Disabled People's Movement has, thus, been influenced by local factors. The lack of engagement with the social model of disability needs, therefore, to be contextualised in the reality that created and shaped the movement. In Portugal, the Disabled People's Movement has generated what I call a counter-narrative of disability, i.e., a new understanding of disability and of being disabled which challenges traditional oppressive views of disability and of disabled people, but that failed to identify the roots of their oppression. It was this newly crafted narrative that provided, to a certain extent, a common ground for the organisations to work from, that steered the debate on disability issues and that mobilised people into collective action. These are some of the issues analysed in the next section.

6.2. Building up the movement

Unity within a social movement, as Melucci (1989) argues, should always be considered as a result and not as a starting point. In order to create this unity – as Melucci terms it (1989), the “we” – the movement must negotiate and adjust three orientations: goals, the means to be utilised and the environment in which the action should take place.

6.2.1. Aims, means and spaces of collective action

In the UK, the critique of the disabling society extended by the movement and its academic arm, politicised disability and provoked a change in disability policies and politics. In Portugal, as was analysed above, the movement never totally embraced the social model of disability, nor was there an academic input, and the unity of the movement was frail.

My empirical data shows that the embodied reality of impairment has been at the forefront of the movement’s demands. Additionally, the spotlight of its critics has been directed at the government and to its policies. This is not only the result of a lack of engagement with the social model of disability or of a lack of political understanding of disability, but is also the result of the frailty and incongruence of the social and political citizenship project in Portugal, as was discussed in Chapter 5.

Therefore, I argue that, if the main aim of the Disabled People’s Movement in the UK has been to overcome a disabling society, in Portugal its major objective has been to achieve a minimum standard of social citizenship for disabled people. The difference between the movements in both countries, again, stems from their contexts, economic circumstances and, as I will discuss later, from the specific dynamics established between the organisations of disabled people and between the movement and the state. In Portugal, the lack of a welfare-state until the mid-1970s and the low level of social protection achieved after its implementation (Santos, 1999; Hespanha, 2001), placed disabled people in a difficult economic situation, sometimes below the poverty line (Hespanha, 2001) (see Chapter 5). This major factor, I believe, framed the Portuguese Disabled People’s Movement.

In the UK, the existence of a long established welfare state and the growing awareness of the financial circumstances of disabled people since the 1960s (Barnes, 1991: 98) led to the establishment of disability specific benefits in the 1970s. In contrast to Portugal where, since 1974, the movement has had the major task of fighting for the creation, establishment and application of minimum standards of living for disabled people, in the UK the movement's establishment in the 1970s enabled disabled people to achieve a minimum standard of living, a base from which the movement could then build upon. Otherwise the movement would risk becoming detached from its grassroots. As Hindess suggests, social rights are a critical element of citizenship and their absence implies that "the formal equality of civil and political rights will be somewhat restricted." (1993: 25). An analysis of the conclusions of the nine National Congresses of Disabled People held in Portugal since 1981 is very illuminating. In these documents, which inform the strategies of the movement for the following year, basic rights make long lists of demands to the government, ranging from the right to free education and the establishment of disability specific benefits, to the formation of a network of support services for disabled people and the creation of rehabilitation services, and from the elimination of physical barriers in public environments, public buildings and in the workplace, to the establishment of work quotas for disabled people, to name just a few (CNOD, 2007). The same scenario emerges in the conclusions of the four congresses held by ADFA since 1976, despite its additional focus on military issues (ADFA, 1981, 1989, 2001).

I suggest, thus, that most of the demands put forward by organisations of disabled people in Portugal may be described as 'first level demands', i.e. demands that focus on basic daily-living rights or rights needed for the achievement of a minimum standard of citizenship for disabled people. 'Second level demands', i.e. demands that transcend the attribution of rights to disabled people and emphasise social and political issues, are less common and have never achieved centrality within organisations of disabled people. Instead, 'first level demands' have commanded the movement's agenda. The exception here is the demand for recognition of Portuguese Sign Language, which assumed total prominence within deaf organisations like APS. The specificity of the demands made by deaf organisations stems from their position within the Disabled People's Movement. In fact, deaf people do not see themselves as disabled, just like in the UK and the USA (Ladd, 1988; Davis, 1995; Corker, 1998), but rather as belonging to a cultural and

linguistic minority, comparable to any other minority group. As one of my interviewees illustrates:

I was born without hearing, nothing else. Someone who is motor impaired doesn't have a community, only has problems of accessibility, there is something missing. In the case of deaf people, this missing element can be adapted as a visual element. We have a language, the Portuguese Sign Language. We have vision and, therefore, we don't lack anything else. [...] We have a language as other people have their own language. Our language mirrors the way we see the world. We have our own culture and our identity. We don't feel disabled at all. (Joana, interview)

This standpoint draws a line between the organisations of deaf people and other organisations of disabled people, at the same time that it also generates tension within the Disabled People's Movement when considering issues such as the education system and the principle of inclusion. For example, deaf organisations have made claims for the maintenance of special schools for deaf children taught by deaf teachers (e.g. letter from APS to the Ministry of Education David Justino, 2003; electronic communication from the Deaf Organisation of Oporto to the Portuguese MPs, 06/03/2008).

The lack of income security, the shortage of medical and vocational rehabilitation, the pervasiveness of traditional visions of disability, the tendency of the state to make itself invisible in social areas delegating responsibility to civil society, in conjunction with the absence of a strong alliance within the Disabled People's Movement, left no alternative to the Portuguese organisations of disabled people but to embrace a diverse and flexible action strategy. In fact, as I was able to verify during fieldwork, the organisations opted for the use of different strategies according to each issue. Action strategies ranged from raising awareness about general issues of disability, seminars, congresses and assemblies, to formal meetings with central and local authorities, political lobbying, sit-ins and demonstrations. For example, in 2008, as I observed during my fieldwork, APD organised several seminars on issues of human rights and disability (e.g. "Terminology in Disability: To adjust the definitions to the language of human rights. One definition of Disability", 30/06/2008), at the same time as they participated in street demonstrations (e.g. a demonstration against the new labour package organised by the communist workers trade union – CGTP, 28/06/2008) and kept up its political lobbying too (e.g. Associação, 2008b). The use of a diversified action strategy gives the

movement the much-needed flexibility, which is essential for adapting to specific circumstances.

Contrary to what has been described in new social movements' literature (Abercrombie *et al.*, 2000; Lawrence and Turner, 1999), the Portuguese organisations of disabled people have favoured traditional action strategies, namely government lobbying and raising awareness of disability issues in public bodies and society, instead of more direct action or political protest, namely sit-ins and mass demonstrations of disabled people. Despite the few demonstrations mentioned earlier, these are a 'last resort' strategy, to be used when other strategies fail or in cases when the state seems unwilling to act and/or negotiate. The use of direct action is, thus, not intended to overcome the dominant system of power relations, but rather to be included and considered by it. David observes:

Concerning this last demonstration, [...] if you ask me if in my opinion that was the right timing for that demonstration, I don't think so. [...] I think that we didn't have all the negotiation that was necessary in order to clarify and to assess if there was good or bad will from the politicians to give us an answer. (David, interview)

I argue therefore that the Portuguese Disabled People's Movement opted for the use of a soft action strategy, i.e., a strategy that does not involve questioning mainstream society or the organisation of power but that tries to fit itself into the existing structure and make its voices heard from there.

The use of a hard action strategy – i.e., a strategy which contests the way society is structured, the power relations within it and that uses corresponding strategies to overcome it – has been sporadic and limited to particular moments in time. More specifically, the history of the movement reveals that the use of a 'hard action strategy' was limited to Portuguese society's revolutionary period (1974 – 1976). After this moment, the movement entered into a period of institutionalisation or 'normalisation'. Within the Portuguese Disabled People's Movement, ADFA was the archetypical organisation of this first phase. Closely linked to the military movement that led the revolution in Portugal in 1974, imbued with the political spirit of the time (freedom of speech, anti-fascism, nationalisations, workers demonstrations and huge participation of civil society) and fuelled by a sense of justice, ADFA emerged as a radical organisation. José recalls:

In S. Bento Palace, when we were seen by the Prime Minister, [...], we were very troubled by his secretary who said to us: ‘With a demonstration like the one you did, you are serving the counter-revolution!’ [...] After that fight by the end of September... it was a fight that had political consequences for the country, as was said here in this house by XXX [name] – ‘You almost initiated a civil-war’, he said. It had political consequences for the country. [...] We offered the idea that the country couldn’t continue as it was, the country was in chaos and we helped provide this idea of chaos. (José, interview)

The return to ‘normal’ after this turbulent revolutionary period (Santos and Nunes, 2004), also meant the neutralisation of the Portuguese Disabled People’s Movement and the rise to dominance of conventional politics which favours the use of a soft action strategy. As my interviewee continues:

Following that fight, the organisation was very fragile, it halted... It caused vast damage after the 25 of November [1975] [...] and, after that, great internal problems emerged with the reaction of our colleagues from XXX [name of town] and after that the party politics. [...] All the military that were our allies were arrested [...] and the organisation was a bit vulnerable. (José, interview)

ADFA, the most radical organisation in the 1970s, is a paradigmatic example of this embrace of a soft action strategy. From 1981 until 2008, there were no public demonstrations (*ELO* 1981f, 2008a). ADFA’s strategy during this period consisted of making direct contact with the government, especially with the Ministry of Defence (*ELO*, 1983; 1987a; 1990; 1991). The use of this strategy is also visible in the organisations’ public outcry when these channels of ‘soft action strategy’ were blocked. This is particularly evident in the case of APD from 1985 to 1995, during which it publicly denounced being blocked out by the centre-right wing government that was in power at the time (Associação, 1986a, 1986b, 1990, 1991a, 1991b, 1994a, 1995). The organisations used these meetings to present their demands, disseminate their opinions and, most importantly, gain access to the corridors of power. Public demonstrations and other forms of direct action were used only when all of the other strategies had been exhausted. Raul explains:

It all depends on the meetings with them [the government]. If we notice that there is flexibility on their part, that’s ok, but if we notice that it doesn’t exist, then yes,

we organise a demonstration and demand. If we see that they don't care... [...] In the end it works as a last resort. (Raul, interview)

The use of a 'radical action strategy' in the first years after the revolution may be explained by the political climate of the time and by the acute situation experienced by disabled people within Portuguese society. The urgent need to stabilise the country, pushed the government to acknowledge some of the demands put forward by the organisations. An example of this is the publication of Law-Decree 43/76 (20/1/1976), after ADFA's demonstration in 1976, as was mentioned in Chapter 5.

However, as Oliver and Barnes (2006: 10) noted in relation to the UK from the mid 1990s:

The coming to power of a new government seemingly more willing to listen to the voice of disabled people was a problem in itself. This was because the movement had cut its teeth on oppositional politics and had little experience of participating with politicians.

Similarly, in Portugal the creation of the National Secretariat for Rehabilitation (SNR) and of the National Council for Rehabilitation in 1977 (Law-Decree 436/77, 20/8/1977) also signalled a loss of 'steam' and the beginning of the institutionalisation of the movement. Despite being a consequence of the movement's demands, these two institutions have been used as an instrument of pacification and control of the movement by the state. Operating as channels for dialogue at the state level, these institutions had dragged the movement out of the streets into the corridors of power and onto government's desks, before the organisations of disabled people had been able to join together. Arguably, the movement was incorporated by the government before it was able to create a powerful internal alliance. The failure of the organisations to unite in conjunction with a strong financial dependency on the state made the movement extremely vulnerable to the government's initiatives:

When I'm talking with colleagues of mine, leaders of other organisations, at the table of a café, we have similar positions and we are a step away from merging, but when we get to a formal meeting in front of a member of the government, everything we have talked about over lunch or over a coffee, melts into the air and is transformed into a silence or into something even more perverse, like supporting a totally different view. [...] When I challenge them on that [...] [and

they say] ‘Yeah, yeah Daniel [pseudonym], the fact is that I have wages to pay in my organisation and I need to solve issues in project X and I need project Z to be approved, and if I keep up a discourse contrary to the power I’ll have problems!’. Obviously they didn’t word it this way, but this was what they meant to say. (Daniel, interview)

The government has used this financial dependency to control the movement and to prevent the formation of close liaisons between organisations. An example of this is the economic constraints of APD between 1985 and 1995 by the centre-right wing government (Associação, 1986b, 1991c, 1994a). An analysis of the newspaper published by this organisation – *Associação* – during this period reveals that APD was extremely active in denouncing and fighting against the government’s disability policies and politics (Associação, 1992a). One of my interviewees is clear about this situation when he justifies one of his former plans, as leader of one organisation, to construct a hotel for disabled people on the Portuguese coastline:

That would turn into a funding source for XXX [organisation], which would allow it to become autonomous and independent and fight against the government, because it would be autonomous and independent which is currently not the case. If I say something, next year they will block my way, won’t give us the money and we’re done! (Rui, interview)

As he clarifies:

Why did we, a couple of years ago, fight to have the funding for the organisations coming directly from the state’s general budget? [...] and not through the SNR, because if I like your eyes I’ll give you money, if I don’t like them I’ll give you less. [Giggles] One organisation receives one sum, and the other receives another sum, but the one who has been licking their boots gets more. [...] This has divided the organisations, with each trying to survive independently, because nobody wants to kill its own organisation, do they? Thus, a way of dividing the movement is by asphyxiating it. (Rui, interview)

Government control has created great awareness in the organisations in relation to the implications of their actions towards the state. This fact has reduced the political campaigning of the organisations to a minimum and has erased much of the radicalism within the movement, as the case discussed above about ADFA not demonstrating for

27 years exemplifies. The movement has become a captive, not only of the state, but also of itself. In fact, the high level of awareness of the consequences of their actions at the state level has transformed any radical within the movement into an outsider and has transferred radicalism from a collective to an individual level. An example of this is the campaign launched by ADFA against the reduction of medical support to military veterans by the government in 2008. During the contestation a group of people raised a banner outside *Casa do Alentejo*, in downtown Lisbon, reading: 'Hitler killed the Jews. Sócrates [the Portuguese Prime Minister at the time] slowly kills the impaired people of the armed forces'. In a public statement, ADFA repudiated that action, due to the insult to the Prime Minister and its distance from the civic and democratic behaviour typical of ADFA (ELO, 2008b). Therefore, I suggest, that the only way to be radical within the movement is by transforming collective claims into personal ones. This argument is supported by some of my interviewees:

But they are the type of people able to go onto the streets, to the front of demonstrations with banners without asking anyone's permission! Although, they are very careful not to include the name of the organisation, and that is the important point. (Afonso, interview)

Not a long time ago I was in XXX [name of town] in the general assembly, and they [...] only gave permission to use posters and slogans that were authorised by the assembly. And I [...] said to XXX [name] the president 'you have to let me take the poster I have prepared for the event!' and he said 'Well... they don't want to create an exception, and if they create one for you, they will have to do the same for others as well!' [and I said] 'But you know that this is not offensive to anyone, it only raises awareness!' and I got his permission, he said 'Ok, you can take that!' and I took it. (David, interview)

Therefore, the incorporation of the movement by the state, together with its economic dependency, made the movement extremely vulnerable to the state and to its agenda. Service provision seemed the only way ahead:

The fees paid by our associates are not enough to support the amount and quality of human resources needed by the organisation and government funding is clearly insufficient. All this led us to celebrate cooperation agreements with Social Security [for the provision of services]. (Jorge, interview)

Thus I believe that XXX [organisation] should develop an array of services taking the state's place, [...] it should secure contracts with the state for the transfer of the necessary financial resources to support those services and support XXX [organisation] in the provision of those services. I believe this is the model that should be followed. The organisation should be making political demands, but via the perspective of creating awareness of public power. (Paulo, interview)

The side effect of this strategy is clear in the words of one interviewee:

At a certain point it became more important to solve specific problems presented by the associates. If this person needs a ramp in his house, the association will try [...] to solve that specific problem. If there is someone [...] who is looking for a job even if he is looking for self-employment, the association will try to find him something, almost all structures of the association will be devoted to solving a specific problem, that needs to be solved. But that leaves the organisation with no time for the big questions, questions that concern everyone [...]. The movement is, thus, very focused on solving specific problems. (Jorge, interview)

In sum, I argue that the lack of politicisation of disability in Portugal originates, precisely, at the intersection of the state's action and the organisations dependency, i.e. in the dynamics established between the state and the organisations of disabled people. From this stems other important individual and collective consequences, such as the maintenance of psychological, social and physical barriers to the integration and inclusion of disabled people in the different spheres of Portuguese society, and the creation of disabled people's dependency on benefits, both of which impacts on their life expectancies but also on their expectations of their representative organisations. Above all this has prevented the development of a disabled people's citizenship project.

It is also my contention that despite the state's attempt to create docile bodies (Foucault, 1991), there is always some core of resistance. In the final section I explore the issue of unity and fragmentation within the Portuguese Disabled People's Movement, and consider to what extent the movement has been able to resist the obstacles to its unification.

6.2.2. Unity within fragmentation?

As has been mentioned in previous chapters, the unity of the Portuguese Disabled People's Movement has been very frail. My argument is that this separateness mirrors not only a lack of politicisation of the Portuguese Disabled People's Movement, as was previously highlighted, but also a permanent leadership crisis. These facts have prevented the formation of a collective identity and a correspondingly strong alliance between the organisations, and they have amplified the process of differentiation within the movement.

To reiterate, contrary to its British counterpart, the Portuguese Disabled People's Movement did not develop a politicised understanding of disability, i.e. did not regularly engage with a hard action strategy which would question power relations within mainstream society. In the UK early internal dissent about poverty and the oppression approaches to disability led to a split and the formation of two distinct projects for the movement. The split also constituted a rejection of non-disabled experts speaking for disabled people and their colonisation of disability politics with the formation of the Disability Alliance (Campbell and Oliver, 1996, Oliver, 1996). In Portugal, for reasons analysed earlier, the movement embodied both approaches without problematising them and did not develop an awareness of the colonisation of the movement by non-disabled professionals. As Campbell and Oliver summarise for the British case:

By the 1970s there was major tension in the emerging movement between what might be called the incomes and the oppression approaches to disability. The DA [Disability Alliance] was formed to take forward the former, and UPIAS became a think-tank to develop the latter. (1996: 55)

The creation of UPIAS in 1972, with its politicised vision of disability, was crucial for the development of a political understanding of disability in the UK and, furthermore, for the focus and direction of the Disabled People's Movement. The publication in 1976 of its political manifesto – The Fundamental Principles of Disability – shaped disability policies and politics thereafter. As was analysed in Chapter 2, one of the biggest achievements of this document was introducing the distinction between impairment (i.e. biological) and disability (i.e. social). With this conceptual redefinition of disability, UPIAS transformed 'disability' into a socio-political issue (UPIAS, 1976),

revolutionising its theorisation through the creation of the Social Model of Disability and thus fostering a common ground for the development of the Disabled People's Movement in the UK.

In Portugal, dissent has also been at the roots of the movement since its inception as one of my interviewees, and a founding member of an organisation of disabled people, testifies:

We got to the 25 of April [1974] and XXX [organisation] emerged as a new type of organisation, with a new mentality, totally different from the existing organisations of disabled people. [...] Even before the 25 of April, when we analysed our situation, we were conscious that the existing organisations were serving the political regime more than disabled people. There was the XXX [organisation] that, in my perspective, did nothing before the 25 of April. And with our radical perspective at the time, we thought that there were only two solutions for this organisation: either to disappear or to overhaul itself completely after the 25 of April, because otherwise it would only [...] harm the work being done by other disabled people, it wouldn't help at all. (José, interview)

This dissent revealed itself when trying to reach solutions and directions for the movement:

XXX [organisation A] wanted to enforce the application of Law 6/61 [Law 6/71] that created the CPR, the Permanent Commission for Rehabilitation [...] which was a Commission, a discussion commission, and XXX [organisation A] thought that was OK, and that it would solve the existing problems. XXX [organisation B] thought it was wrong, and at the time was arguing for a Shadow-Ministry for Rehabilitation, headed by a member of the government, not a Commission which wouldn't solve anything. We wanted a state department. XXX [organisation A] continued to insist on that Commission, XXX [organisation B] had completely opposite thoughts. (José, interview)

The difference regarding the British case is that, despite the brief moments of unification at the end of the 1970s (Associação, 1978c, 1979), which culminated in the first National Congress of Disabled People in 1980 (Associação, 1980b), the Portuguese Disabled People's Movement never managed to define an internal focal point. In the UK this was achieved by the formation in 1981/1982 of the British Council of

Organisations of Disabled People (BCODP) (later British Council of Disabled People and United Kingdom's Disabled People's Council – UKDPC – since 2006). The BCODP became the visible face of the Disabled People's Movement in the UK onwards (Campbell and Oliver, 1996):

the BCODP became the formal organisational focus for a range of issues including critiques of state-based and voluntary-sector-based welfare, struggles for IL [independent living], campaigns against discrimination in all its forms, self-help, and challenges to the negative imagery and stereotypes with which disabled people constantly have to live. (1996: 80)

The action of the BCODP in connection with the Disabled Peoples' International (DPI) has had a remarkable impact on British society by challenging attitudes towards disability and disabled people, as well as advocating and making “disabled people proud of who they were” (Campbell and Oliver, 1996: 103). In addition, and in contrast to Portugal, as will be explored in Chapters 7 and 8, the movement in the UK also incorporated organisations devoted to developing a disability culture. This was the case with the Liberation Network of People with Disabilities, which was created at the end of the 1970s and of its magazine ‘In From The Cold’ (Sutherland, 2006).

In Portugal, despite the consensus generated during the preparation of the first National Congress of Disabled People in 1981 – in which the first disability umbrella organisation was created, the National Coordinating Commission of Disability Organisations (CCNOD) (later renamed UCNOD and more recently CNOD) – this apparent unity was shattered by ADFA. In fact ADFA pulled out just before the event took place (*ELO*, 1980a) and did not recognise CCNOD as the representative of the Disabled People's Movement accusing it of having connections with the Portuguese Communist Party and of attempting to control the movement politically (*ELO*, 1980a; 1982a; 1982b, 1982c; 1982d; 1984a; 1984b; 1984c; 1985a). Thus, CCNOD never managed to be the focal point of the movement. This meant that it was never possible to bring disabled people together, nor to give them a sense of collective identity beyond the daily specificities of their impairments, biographical narratives and institutional affiliations, as the BCODP did in the UK with the politicisation of disability.

In fact, as was analysed above, CNOD never presented a space of collective action and collective demanding for the Portuguese Disabled People's Movement, to the same extent that the BCODP did in the UK (Campbell and Oliver, 1996).

According to Butler (1988, 1990, 1993), the existence of an identity category is dependent on two factors: the identification of an opposite through which an identity acquires a sense of existence and the public repetition of those elements that allegedly constitute that identity (performativity). In the case of the Portuguese organisations of disabled people, it is interesting to note the absence of a single and shared identity category. My analysis reveals the existence of a diverse range of opposites through which impairment specific and collective specific identities constitute themselves. If for some organisations the opposite is the government and its policies, which is the case for APD and CNOD, for others, like ANDST, the opposite is the insurance companies (which are responsible for paying benefits to people impaired at work), while it is the colonial war for ADFA, the previous organisations of blind people for ACAPO, and the 'hearing society' for APS. Hence, except for APD and CNOD, the movement does not share opposites, as happened in the UK where non-disabled professionals, disabling society and its barriers were elected as such. Therefore, these impairment specific and collective specific identities take precedence over the possibility of a collective identity.

In the absence of those unifying elements advanced by Butler (1988, 1990, 1993), there has been an emergence of basic channels of solidarity and identification (Melucci, 1989), such as impairment, biographical history or organisational belonging. This process was described by Parsons (1975) as the need for 'de-differentiation', i.e., the need for the development of a specific collective identity by particular groups that form a more complex unity. This phenomenon emerges in my interviews in the need to respect impairment specificities and in the creation of exclusionary categories of impairments within the organisations:

Of course the more united, the stronger we are, but a global movement would have to respect specificities which doesn't happen currently [...] Because the blind have specific problems. (André, interview)

A deaf person has his/her own deaf identity, his/her own culture and his/her own social and communicational specificities, face-to-face communication, the way we eat, the knock on the table with the palm of the hand to say 'enjoy your meal', the

waving. There are specificities that are connected with the deaf culture, and the identity is there. (Raul, interview)

Therefore, the characteristics and achievements of the Portuguese Disabled People's Movement partly result from the limited development of a collective identity among disabled people. This has left its mark on the history of the movement and can still be seen today. One clear mark is the constant difficulty faced by the organisations to mobilise disabled people for collective action, particularly after the heated post-revolutionary years had passed:

It is extremely difficult to mobilise members. [...] There is a sense of frustration, great disillusionment that leads people to avoid participating. [...] There is a group of people who remain active, who participate. Others don't, they come here because they need to solve a specific issue. (Jorge, interview)

Disabled people, as an organised force that should proceed as a bloc... but no! They go to where their family members or friends go. Then there are a few wheelchairs [in the middle of a demonstration] and they are always the same people, the same people who show up with their banners (Alberto, interview)

These processes have hindered any attempt to achieve a unified movement, granting it, instead, its current patchy status. This fact confirms Melucci's idea that a social movement is not a unified 'subject "but always a composite action system" (1989: 28) where everything needs to be continuously negotiated and adjusted. This also means, as the author singles out, that unity might never be a reality and that there is always a plurality of possible meanings within collective action and within a social movement. In the case of the Portuguese Disabled People's Movement I argue that unity has come in an episodic and time limited format. Regardless of the existing fragmentation, the organisations have been able to set aside their disputes to support each other and to create the much-needed unity at specific moments in time based on particular goals:

We need to highlight some positive aspects. The common fight that we had related to tax benefits, was very interesting to see APD, ACAPO, CNOD, ADFA, ASBIB, the Impaired at work [ANDST], [...] fighting together for the same cause. [...] I'm talking about one [demonstration] we organised in front of the Assembly of the Republic [Portuguese Parliament]. (Daniel, interview)

Another example of this is the formation of the Commission for the Recognition of Portuguese Sign Language in 1995, a platform created by the Portuguese organisations of deaf people to focus on a single issue and which melted away after it had achieved its purpose in 1997. More recently, the creation of the Movement of the Impaired Workers in Defence of Tax Benefits (MTPD-DF) in 1997, signalled another moment of unity within the Disabled People's Movement. In contrast to the previous platform that formally gathered the different organisations of deaf people together, this movement, despite being formed by people from different organisations, worked as an alternative space separate from other organisations.

Conclusion

To conclude, the Portuguese Disabled People's Movement emerged in the post-revolutionary period. Parallel to the British case, the emergence of the Disabled People's Movement stems from the long standing exclusion of disabled people from the citizenship project. Therefore, in order to participate in the definition of their future and to make their voices heard at the political level disabled people had no alternative than to associate in organisations of disabled people. As analysed throughout this chapter, the Portuguese Disabled People's Movement shows three major differences from its British counterpart, which account for the distinct paths and demands put forward by disabled people in both countries and consequently for the different solutions adopted. Firstly, and in contrast to the UK case, the Portuguese Movement did not coalesce into a single organisation and did not develop a coherent political strategy or a socio-political understanding of disability. As was argued, the Portuguese Disabled People's Movement stems from wider social and political processes that characterise Portuguese society as a whole. Secondly, the Portuguese Disabled People's Movement lacked an academic arm capable of feeding the movement with theoretical thinking, suggesting new directions and providing the necessary evidence for political change. Thirdly, the Portuguese Disabled People's Movement focused on rehabilitation rather than on controlling services as was the case in the UK.

I have demonstrated that this lack of engagement with the social model of disability was one of the most striking features of the Portuguese Disabled People's Movement. This socio-political understanding of disability was replaced by a counter-narrative of

disability. Despite the centrality of the body in this newly crafted counter-narrative, it represented an alternative vision of disabled people in Portuguese society based on the ideas of rehabilitation and aptitude to work from which much of the movement stemmed.

This political and ideological standpoint had a direct impact on the type of demands and strategies taken by the Portuguese Disabled People's Movement, visible in its use of a soft action strategy and in the primacy of first level demands, and consequently, in the characteristics of the disabled people's social citizenship project in Portugal which was analysed in Chapter 5. The lack of politicisation of disability in Portugal is largely accountable for the movement's frail collective identity. This, however, did not prevent the movement from having an impact upon Portuguese society as will be analysed in the following chapter.

7. Balancing the movement: influences and impacts of the Disabled People's Movement in Portugal

Introduction

The historical relationship between capitalism and citizenship has been fraught and turbulent. Hoffman (2004: 79) has phrased it in the most direct way, when he says “Capitalism, as a system, has a contradictory relationship to citizenship”. In fact, this political and economic system, dominant in western democracies, feeds itself on the freedom and equality entailed by the notion of citizenship, despite constituting at the same time a limit to the realisation of equality itself. As was analysed in Chapter 2, the influential theorisation of citizenship proposed by Marshall (1950) was based on the rather optimistic belief that a compromise between capitalism and citizenship was possible. Recent developments, enacted by the acceleration of the processes of economic, financial and political globalisation, question that belief. The great pressure exercised by liberal-capitalism over welfare states eroded social rights and transformed social policies towards a greater emphasis on individual responsibility, with a concurrent decline in welfare-rights (Dwyer, 1998, 2002, 2004a, 2004b; Taylor-Gooby, 2009). An example of this is the way benefit recipients and claimants have been demonised and pushed into work by third way politics and policies in the UK (Giddens, 1998; Dwyer, 2002, 2004b; Prideaux, 2005) and by activation policies in Portugal (Matos and Hespanha, 2000; Hespanha, 2007).

Therefore, as Hoffman suggests:

The process of deepening and broadening citizenship requires continuous inroads into the logic of capitalism so that the system is gradually and increasingly transformed. (2004: 80)

This task has been accomplished by different social movements around the world, including the Disabled People's Movement.

Drawing on the analysis provided in the previous chapters, this Chapter considers the growing influence of external actors and documents in disability issues in Portugal and

offers a critical evaluation of the Portuguese Disabled People's Movement's achievements.

7.1. Disability policies in an era of globalisation, Europeanisation and Human Rights

Global interconnections can be traced back to the sixteenth century with the economic expansion of most European countries including Portugal. This process, however, accelerated after the end of the Second World War with the rapid growth of international organisations (Held, 2006). This development, commonly referred to as globalisation, encompasses the increasing “growth of world unity [...] [and] the reordering of time and distance in social life” (Giddens, 1993: 528). Even Portugal, dominated by a dictatorial regime for most of the twentieth century, could not stay isolated from this process and joined the European Free Trade Association (EFTA) in 1959 (Barreto, 2003).

This process became more evident in Portugal with its accession to the European Economic Community (EEC) in 1986. The deepening of international and regional integration at political and social levels also meant that many rights acquired a supranational character and that countries could influence one another more directly. Nevertheless, as Taylor-Gooby stresses, globalisation also has:

Implications for the authority of governments over national economies, and consequently, their capacity to resist market imperatives and pursue independent welfare policies. (2009: 20)

Portugal is not an outsider to this process. As was signalled in Chapter 5, the development of the Portuguese welfare state after 1974 was curtailed by the international economic crisis of the 1970s and by the economic imperatives of joining the EEC. All these factors led to a retrenchment of the Portuguese Welfare-state in 1980 (Hespanha *et al.*, 2000) (see Chapter 5).

Globalisation also represented an opportunity for the development of an international Disabled People's Movement. Disabled people could therefore unite globally to influence key western international actors such as the United Nations (UN) and the European Union (EU). In fact, the growing interest of organisations such as the UN and,

later, the EU transformed disability in global and regional issues through issuing appropriate recommendations, declarations and directives (Oorschot and Hvinden, 2001; Priestley, 2007). This also meant that these institutions gained increasing power in these areas, setting the standards and ways of action for the different nation states. This section considers external agents, actions or acts that might have influenced disability policies and politics in Portugal. Firstly, it contextualises disability within supranational bodies like the UN, the EU and the OECD (Organisation for Economic Co-operation and Development). Secondly, it looks at the internationalisation of the Disabled People's Movement and of disability politics. Finally, it considers the challenges and opportunities offered by these changes to the Portuguese Disabled People's Movement and analyses the impact they have had on national disability policies and politics.

7.1.1. The framing of disability policies in an international context

As was analysed in Chapter 6, by the 1960s there was a groundswell of action in the field of disability and of opposition to traditional assumptions about disability. At the heart of this was a rise in the number of organisations of disabled people in countries like the UK, the USA and Sweden (Driedger, 1989; Campbell and Oliver, 1996; Fleischer and Zames, 2001) and the pioneering civil rights movement and the women's movement (Barnes and Mercer, 2010). The development of a Disabled People's Movement at national and, later, at international levels prompted a growing interest in disability issues by supranational bodies like the UN and the EU. From an invisible topic, disability emerged in the 1970s as a new field of political intervention at both the national and international level.

Given the economic and single market focus of EEC (current EU), the UN took the first step in the area of disability at this supranational level with the approval of the Declaration on the Rights of Mentally Retarded Persons in 1971 (Resolution 2856 - XXVI), followed shortly by the Declaration on the Rights of Disabled Persons (Resolution 3447 (XXX)) in 1975. 1981 was declared International Year of Disabled Persons (Resolution 31/123) by the UN, at the end of which it created a World Programme of Action Concerning Disabled Persons (Resolution 37/52) defining a global strategy for impairment prevention, rehabilitation, equal opportunities and social

participation of disabled people. In order to allocate time for states to implement this Programme, the UN declared 1983-1992 as the United Nations Decade of Disabled Persons (Resolution 37/52). In 1989 the UN adopted the Tallinn Guidelines for Action on Human Resources Development in the Field of Disability (Resolution 38/28) in the area of education and employment. In 1991 it created the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (Resolution, 46/119). 1992 was the year in which the 3 of December was declared the International Day of Disabled People (Resolution, 47/3) (changed in 2007 to International Day of Persons with Disabilities – Resolution 62/127). In 1993, at the end of the United Nations Decade of Disabled Persons, the UN approved the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Resolution 48/96). In 2002, the UN proclaimed the period between 2003 and 2012 as the Arab Decade of Disabled Persons, and the same period was chosen to celebrate the Asian and Pacific Decade of Disabled Persons and the African Decade of Disabled Persons. The continuing involvement of the UN in the area of disability culminated in the approval in 2006 of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol (Resolution 61/106).

This series of measures highlights the significant involvement of the UN in the area of disability over the years. The approval, first, of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities and, more recently, of the Convention on the Rights of Persons with Disabilities evidences the UN's deep involvement in the rights of disabled people across the globe and its attempt to influence and engage nation states to respect those rights.

The EEC entered the disability field in the mid 1970s. In 1974 the Council of Ministers of the EEC adopted a Social Action Programme (Council Resolution adopted on 21 of January 1974) with a number of objectives to be achieved in the period 1974-1976, including seven immediate actions to be taken by the Council:

1. Assistance of the Article 4 of the Social Fund for migrant and handicapped workers;
 2. an action programme for handicapped workers in an open market economy; [...]
- (Commission of the European Communities, 1974; 1)

This declaration of intentions was accomplished with the establishment of the Community Action Programme for the Vocational Rehabilitation of Handicapped

Persons (Council Resolution of 27 June 1974). In consonance with the UN's measures, at the European level there were also signs of a deep engagement with disability issues with the formation in 1981 of a division within the EEC for the economic, social and cultural integration of disabled people and the adoption of multi-annual action programmes on disability. The 1st Community Action Programme on the Social Integration of Handicapped People was launched in 1983 (1983-1988) (Council Resolution of 21 December 1981) (Commission of the European Communities, 1992; Mourão-Ferreira, no date). In 1988 the 2nd Action Programme for the period 1988 – 1991 (Council Decision 88/231/EEC of 18 April 1988) was launched under the title 'Handicapped People in the European Community Living Independently in an Open Society', generally known as HELIOS. This programme maintained most of the activities of its predecessor (mainly focused on work and employment) but supplemented them with a new issue – independent living. The third and last Action Programme was launched in 1993 (Council Decision 93/136/EEC of 25 February 1993), generally known as HELIOS II. Meanwhile, a Recommendation on the Employment of Disabled People in the European Community was issued in 1986 (Council Recommendation 86/379/EEC of 24 of July 1986) and in 1993 the 1st European Parliament of Disabled People was organised. The Amsterdam Treaty, in 1997, was another crucial step away from the typical issue of employment and work of disabled people and towards the area of discrimination. It included a new Article 13 which provided measures to combat discrimination based on several grounds, namely on disability. As Priestley (2007: 67) acknowledges:

Treaty recognition was a landmark achievement, establishing disabled people's claims to full participation and equality as a legitimate concern of the European legislature.

In 2000, the EU took further measures to protect disabled people from discrimination by approving a Directive prohibiting discrimination in employment on grounds of disability as well as age, religion, belief and sexual orientation (Council Directive of 27 November 2000) (EU countries were required to incorporate it into national law by the end of 2003 or, due to cultural issues, by the end of 2006). The EU also declared 2003 as the European Year of People with Disabilities (Resolution 2001/903/CE of 3 of December 2001), to commemorate the tenth anniversary of the UN approval of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

Despite the increasing legitimacy given by the participation of these international bodies in the struggle of disabled people and its framing as an human rights' issue (Oorschot and Hvinden, 2001), this also signals the affirmation of a 'rights' or idealist vision of the social model of disability at national and international levels (Sheldon, 2005). Arguably this approach, as was analysed in Chapter 2, focuses on the elimination of prejudice and other deep-rooted disabling attitudes in our culture, without challenging the roots of disabled people's oppression, i.e. the capitalist system (Finkelstein, 1980; Oliver, 1990; Sheldon, 2005). This represented, however, only a minor revolution with little impact on the lives of disabled people, as the recent 'World Report on Disability' (WHO, 2011) and the Portuguese case reveals. In a world dominated by a capitalist mode of production, the attribution of rights is not enough to eradicate the exclusionary nature of citizenship, because their enforcement continues to be compromised by the capitalist system. My analysis of the Portuguese case is illustrative of this reality. As it highlights, until recently the UN's and the EU's disability policies had limited impact in Portugal. More precisely, only after 2006 did the influence of these supranational bodies impact structurally on Portuguese disability policies and politics. This does not mean that previous initiatives and documents approved by these supranational bodies had no resonance in Portugal. On the contrary, they were often transposed to the national level, but their implementation compromised many of their original principles and philosophies. This is obvious in an opinion piece published in 1999 by an activist in the APD's newspaper in relation to the (at the time) recently created CNRIPD:

Despite the progress, the current Council [CNRIPD] does not respect the principles defined by the Harare Declaration [on Legislation of Opportunities for Disabled People - DPI] or even those inscribed in the equal opportunities rules [Standard Rules on the Equalization of Opportunities for Persons with Disabilities] approved by the [...] United Nations. (Cardoso, 1999: 7)

Another clear example was the celebration of the International Year for Disabled Persons in 1981, which was compromised by its inefficient preparation, delayed beginning, by the lack of participation of organisations of disabled people and by the low level of achievements. This led APD and ANSDT to withdraw from the national organising committee that had been defined by the state (Associação, 1981a, 1981b; ELO, 1981c, 1981e). A similar argument could be made in relation to the impact of the Salamanca Statement and Framework for Action on Special Needs. Despite its rapid transposition into Portuguese legislation, it was undermined by structural problems in

the Portuguese Education System (Associação, 1999a; Fontes, 2006), as was explained in Chapter 5. The same scenario occurred in 1981 with the International Year for Disabled Persons, and also emerged in 2003 with the celebration of the European Year of People with Disabilities (JDD, 2002, 2003; Associação, 2003a, 2003b, 2003c, 2004c).

Three reasons may account for the limited impact of the UN and the EU's documents on Portuguese disability policies. At first, the implementation of the European Disability Policy was based on 'soft' mechanisms of policy transfer, i.e. non-binding legal documents such as declarations, guidance notes and recommendations (Prideaux, 2006; Priestley, 2007). In the cases where 'hard' mechanisms were used, they were softened by the call for subsidiarity as the guiding principle thus rendering them noncompulsory (Priestley, 2007). Secondly, none of these documents were accompanied by an allocation of financial resources at the international levels. The pressure this might put on welfare states rendered them inefficient. This is obvious in the changes introduced to disability policy at the EU level. As Priestley (2007) highlights, there was an evolution from a perspective based on care, rehabilitation and compensation, which, of course, involved the allocation of economic resources, to one based on human rights, citizenship, participation and inclusion, which apparently puts less pressure on welfare-states. This change in strategy was achieved by the 1997 Amsterdam Treaty, which directed EU disability policy towards combating discrimination on different grounds, including disability (Hvinden, 2003). Finally, their low level of impact also stems from the action characteristics of the Portuguese state, which I outlined previously. As was seen in Chapter 5, the Portuguese state is renowned for its politics of self-subversion (Santos, 1990, 1993), which has limited the practical impact of any of the previously identified measures adopted in Portugal.

Nevertheless, 2006 represented a turning point. The publication of disability anti-discrimination legislation (Law 46/2006, 28/08/2006) and of the 1st National Plan for the Integration of People with Disabilities or Impairments (PAIPDI) (see Chapter 5) marked a shift in national disability policy towards the disability policy proposed by the EU and the UN. However, as happened in most EU countries, such convergence at the EU level was only verifiable within this newly adopted field of 'regulation' (Hvinden, 2003), i.e. anti-discrimination legislation, inclusion and removal of physical barriers. At the level of redistribution (Hvinden, 2003), i.e. social security, employment and care provision, the national disability policies showed no sign of convergence.

7.1.2. The internationalisation of the Disabled People's Movement and of disability politics

By the end of the 1960s, disabled people, like other socially oppressed groups, started to develop a political consciousness and to organise collectively. This political mobilisation spilt over from the national to the international level creating an international Disabled People's Movement. Organisations like Disabled Peoples' International (DPI) or the European Disability Forum (EDF) took form and became important actors in the definition of disability policies and politics at the national and international levels. These newly emergent international organisations of disabled people were different from their predecessors – such as the *Fédération Internationale des Mutilés, des Invalides du Travail et des Invalides Civil (FIMITIC)* founded in 1951 or other international impairment specific organisations like the International Federation of the Blind (IFB) formed in 1964, the World Council for the Welfare of the Blind (WCWB) formed in 1949 (united in 1984 in the World Blind Union - WBU) or the World Federation of the Deaf (WFD) created in 1951 (Diedger, 1989) – in their non-single impairment focus and in their political approach.

In fact, DPI is an international multi-impairment umbrella organisation for organisations of disabled people, formed by disability activists in 1981. It emerged from Rehabilitation International (RI) – an organisation of professionals and experts founded in 1922 – at the World Congress of RI in Winnipeg, Canada (Driedger, 1989). It was initially called World Coalition of Persons with Disabilities (WCPD) (Driedger, 1989). Its current name was voted in 1981 during its first world congress, held in Singapore, which recorded the presence of 400 disabled people representing 51 countries from around the world (Driedger, 1989: 51; Barnes, Mercer and Shakespeare, 2000: 170). Soon after its formation, DPI obtained consultative status in the UN and, since then, has worked closely with it (DPI Europe, 2010).

Portugal has been represented in DPI by APD since 1981, having a seat on DPI's World Council and on DPI's European Regional Assembly (APD, 1997; Associação, 1997d). APD is an active member of DPI, participating in its activities and meetings around the world (Associação, 1986b, 1988c, 1993, 1999b, 2004d), as well as contributing members to its managing boards (Associação, 1988a, 1991b, 1999b, 2005) and, in 1988, APD hosted the DPI's European Regional Assembly in Lisbon together with an international seminar (Associação, 1988b). APD has been the 'voice' and 'arm' of DPI

in Portugal, disseminating DPI's statements and executing its campaigns, alongside organising demonstrations, sit-ins, and sensitisation events in accordance with DPI's requests (Associação, 1992b, 1992c, 1994c, 1997e, 2001).

At the European level, in 1996 the European Disability Forum (EDF) was created. EDF is a lobby-driven disability rights organisation working as a platform for discussion and political lobbying for the rights and needs of disabled people in Europe at the EU level. The EDF is formed by a network of national councils of disabled people (27 councils from different EU member states plus Norway and Iceland) and by a network of European disability NGO's, representing over 50 million of people (EDF, 2010). Portugal is represented in the EDF by CNOD, which brings most of the EDF's campaigns to Portuguese territory.

This scenario is repeated with single-impairment organisations like APS, and ACAPO, which both developed close connections with their international counterparts like the WFD, the WBU and the European Blind Union, as well as with single-focus disabled peoples organisations like ANDST or ADFA. ADFA is the national representative on the International Federation of Persons with Physical Disability (FIMITIC) and ADFA represents Portugal on the World Veterans Federation. The national impact of the connections between these Portuguese organisations and their international counterparts is, however, less visible due to APS and ACAPO's limited political activity in the area of disability.

The Portuguese Disabled People's Movement is, thus, closely connected to the International Disabled People's Movement, bringing in many of the debates taking place elsewhere and participating in events featuring current disability policies and politics at the international level (Associação 1986c, 1991, 1997d, 2004d). An example of this is the fact that the CNOD's weekly newsletter regularly includes a section disseminating events and demands put forward by the EDF. Accordingly, disability policies in Portugal result from a symbiotic relationship between national and international forces, particularly supranational bodies like the UN and the EU, nation states and national and international Disabled People's Movements. An example of this is the approval of disability anti-discrimination legislation in Portugal (Law 46/2006, 28/08/2006). In fact, despite anti-discrimination legislation having been demanded by the Portuguese Disabled People's Movement since 1994 (Associação, 1994b), as a result of international influence – DPI and EDF (Associação, 1988b) –, it was finally

adopted at national level in 2006, but only after the Portuguese state was pushed by the EU (e.g. Directive 2000/43/EC of 29 June 2000 and Directive 2000/78/EC of 27 November 2000). In sum, it was these symbiotic relations forged across different settings and at different levels that created the environmental conditions for channelling the changes demanded by the Disabled People's Movement. The next section will consider the impact of the Portuguese Disabled People's Movement.

7.2. The Portuguese Disabled People's Movement as an agent of change

The Portuguese Disabled People's Movement has been the driving force behind many changes concerning disability issues and disabled people in Portugal, by raising awareness and drawing public attention to disability issues at the national level. It is my argument, however, that the internationalisation of disability issues and the affirmation of a rights-based approach to disability (Sheldon, 2005) has redirected the movement's agenda towards legalistic strategies, as was seen in Chapter 6, and has focused the movement's demands on rights, whilst disregarding structural change (i.e. tackling oppression). The consequences of these strategies have had a great impact on the outcomes of the Portuguese Disabled People's Movement and consequently on the disabled people's citizenship project. This section will consider three areas of impact: policies and politics, living conditions of disabled people and culture.

7.2.1. Political impacts of the Portuguese Disabled People's Movement

As was seen in Chapter 6, the state, and legal change, have been the focus of most of the Disabled People's Movement's strategies of action. Since its beginnings, the movement has attempted to influence disability policies and politics by mobilising resources, advancing new ways of thinking and proposing alternative solutions.

In order to grasp the political impact of the Portuguese Disabled People's Movement and drawing on the different conceptualisations of political impact explored in Chapter 2, I developed the following strategy: firstly, I compared the agendas of the movement set out by national congresses and meetings of disabled people with the programmes of the government presented at the beginning of each term of office; secondly, I contrasted this initial analysis with the state's 'disability action repertoire', i.e., the state's

performance in the publication and implementation of disability and impairment specific legislation and initiatives; and, thirdly, I compared the state's 'disability action repertoire' with documents produced and distributed by organisations of disabled people and with the testimonies of disabled people gathered in my interviews and from other publications of the movement.

This analysis reveals that the political impact of the Portuguese Disabled People's Movement has been diverse and has changed considerably over time in terms of the type of consequences, levels of access to the state and the depth of the impact. Evidence suggests two major trends in the political impact the movement. The first trend, here referred to as the 'period of responsiveness', spans from the emergence of organisations of disabled people until the end of the 1970s, and is characterised by a high level of access to the state and by the structural impact it had on the government's disability politics and policies. A second trend, which is still pervasive today, is referred to here as the 'period of detachment', and is characterised by low levels of access to political power and by a low level of political impact.

During the 1970s, the new alliances formed between the main organisations of disabled people, the extensive use of direct action (see Chapter 6) combined with the dominance of centre-left wing governments and all framed by the politically unstable situation (Reis, 1996), made the Portuguese state particularly permeable to the claims of the Disabled People's Movement. A clear example is the publication of Law-Decree 43/76 (20/01/1976), which granted social rights and benefits to impaired war veterans. As was analysed in Chapter 6, ADFA was extremely active in the period preceding the publication of this law. It was the pressure exercised by this organisation of disabled people that enabled the creation of the DFAs' legal project and that later pushed its publication. As José recalls:

We blocked bridges and roads, we invaded the national broadcasting radio station, we abducted the government in S. Bento [the parliament], the Prime Minister and the ministers were locked inside without being able to leave the building! (José, interview)

This was, however, a unique moment in Portuguese history during which the political power was still vulnerable to external actions and influences. It is, thus, not surprising that the civilian sector of the Disabled People's Movement had to wait for almost four

years to acquire some of the social rights granted to the impaired war veterans in 1976. This sector, which at the time was quieter and less radical in its actions, posed no threat to the political stability of the new regime. The permeability of the period allowed, however, the movement to exert its influence at the structural level. An example of the high level of impact achieved by the Disabled People's Movement at the time is the 1976 Portuguese Constitution, which included an article (71st) dedicated entirely to disabled people, as was shown in Chapter 5. Another example is the creation of the National Secretariat for Rehabilitation and the National Council for Rehabilitation.

Despite not being accountable to disabled people, these two bodies, both formed in 1977, were the result of the movement's demands for a national body to coordinate disability policies and politics in Portugal and to allow them to participate in the development of these policies. In addition, by the end of this period, disabled people had a basic but universal network of social welfare benefits and services (see Chapter 5), and even succeeded in passing the first special educational law (Law 66/79, 4/10/1979), which would, however, never be implemented.

By the beginning of the 1980s, the economic crisis of the 1970s, the growing political stability of the new regime, the preparations for joining the European Economic Community (currently the EU) and the political victory of centre-right-wing parties to form a government turned the tide against the movement, reducing its political influence, a situation which remains today. This was the beginning of the 'period of detachment'. This period spans from 1980 until today. In fact, political change in Portugal after the 1980s had little impact on disability politics. Despite this long period and the different political cycles we see within it, this time is characterised by the creation and maintenance of barriers to prevent the Disabled People's Movement from exerting a powerful political influence over disability politics and policies. These barriers range from the financial asphyxia of organisations like APD, which was analysed in chapter 6 (Associação, 1986b, 1991c, 1994a), the division of the movement by triggering fierce competition for scarce financial resources without clear criteria (ELO, 1984e, Associação, 1994a) and the restructuring of public bodies in order to block the political participation of the movement.

In a movement similar to the one observed in the UK following the arrival of the Conservatives to power in 1979, in Portugal a succession of centre-right wing governments initiated a new trend in disability politics and policies. Since then the

existing social rights of disabled people have been seized by the state and the role played by organisations of disabled people in designing disability policies and politics has been limited. One of the first measures adopted in this new period was the removal of the decision-making power of and the demotion of the National Secretariat for Rehabilitation and the National Council for Rehabilitation to consultancy bodies (Law-Decree 574/80, 6/9/1980). These same restrictions still apply today. Despite the multiple reforms undergone by these public bodies (Law-Decree 355/82, 6/9/1982; Law-Decree 184/92, 22/08/1992; Law-Decree 35/96, 2/05/1996; Law-Decree 217/2007, 29/05/2007), their political power within the structure of government was kept to a minimum, rendering the influence of organisations of disabled people in the political system as almost nil and making it extremely hard to air their political views (Elo, 1985b, 1985c, 1985d, 1987b; Associação, 1982, 1992d, 1997c, 2007b). In the 1990s there was a resurgence of these structures but they never achieved the same level of influence as they did in the 1970s (Associação, 1997b, 1997c), as one of my interviewees signals:

It has no practical impact. [...] We were always against the composition of the National Council for Rehabilitation [...] because [...] it has, since the beginning a wider representation of governmental bodies [...], a group of entities which may have some connection, but that do not represent disabled people. This has meant that we have always had limited space and huge difficulty in influencing positively the decisions that come out of that Council. (Daniel, interview)

To reiterate, the political impact of the movement was reduced and limited to minor level changes related to benefits and/or to specific rights for specific groups of disabled people. During this period several ‘transformative laws’ (Krieger, 2003) were also published, with potential structural impact. However, most of them had no impact at all, rendering the political influence of the movement unfruitful in practical terms. Several examples may be offered: the first one is the publication of Law-Decree 43/82 (08/02/1982), which was intended to eliminate physical barriers in new-buildings, the second is the publication of the core law for the rehabilitation and integration of disabled people into society (Law 9/89 02/05/1989) and, most recent, is the publication of disability discrimination legislation (Law 46/2006, 28/08/2006). These documents, which were supposed to produce structural effects, were, however, transformed into ‘captured laws’ (Krieger, 2003). As was analysed in Chapter 5, the first two documents were never implemented and, contrary to the expectations of the Portuguese

organisations of disabled people, who had campaigned and lobbied for the publication of disability anti-discrimination legislation at least since 1994 (Associação, 1994b), the impact of the third document has also been very limited. In 2007 only 37 complaints of discrimination were received, out of which only one was followed through (INR, 2008: 19). In 2008 the new piece of legislation generated only thirteen complaints out of which there were no convictions (INR, 2009: 12). Arguably, one reason for this, as is the case with Britain's 1995 Disability Discrimination Act (Roulstone, 2003; Roulstone and Warren, 2006), is the reactive, rather than proactive, nature of this legislation. In fact the Portuguese Disability Anti-discrimination legislation only defines which practices should be considered discriminatory, the compensation due to the claimant and the applicable penalties to the defendant, the role of the organisations of disabled people and the role of the SNRIPD in monitoring the application of the law. What is missing here, however, is a definition of what is meant by disability, any proactive measures for promoting non-discriminatory practices, as well as 'barriers monitoring' (Roulstone and Warren, 2006) of disabled people in order to identify what limits disabled people.

Nevertheless, the government did not face fierce opposition from the Disabled People's Movement. In fact, as was analysed in Chapter 6, during the 1980s and the post-1980s period a fracture emerged within the Disabled People's Movement, which resulted in the isolation of organisations of disabled people and the loss of their political influence.

In the UK, despite arguments suggesting that it had lost both its path and steam since the 1990s (Oliver and Barnes, 2006), the Disabled People's Movement has, in fact, become more politically influential in this period. Indeed, the formation of BCODP in 1981 (renamed the United Kingdom's Disabled People's Council – UKDPC – in 2006) signalled the politicisation of disability issues (Oliver and Barnes, 1998), the unification of organisations of disabled people and the formation of a strong and politically influential movement, presenting “a significant alternative to mainstream approaches, and [...] an increasing influence on politicians, policy-makers and the population at large.” (Barnes and Mercer, 2010: 157). In Portugal the Disabled People's Movement never offered a significant alternative to the state's perspective. The lack of radicalism in its political message and actions prevented it from gaining the level of political influence achieved by the British movement. In fact, as my analysis shows, the Portuguese movement's demands have been dominated by calls for rehabilitation and disability specific social rights and its actions have mirrored this political perspective by

favouring lobbying and other traditional action strategies. There is no Portuguese equivalent to the radical perspective of groups such as the UK's Direct Action Network (DAN). This disability group, formed in 1992 (Oliver and Barnes, 2006), represented the best example of the politicisation of disabled people in the UK and their 'increasing self-confidence' (Oliver and Barnes, 2006). DAN performed a rally of mass demonstrations in the first half of the 1990s, which was central in gaining approval for the anti-discrimination legislation in the UK (which was finally achieved with the 1995 Disability Discrimination Act). Its action repertoire included other forms of radical direct action, namely the 1997 episode of red paint being thrown at the Prime Minister's front door, which represented the blood of disabled people, as a protest against the government's plans to reduce expenditure on Incapacity Benefit (Oliver and Barnes, 2006).

Despite the differences between the British and Portuguese Disabled People's Movements in terms of their impact, action strategies and disability politics, it is my contention that the action of the Portuguese movement has had two main political consequences in the area of disability.

The first political consequence was the state's acknowledgement of disability as a valid political subject and its recognition of disabled people as political actors. The action of disabled people after the 1974 revolution brought disability to the fore. Disability issues became part of the political agenda of the government and of the political parties with parliamentary representation. An analysis of the programmes of the constitutional governments (after 1976) evidences disability as a political issue. The first constitutional government (1976-1978), for example, devoted an entire section of its programme to the rehabilitation of disabled people:

1. The marginalisation of disabled people is a consequence of the anti-social policy that victimised the Portuguese population in general. Over five decades, disabled people suffered an array of assaults which were due to economic reasons, or to social, political and psychological ones, which explains the existing number of disabled people, which is estimated in the hundreds of thousands. This reality, which has been ignored until today, will not be ignored anymore and the government will face this problem with the required amount of determination and rigour. (Programme of the 1st Constitutional Government 1976-1978: 122)

Despite its focus on rehabilitation, a major improvement for the time, this denotes an acknowledgement of disabled people's claims and the political impact of their actions. Thereafter, despite its political trivialisation, disability became an ever present topic in the government's agendas, and was disputed by the different political parties.

If disability was widely represented in the governments' programmes during the 1970s, it became a marginal issue during the 1980s, being addressed only sporadically and, when it was, this mostly focused on benefits and/or service provision, only returning to strength in the 1990s and 2000s. It is interesting to note that the dormant political status of disability issues during the 1980s and the early 1990s corresponds to the passage from a phase of strong influence of the movement over the governmental agenda to a new phase in which the influence of international agencies, became more evident, which again reinforces the argument that this rights-based approach to disability has had little impact on the lives of disabled people.

Another example of the transformation of disability into a political issue was the colonisation of the movement and of organisations of disabled people by political parties. As it is widely documented by my interviewees, political parties remain at the core of the Portuguese Disabled People's Movement:

The people who make up the management of the organisation usually have some kind of connection to the political sector, which sooner or later will win this. I mean, [...] the debate [within the organisation] is dominated more by political-party issues than by what interests people, each person's own interests. At the organisation everybody has the same interests, but sometimes that... [...]

This depends mainly on the capacity for discussion, the capacity to get people together [...] sometimes it is possible, even whilst knowing that there are people belonging to the PS [Socialist Party], to the PC [the Communist Party] or to the MRPP [the Portuguese Workers' Communist Party]. They are all there and everybody is more or less identified, aren't they?! (Armando, interview)

The political parties, especially the Communist Party, found in the Disabled People's Movement an opportunity for political action. This process of colonisation, backstage in-fighting and the political parties influence on the Disabled People's Movement has resulted, I argue, in the neutralisation of the movement by the political powers. In fact, the association of the movement, or of parts of it, with certain political parties is used by

the state as a reason to reduce the credibility of the movement and thus ignore its demands.

Through the political recognition of disability, disabled people also came to be acknowledged by the state as political actors fighting for their rights. In fact, from the outset disabled people negotiated with the state over disability issues and organised direct actions, which enhanced their status as political actors fighting for a cause. This process of political recognition is yet another point of difference between the Portuguese and the British cases. In Portugal, the incidence of leaders of organisations of disabled people being incorporated into mainstream politics is negligible, with very few being appointed to government organisations. Instead, the leading positions within these bodies have been occupied mostly by non-disabled politicians. Conversely, in the UK, despite the constraints to becoming active members in political parties (Barnes and Mercer, 2010), the risk of incorporation is higher, with the related danger of leaders of the Disabled People's Movement being co-opted into mainstream political parties and with the concomitant normalisation of the movement's politics by the government (Barnes and Mercer, 2001, 2010; Oliver and Barnes, 2006; Oliver, 2008). In Portugal disabled people's access to power has been constantly denied, as one interviewee testifies anecdotally:

During the European Year [of People with Disabilities] we delivered a petition to parliament [...] in which we questioned issues of representation. [...] Why is it that in parliament, in the Lawyers' Association, etc. there are no disabled people? [...] When we handed in the petition with the signatures to XXXX [name of the president of parliament], we asked him how many local mayors there were with impairments?, and within the trade unions?. And he said 'Can you imagine what it would be like for you to be politician, one day in Lisbon, and then the next day having to be in Oporto to finish an electoral campaign, and with all those difficulties...' And he continued: 'did you know, Parliament is now accessible and you can use the library...' and we said 'No, we don't want to use the library, we want to go there [the assembly room], to the power! To speak!' [giggles] (Alfredo, interview)

The second major political consequence of the Portuguese Disabled People's Movement was making the state accountable for disabled people, i.e. the recognition of the state's responsibility for disabled people and for the development of disability policies. In

contrast to the UK, where the state has assumed responsibility for the social provision of disabled people since the formation of the welfare-state in the 1940s (Oliver, 1990; Drake, 1999), and despite the lack of disability specific benefits (Barnes, 1991), in Portugal disabled people and disability remained mainly a private issue to be dealt with by the individual and by his/her family until 1974, as was discussed previously in Chapters 4 and 5. Consequently, there was no 'safety net' for disabled people, because until 1974 the state played only a supplementary role to the family and to civil society. It is my contention that the Disabled People's Movement played a crucial role in making the state accountable for disabled people after 1974. In order to make this point more clearly I want to discuss a few examples.

In relation to the disability and impairment specific benefits granted in 1979 by the welfare-state, the analysis reveals that some of the rights granted to the impaired civilian population were in fact an extension of rights that had formerly been granted to the impaired war veterans as a result of their direct actions in 1974, 1975 and 1976. In relation to the education of disabled children, the liability of the state in this area was, at least until 1994 and the Salamanca Declaration, a direct result of the action of the Disabled People's Movement, of the Disability Movement and of some professionals who took a leading role (Costa, 1981; Costa and Rodrigues, 1999; Fontes, 2006). The same scenario is found in the areas of work, health, removal of physical barriers, etc. Notwithstanding the meagre advances in practical terms, through political lobbying the Disabled People's Movement pushed the state to recognise its responsibility and to consider disability issues and disabled people in political terms.

Forging connections with the government, political parties and/or MPs – what can be understood as lobbying – has been the main action strategy of the Portuguese Disabled People's Movement. The high number of meetings between leaders of disabled people's organisations and MPs, ministers and other political decision-makers, particularly to discuss and suggest new legislation, evidences the increasing connections (Elo, 1990, 1991; Associação, 1996). This signals the great emphasis placed by the movement on the use of legislative machinery to secure and enforce change. The publication of legislation has thus been a victory for the organisations. In contrast, less emphasis was put on the enforcement and implementation of legislation or on social change, as I discuss in the next two sections.

7.2.2. Social impacts of the Portuguese Disabled People's Movement

The action of the Disabled People's Movement has changed the panorama of Portuguese politics concerning disability but, above all, it has had a significant impact upon the lives of disabled people:

The emergence of this movement gave disabled people the right to aim for full citizenship, [...]. It is this movement, through the organisation of events, through appearances in the media... This movement raised disabled people's awareness of their rights and raised their political consciousnesses. (Alfredo, interview)

In the area of disability, for example, there is today a significant percentage of disabled people with an invalidity pension, which didn't exist before the 25th of April [1974 – revolution day]. [...] In comparison to thirty years ago, today there is wider access to work, a better understanding of rights and of the way to claim them. [...] Today people exercise their citizenship rights and, naturally, helped the country to be more democratic and more participatory. (Jorge, interview)

As the above quotations testify, the positive changes that have been made in disabled people's lives over the last three decades is an important theme amongst disability activists. Such change is often linked to the role played by the organisations of disabled people. As one interviewee stresses:

Everything that was done in Portugal up until 1980, 1990, it is all the doing of the organisations. [...] Everything that was done, since the formation of the Secretariat [National Secretariat for Rehabilitation], which was the beginning, to the first legislation that was passed, [...] the development of the movement to educate the kids, these organisations gained strength and became the political core. [...] Until the 1990s the state did not pay much attention, it was doing things, but... after 1994, '95, '96, with the 123 [Law-decree 123/97], etc., we then find stronger institutional answers [...], not so much as a direct consequence of the Disabled People's Movement but as a result of its previous actions. The first conference on physical barriers was organised by APD, the first sports meeting for disabled people was organised in Alvalade by APD. (Matias, interview)

According to some of my interviewees, progress has undeniably been made in the lives of disabled people since the 1970s and the Disabled People's Movement should take

most of the credit for this. I would argue, however, that this is only partially accurate. In fact, progress is only identifiable when comparing the situation of disabled people before and after 1974 and is linked to the arena of welfare benefits, where disabled people moved from a period of almost no support to a new period of state welfare provision. However, from 1980 until today there have not been many real changes made to the lives of disabled people. As was analysed in Chapter 5, the comparatively low redistributive design of the Portuguese Welfare-state which is based on low benefits (Santos, 1999; Andreotti *et al.*, 2001; Hespanha, 2001) has meant that most disabled people have lived with insufficient social benefits meaning they live below the poverty line (Hespanha, 2001). An example of this is, for instance, the Lifelong Monthly Disability Benefit created in 1980 for disabled people above 24 years old which was protected by the contributory system. In 2009 this benefit amounted to €176.76 (Portaria 511/2009, 14/05/2009), when at the time the minimum wage in Portugal was €450.00 (Law-decree 246/2008, 18/12/2008). In addition, disabled people continue to be excluded by an educational system that does not provide for their needs and by a labour market that excludes difference:

I was aware of a case of a disabled woman that they [the employer] wanted to dismiss and when the lift got broken, they wouldn't fix it and then they eventually asked that she was transferred to another department. [...] 'Well, we are still waiting for the equipment, and you'd be better off moving to another service!'.
(Matias, interview)

Recent statistics, opinion polls and other comparative reports provide further support for my argument. In the area of employment, despite the average age difference between the Portuguese population as a whole (39.5 years old) and the disabled population with at least one impairment (52,7 years old) (Gonçalves, 2003: 76), the 2001 Census mirrored the fact that most people with any kind of impairment did not take part in the labour market. According to the results, the activity rate is 29% for those with impairments whereas the figure for the general population is 52.6%. The remaining 71% of inactive people were retired (42.2%), considered unfit to work by the authorities (18.5%) or were unpaid home workers (3.5%) or students (3.2%) (Gonçalves, 2003: 80). The unemployment rate among those who were active also revealed that for the disabled population the figures were higher than for the rest of the population – 9.5% compared with 6.8%, respectively. These figures become even higher when we consider

people with cerebral palsy or mental impairment (12.7% and 15.2%, respectively) (Gonçalves, 2003: 81).

In the area of education, 37% of disabled people had no formal education (no academic qualifications) compared with only 26.4% for the general population (Gonçalves, 2003: 78). The 2001 Census also released important information concerning the living conditions of disabled people in Portugal. For instance, 55.2% of the disabled population over 15 years old rely on retirement schemes or on pensions (Gonçalves, 2003: 82). The Census also revealed that a significant number of impaired people continued to be disabled by their living environments, such as non-adapted and non-accessible homes. Around 37% of people with impairments at the time of the Census were living in houses not accessible to people with motor impairments, 52.8% lived in houses with no ramps but with some accessibility and only 9.1% lived in houses with ramps and with total accessibility. In the specific case of people with a motor impairment, 36.3% were living in houses where ramps were absent (Gonçalves, 2003: 88). In the UK, despite the existence of a better scenario, the statistics still suggest the persistence of a situation in which disabled people are socially excluded and oppressed. The employment rate of disabled people, for example, is still well below the employment rate of non-disabled people, 55.3% versus 84.4% respectively (ONS (2006) cited in Barnes and Mercer, 2010: 113).

Arguably the impact of the Disabled People's Movement in Portugal has been more evident in governments' agendas, which does not mean, however, any practical impact on disabled people's lives. Indeed, as my analysis highlights, the transformation of governments' agendas into political acts is a difficult and slow process. In addition, in those few cases when the movement did manage to transform the governments' intentions into disability legislation, it was hardly ever enforced. This means that, despite the movement's high impact on the establishment of governmental agendas, only some of its promises materialised and it had no influence on the way these policies were applied. In one of my interviewee's own words:

A great number of the legal projects are approved unanimously, everyone agrees, however to implement them is much more complicated. (Alfredo, interview)

Several examples of unenforced or partly-enforced legislation, which contain social, economic and civil rights for disabled people, have already been discussed in Chapter 5,

and range from rulings in the areas of education, social welfare, employment to the elimination of physical barriers in the built environment or the employment quota scheme for disabled people. Moreover, the low impact of the Disabled People's Movement on the lives of disabled people results not only from the strategies of action of the Portuguese state, which was analysed in Chapter 5 ('Parallel State' and 'Heterogeneous State'), but is mainly the result of the unfinished cultural revolution initiated by the movement in the 1970s. This cultural revolution has been on-hold since the 1980s, when the movement's action strategies fell into conventional politics, as will be discussed in the next section.

Overall, the action of the Portuguese Disabled People's Movement has not changed considerably the lives of disabled people. Despite some improvement in the area of social citizenship, with the creation of disability and impairment specific benefits and other social benefits within the welfare-state, these changes remain insufficient to generate a real change in disabled people's lives.

7.2.3. Cultural impacts of the Portuguese Disabled People's Movement

Most analyses of the consequences of social movements focus on the policy outcomes, on the "'measurable' aspects of the collective action (confrontation with the political system and effects on policies) and ignored the production of new cultural codes" (Melucci, 1988: 334). In fact, even today, and despite the centrality of values, ideas and beliefs to new social movements' repertoires of action (Melucci, 1989, 1994, 1996), the cultural revolutions produced by social movements seem to be downplayed (Earl, 2004). This is especially important in the area of disability, where traditional cultures and non-disabled people have surrounded disability with oppressive assumptions, ranging from the charitable, individual, medical and tragic to eugenic ideas (Oliver, 1990; Barnes, 1991; Hubbard, 1997; Barnes and Mercer, 2001, 2010; Borsay, 2005). This was certainly the case in Portugal, as a result of its strong Catholic background (Pais *et al.*, 1998) and from the long dictatorship, which held that physical and mental 'perfection' should be aimed at in order to improve the Portuguese 'race' (Pimentel, 2001). The development of a new disability culture, understood as a new set of values, beliefs, social norms and the production of material goods (Giddens, 1993) associated with disability, is therefore a central aspect in the emancipation of disabled people.

In the UK the Disabled People's Movement initiated a cultural revolution by challenging the dominant understandings of disability and impairment as well as the role ascribed to disabled people within British society but, above all, it did so by suggesting alternative conceptions of disability and impairment and by spreading emancipatory roles for disabled people and "developing positive disabled identities, values and representations of living with an impairment." (Barnes and Mercer, 2010: 202). This disability culture is largely a worldwide phenomenon (Peters, 2000). However, as Barnes and Mercer acknowledge, "The potential for disability consciousness is enhanced when there is agreement on the source of their collective social exclusion." (2001: 522). In the British case, it was the social model of disability, by refocusing disability onto society, that offered

a counter-narrative which has enabled many disabled people [...] to construct a new ontological narrative and to identify with other disabled people in a collective political struggle for disability rights and cultural change. (Thomas, 1999: 120)

In fact, "disability culture has been built out of political struggle" (Barnes and Mercer, 2001: 523). Disability culture, promoted internationally by disabled people's new self-understanding, enabled the re-conceptualisation of disabled people's lives from a narrative of tragedy to a narrative of oppression, from an attitude of dependence and inactivity to the idea of disabled people being independent, socially and economically active and autonomous. The development of this new consciousness since the 1970s at the international level (Peters, 2000) has been visible, for instance, in the British case in the emergence of numerous magazines, newsletters, TV programmes and in the opposition to and combating of disabling images of disabled people portrayed by the media and at disability charity fund-raising events (Barnes and Mercer, 2001, 2010; Morrison and Finkelstein, 1993; Sutherland, 2006). A good example of this new international disability culture (Peters, 2000) was the development of a disability arts movement, marking "a significant stage in the transition to a positive portrayal of disabled people" (Barnes and Mercer, 2001: 528). In fact,

From the mid-1980s, there has been a substantial increase in work by disabled poets, musicians, artists, and entertainers that articulates the experience and value of a "disabled" lifestyle. (Barnes and Mercer, 2001: 528)

The creation of this new value system and the celebration and exploration of difference proposed by the disability arts movement is still problematic for many disabled people (Barnes and Mercer, 2001). In fact, disabled people and scholars have been calling our attention to the exhaustion of the social model, on which this culture is based (Shakespeare and Watson, 2002; Shakespeare, 2006), to the diverse oppressions experienced by disabled people (Morris, 1991, 1996; Stuart, 1992, 1994; Crow, 1996; Corker and French, 1999), to the impact of impairment effects (Thomas, 1999; Barnes and Mercer, 2001) and to the use of essentialist arguments about the nature of impairment to support a minority group approach and a minority culture. This is the case of 'deaf people' (Davis, 1995; Corker, 1998). However, as Peters (2000) points out, if we take a syncretic world-view of disability culture – one that considers the three-pronged model of culture as historical/linguistic, culture as socio/political and culture as personal/aesthetic – we can acknowledge the importance of disability culture as a “thriving cross-cultural phenomenon which knows no national boundaries” (2000: 583).

In Portugal the formation of the Disabled People's Movement has also triggered a cultural revolution which had a great impact on the lives of disabled people. The cultural revolution that was initiated was, however, distinct from the one in the UK. To begin with, the cultural revolution initiated by the Portuguese Disabled People's Movement did not question the existing social order or existing conceptions of disability. For example, as has been seen throughout this thesis, the movement endorsed the idea of rehabilitation as the central focus of disabled people's social inclusion proposed by the state. In so doing, as my analysis reveals, the movement only questioned the roles ascribed to disabled people within the existing social order, trying to push its boundaries in order to accommodate disabled people. For instance, the previously mentioned slogans used by ADFA in the 1970s when demanding access to jobs – e.g. “the disabled can produce the same as the normal worker” – illustrate this desire for accommodation (ELO, 1978, n. 56).

Secondly, as was analysed above and contrary to the British case, there was no effort from the movement in Portugal to identify a common source of oppression. Again, the Portuguese Disabled People's Movement did not engage with the social model of disability. However, it offered a counter-narrative of disability, i.e. “critiques of the dominant public narratives” (Somers 1994: 631), based on the idea of disabled people as active and autonomous individuals, who are able to overcome their bodies through

the use of rehabilitation and work (see Chapter 6). So, despite being partially anchored in the (medical) notion of rehabilitation, the movement managed to escape the early tendency to connect impairment to tragedy, which stemmed from the articulation between the medical model and the capitalist mode of production (Oliver, 1990), by producing a counter-narrative based on the ability and availability of disabled people to work.

It is my contention that this is an unfinished cultural revolution, which did not reach its intended consequences. As a founding member and leader of APD in the 1970s (APD, 1997) signalled in an interview in 1984:

We made the 25th of April [revolution day], we are now commemorating its tenth anniversary. However, in my opinion there was no significant cultural change in Portuguese society. There was no debate about ideas, which would have held great interest for us disabled people. A few attempts were made up to 1976, 1977; but after that the movement moved backwards. This debate, which would have been unique in Europe's recent history, was missing from the Portuguese political process in 1974, 1975 and 1976. (ELO, 1984d)

Arguably, the cultural revolution initiated in the 1970s did not travel into the following decades. It died out when the movement's action strategies fell into conventional politics. The cultural revolution that was initiated and epitomised by ADFA's early claims for employment, reintegration, rehabilitation and its resistance to charity, benefits and disabled people's dependence on the state or on their families, found no echo in other organisations of disabled people and was discarded by ADFA soon after it had achieved some of its demands and with the simultaneous reshaping of its aims and strategies of action. The cultural revolution was resumed only at the end of the 1980s and in the early 1990s through the introduction of the language of human rights by APD into national disability discussions. This is, however, a very different revolution – if the first questioned disabled people's role within Portuguese society, the second revolution did not challenge the existing order, but raised awareness regarding the rights of disabled people as well as denouncing discrimination.

Arguably, the pragmatism that was needed to deal with the poor living conditions of most disabled people due to the absence of a welfare system before 1974, the lack of an academic arm and the movement's incorporation of the international language of human

rights, prevented the Portuguese Disabled People's Movement from identifying the roots of the exclusion and oppression experienced by disabled people in Portuguese society. Therefore socio-political interpretations of disability remain absent from the Portuguese Disabled People's Movement's discourse.

Nevertheless, it would be inaccurate to suggest that the Portuguese Disabled People's Movement had no impact on Portuguese culture. Far from it, the creation and existence of the movement alone would have had a cultural impact. As has been evidenced here, the action of the Portuguese Disabled People's Movement has had two major cultural consequences, both of which were anchored in wider processes linked to the modernisation of Portuguese society (e.g. the democratic regime after 1974, and Portugal's integration into the EU in 1986), as well as the growing international awareness regarding disability rights (e.g. the UN Declaration on the Rights of Mentally Retarded Persons in 1971 and the UN Declaration on the Rights of Disabled Persons in 1975).

The first cultural impact was the formation of a culture of rights. In fact the formation and action of the movement transformed the traditional culture of pity and charity into a culture of rights. As was discussed in Chapter 4, disabled people were traditionally cared for by their families and by local and national charities for centuries, and were therefore forced to rely on charity and pity. This deeply ingrained understanding started to change in the nineteenth century with the state's acceptance of its responsibility for the care of disabled people, but it was only defeated through the action of the Disabled People's Movement in the last quarter of the twentieth century. This transition was achieved by the affirmation of disabled people's civil, political and social citizenship, framed by a 'rights' approach to disability at both the national and international level.

A second cultural impact of the Portuguese Disabled People's Movement was its take-over of public space. If traditional disabling images of disabled people and inaccessible environments prevented disabled people from accessing and using public spaces, the emergence of the Disabled People's Movement and their public actions made disabled people visible in public spaces, as well as showing them as legitimate users of that space.

Arguably, the abandonment of the first cultural revolution and the lack of politicisation of disability in the second revolution, has impacted greatly on the Disabled People's

Movement and on the disabled people's citizenship project developed by the state. One consequence was precisely the failure to develop a new disability culture based on a shared disability consciousness, while another obvious consequence was the absence of a disability arts movement.

Conclusion

As has been analysed throughout this chapter, globalisation represents both a challenge to and an opportunity for disabled people and for the development of the disabled people's citizenship project. If the rapid growth of international organisations and the hegemony of capitalism in this new political and economic world order has eroded social rights and threatened the idea of equality developed by the citizenship project, the internationalisation of the Disabled People's Movement has raised awareness of disability issues at the global level and has allowed for the involvement of organisations like the UN and the EU. This process has contributed to the affirmation of a rights-based approach to disability issues. As this analysis highlights, such a vision of disability has had great impact on disability policies and politics and on the Disabled People's Movement, but has had little impact on disabled people's lives. In Portugal and elsewhere this approach has not promoted the unification of disabled people in their struggle for an inclusive society. Moreover, the inefficient enforcement of much of the legislation has compromised, rather than developed, the rights of disabled people.

The globalised rights-based approach has framed much of the national debate and initiatives in the area of disability since the 1980s, as well as influencing the majority of the impacts of the Portuguese Disabled People's Movement. Notwithstanding the increasing complexity of assessing the impacts of the Disabled People's Movement within this scenario, the analysis has been clear in highlighting that the major impact of the Portuguese Disabled People's Movement has been on the definition of the state's disability political agenda. As was suggested, and in accordance with the criticisms of this rights-based approach to disability, two major problems were found in the materialisation of this agenda: first, the translation of this disability agenda into real disability policy and, second, the application of these policies. This became visible when considering the impact of the movement at the social level. As was demonstrated, despite the changes introduced into the lives of disabled people in Portugal since 1974,

disability policies were not enough to include disabled people into mainstream society or to overcome the poverty faced by most disabled people. The reason for this lies, as was argued, in the unfinished cultural revolution and in the non-politicisation of disability, as well as in the antagonisms of a capitalist system, which prevents the development of deeper levels of citizenship by constantly limiting the expansion of the Portuguese welfare-state (Santos, 2011).

In sum, this chapter looked at the Portuguese Disabled People's Movement as an agent of change. It was my intention to assess its impacts on the political, social and cultural spheres, as well as to consider wider processes of the internationalisation of disability politics and policies. The next chapter looks at the future of the Portuguese Disabled People's Movement, as well as at wider theoretical discussions within social movements theory and social citizenship scholarship, in order to provide a critical account of the theoretical debates based on the analysis of the Portuguese Disabled People's Movement.

8. Citizenship on the edge: insights from the analysis of the Portuguese Disabled People's Movement and future directions

Introduction

As has been argued throughout this thesis, the Portuguese Disabled People's Movement emerged after the reestablishment of democracy in Portugal in 1974. The previous chapters presented an analysis of the disability policies and politics developed in Portugal post-1974, a critical contextualisation of the Portuguese Disabled People's Movement and an assessment of its political, social and cultural impact. As was argued, the Portuguese Disabled People's Movement was forged by its national economic, political and socio-cultural context, but also by the internationalisation of the Disabled People's Movement and of disability issues. This has had a great impact on its focus, aims and strategies of action. The impact of the movement needs, however, to be interpreted in light of the links between these characteristics and other structural issues influencing Portuguese society, such as capitalism, neo-liberal thought, dominant economic interests, globalisation and increasing Europeanisation (Soares, 2007, 2010; Moreira *et al.*, 2010). As Klandermans states: "social movements are enmeshed in the socio-political networks of the societies in which they develop." (1990: 125).

This final chapter of the thesis will explore the ways the Portuguese case study may contribute to current theoretical debates on social movements and citizenship. In the next three sections an exploration of the theoretical possibilities offered by the particularities of the Portuguese Disabled People's Movement will be presented. Building upon the previous sections, the fourth and final section will critically analyse the future of the Portuguese Disabled People's movement.

8.1. Social movement theory and disabled people's collective action

As was analysed in Chapter 2, the separation between social movements and other forms of collective action is sometimes very fine and a number of categories overlap to some degree. This is the case with social movements and interest groups, understood as

politically oriented collectives representing a cause or a faction for lobbying the government. Based on the definitions of Social Movements and the distinguishable criteria suggested by New Social Movement theorists, like Touraine (1985, 2002), Mellucci (1989) and Diani (1992a), I have suggested that four central elements make social movements distinguishable from other forms of collective action: continuity, identity formation, ideologically driven action and transformative intervention.

Drawing on the discussion begun in Chapter 2, in this section I explore my propositions based on the Portuguese case study and investigate what this overlap of different forms of collective action says about the actions and strategies of a specific movement.

In a recent study on environmentalism in the UK and in Italy, Diani states:

if alliances on environmental issues limited themselves to fighting specific battles, with little identity and solidarity between the organisations involved, and no attempts to connect to broader frameworks, there would be little analytical gain from labelling as a ‘social movement’ what would ultimately be little more than sets of organisations, instrumentally pooling resources in temporary, single-issue coalitions. We can only talk of environmental movements if dense inter-organisational networks and shared collective identity may actually be found among organisations mobilising on environmental issues. (Diani and Rambaldo, 2007: 768-769)

Arguably, this is an unrealistic vision of social movements. Despite the aspect of continuity discussed above, social movements are formed by organisations and activists whose networks evidence different patterns of interaction and intensity over time. In fact, networks of social movements are triggered by events that propel action. These catalysts work as the hubs of social movements’ organisations offering a specific reason for mobilising at a specific moment in time. To make social movements dependent on the existence of “dense inter-organisational networks” (Diani and Rambaldo, 2007: 769) would necessary imply that social movements are only ever sporadic encounters, rather than continuous struggles advanced by collective actors characterised by continuity, identity formation, ideologically driven action and transformative intervention. Moreover, this would imply losing the internal historical legacy that constitutes any social movement.

To be more specific, and in line with the evidence from my case study, it is my understanding that social movements operate in waves of mobilisation, alternating between periods of strong networks and periods of limited exchange. This same conclusion was reached by Wall (1999) in his research about radical environmental collective action. As he states:

A certainty of social-movement theory is that waves of mobilisation ebb and flow; they do not grow in a continuous and sustained fashion (Wall, 1999: 192)

This analysis of the Portuguese Disabled People's Movement evidences precisely such fluctuations. As has been seen throughout this thesis, the Portuguese Disabled People's Movement is characterised by the imprecision of its boundaries, the volatility of the elements that glue it together and the intermittences and changeability of its biography. Arguably, based on Diani's definition, it is difficult to conceive of the Portuguese Disabled People's Movement as a social movement at some points of its existence. The diversity of impairment specific organisations, the centrality of impairment specific identities, the geographical dispersion of disabled people and the movement's embracing of a rights-based approach to disability maintained the idea of disability as an individual experience for most disabled people and prevented, not only the politicisation of disability, but also the emergence of a strong solidarity (Melucci, 1989) or collective identity (Diani, 1992a) that would somehow steer collective action. The sporadic episodes of collective action across history have been enabled by the existence of two central elements: a basic process of identity formation and the emergence of catalysts, i.e. specific structures or events that trigger the unification of the movement's efforts and resources. This seems to have been the case for the Disabled People's Movement in Portugal and in the UK.

In the UK, as has been analysed in the previous chapters, the emergence of disability politics in the 1960s (Barnes, 1991), the foundation of the Disabled People's Movement in the 1970s (Campbell and Oliver, 1996) and the emergence of the social model of disability in the 1980s (Oliver, 1990) triggered the development of disabled people's political consciousness. This process is described by Campbell and Oliver (1996), who highlight the centrality of the movement's rejection of disability as personal tragedy within this process. This cultural revolution (see Chapter 7) has resulted in the formation of a positive disabled identity. In fact, as is evidenced by the British case, disability politics is not just about campaigning and lobbying it is also about identity

politics (Barnes and Mercer, 2010). This has been evident from the beginnings of the movement in the UK, not only with the formation of UPIAS but also with the development of other more culturally focused organisations, such as the Liberation Network of People with Disabilities formed around 1977 and its precedent the London support group (Sutherland, 2006: 1). As Sutherland testifies, this had a great impact on disabled people's lives:

We moved from feeling distressed about our personal circumstances to feeling angry for disabled people as a group. We did have a tremendous sense of solidarity and Network members took that into the wider disability movement. (Sutherland, 2006: 5)

As Sutherland suggests, central to this process is identifying with a particular group. There are, therefore, three central elements to this process of developing a disability identity: identification with other disabled people (Sutherland, 2006), the development of a political consciousness (Campbell and Oliver, 1996) and the formation of a positive culture, which allows people to affirm a positive identity within a disabling society (Swain and French, 2000).

In contrast to what happened in the UK, in Portugal the elements that might have contributed to forging a positive disabled identity have been weaker. Arguably, in the absence of an awareness of the social model this process of identifying with other disabled people was substituted by an organisational identification. This is visible in the lack of engagement and participation by the majority of my interviewees in activities developed by other organisations of disabled people. For example, in her answer to the question about participating in the activities of other organisations, an interviewee responded:

No, only in the X [name of organisation]. No, to participate in their..., no, I've never participated in any other activities. Usually, I think there is... I think people do a bit of separation. Disabled people from one organisation... who have a specific impairment and belong to a specific organisation, are more inclined to socialise, to participate in the activities, to meet other people inside that organisation. People tend not to mix with each other. (Angela, interview)

This has created a hierarchy of belonging, according to which organisational membership is prioritised, preventing the formation of deeper levels of solidarity and

the politicisation of disability based on the generalisation of personal experiences of disability. In addition, some organisations have developed a minority group approach, i.e. an essentialist perspective by which a particular issue or impairment is emphasised. This is the case with ADFA and of APS. In the case of the impaired war veterans, ADFA's activists developed a strong solidarity based on the historical contingencies of their impairments (the colonial war), which facilitated a unity of action and emotional attachment that, in turn, promoted a sense of shared identity.

I'm going to tell you something, I cannot live without X [name of organisation] anymore, I just cannot. We've got a meeting the first Saturday of each month. [...] I go to the organisation and it is rewarding for me to be there, it gives me pleasure to chat with my colleagues, it gives me pleasure to be part of this activism, to be part of this fight. [...] X [name of organisation] plays a central role in my life. Probably I wouldn't now be able to live without X [name of organisation] anymore. I've noticed, especially during the holiday period, [...] people say 'Well, I'm not coming, this Saturday and the one after I'm not coming!', and to listen to this 'I'm not coming!' is very painful for me and I'm dying to go there, because without it there is something missing. (David, interview)

This strong sense of common identity is, however, not shared by all disabled people or organisations. In fact, as has been evidenced throughout this thesis, ADFA has distanced itself from other organisations of disabled people. In the case of deaf people, such a lack of involvement is the result of their self-identification as a minority linguistic group rather than as disabled people or as part of the Disabled People's Movement. Carlos explains:

Deaf people are not considered disabled. Why? Because we have our culture, our history, our language, our identity, exactly as a gypsy [*sic*] community [does] or other migrant groups, Romanian, Ukrainian, all those groups that joined us [the Portuguese people], [do] – that's exactly how we feel. (Carlos, interview)

A similar line of argument has been made by deaf people across the world (Ladd, 1988; Scotch, 1988; Davis, 1995; Campbell and Oliver, 1996; Corker, 1998; Barnes and Mercer, 2001, 2010).

As has been evidenced by my interviewees, most organisations of disabled people function within their organisational boundaries.

The movement is not uniform, even inside CNOD there are disagreements, isn't it?! [...] But there are small movements, there are clusters of organisations that eventually are able to organise some activities together, but I don't see it as a movement, a movement in the sense of, I wouldn't say unanimity, but, unity of action. To begin with, there is a notorious separation between the military and the civilians and even within the civilians the unity is not that strong. (Armando, interview).

The frailty of the collective ethos has meant that the Portuguese Disabled People's Movement has rarely managed to generate unity for collective action. The organisations of disabled people that form the movement are rooted in their specificities –that type of impairment (ACAPO and, in part, APD), the circumstances in which impairment was acquired (ADFA and ANDST) or political ideologies (APD and CNOD) – or they are obfuscated by disabling imagery (APS). This same problem has been identified in the UK. As Beckett suggests:

the movement has not been able to develop a positive identity and group consciousness across its membership. [...] A number of factors have hampered the development of a group consciousness amongst disabled people in the UK. These include divisions that exist between disabled people according to impairment, gender, sexuality and ethnicity. (2005: 414)

Shakespeare (1993) seems to address the problem from the opposite angle. He claims that one of the difficulties that the Disabled People's Movement in the UK has had in mobilising disabled people

has been the tendency to downplay the role of impairments, of the physical condition. Given that the majority of unpoliticised disabled people identify first and foremost via their particular physical impairment, it is an obstacle to their development if this is ignored by the theoreticians of the struggle. (1993: 256)

The Portuguese case reveals, however, that this is not so straightforward. Indeed, the minority group approach suggested by Shakespeare as a solution for the development of the Disabled People's Movement carries with it the danger of fragmenting disabled people and annihilating the movement's shared identity and collective action. In the scenario idealised by Shakespeare, collective action in Portugal has only been sporadic and its bonds provisional. The history of the movement shows the coupling and

subsequent uncoupling of organisations over time and the formation of alliances for specific periods only. A clear example of this is the Movement of Working Disabled People for the Maintenance of Tax Benefits, which was formed in 2007 by members of different organisations of disabled people to fight against the changes introduced to the tax system by the 2008 National Budget. As one interviewee explains:

The issue of VAT and Income Tax... When I realised this was going to happen, I called XXXX [Name of the leader of an organisation of disabled people] 'Listen, be aware that this is going to happen and that we will face these problems!' [...] When it really happened there was already this previous contact and people were already prepared. Obviously there was contact, but the contact was made for a very specific purpose. After that, the way forward is to capitalise on one's privileged relationships in order to gather other organisations. Therefore, the contact is not purely institutional, but more to do with close relations [between the leaders] [...]. Why does it end? Because these actions are casual, are sporadic and after the failure of their aim, in this case the approval of the National Budget, collective action is also exhausted and each returns to their own. (Daniel, interview)

The social phenomenon created across time by the different organisations of disabled people is, certainly, a social movement, because it results from collective effort and from a conflict with the establishment which aims to push the limits of Portuguese society, and the state, in order to make it socially, culturally, economically and politically more inclusive for disabled people.

Arguably there is a need for a more flexible understanding of social movements, in order to accommodate different cases with diverse historical backgrounds and, consequently, with different biographical trajectories. Therefore, the Portuguese Disabled People's Movement encompasses a social phenomenon created by a continually mutating reality formed by a constantly changing plurality of agents – organisations of disabled people, individuals, platforms, etc. – engaged in social change and in the formation of an inclusive society. Therefore, the distinctiveness of social movements resides, I suggest, in the four elements outlined above: continuity, identity formation, ideologically driven action and transformative intervention for an inclusive society. I argue, however, that these elements have been very frail in the Portuguese case. As the analysis reveals, these elements may have emerged at certain moments in

order to sustain specific campaigns or collective action but they soon faded away again when these are over. Therefore, these alliances and collaborations are instrumental and not identity driven. The maintenance of informal networks between the different social movement's organisations, in the Portuguese case, is enabled by a *process of identification by condition*. This shared condition of being disabled in a disabling society makes the organisations of disabled people keener to bond with each other rather than with other social movements' organisations. This is evidenced by the Movement of Working Disabled People for the Maintenance of Tax Benefits, described above, or by the movement created in Portugal for the recognition of Portuguese Sign Language:

A few years ago, in 1997, [...] we questioned all the organisations [of deaf people] with an interest in the recognition of LGP [Portuguese Sign Language] and all of them confirmed their interest in being part of the Commission [for the Recognition of LGP]. We worked together, there were no problems and the document was sent to the Portuguese Parliament. After state recognition was granted, this Commission became... right now, the organisation contacts with, has an easy relation with [names of other organisations of deaf people]. The XXXX [name of one organisation of deaf people] walked away, but when we organise seminars or workshops they are present. But work is not done together nor is there any strong relationship between us. That relationship with XXXX [name of one organisation of deaf people] disappeared after the recognition of LGP. (Xavier, interview)

Arguably, there is a tendency for social movements to become institutionalised. This is also the case with the Portuguese and British Disabled People's Movements (Barnes, 2005; Oliver and Barnes, 2006).

[A]s social movements develop over time, they often become more and more institutionalized, with some of them evolving (at least partially) into interest groups or even political parties." (Snow *et al.*, 2004: 8).

This last option has not been the case in the UK nor in Portugal, where disabled people have rarely had access to formal political power. As Oliver signals "disabled people can hardly expect to articulate and achieve their political ends through the party system" (1990: 103). The analysis reveals, however, that the Portuguese organisations tend to

adopt a minority group approach (Hahn, 1996; Liggett, 1997) towards the state. These organisations have tried to become part of the Portuguese political system mainly as interest group rather than as a social movement. This is confirmed by their privileging of a ‘soft action strategy’ (see Chapter 6). Rather than challenging or aiming to change the structures of their oppression and/or exclusion, the organisations of disabled people have been engaged in constructing themselves as a special group which can participate in decision making processes for disability policies. This has been evident from the beginning of the movement. The coalescing of disabled people into organisations of disabled people and, later, their unification under umbrella-organisations was regarded as a strategy to influence political power and participate in the process of decision-making. Examples of this include the initial demand put forward by the movement for the creation of a public body to allow the organisations to participate in the making of disability policies and the formation of umbrella organisations to converse with the government:

In the old days X [name of organisation] was the focus. Later on it was created federation X [name of the federation] because the government suggested that a body was needed to receive the funding. (Raul, interview)

To reiterate, organisations of disabled people have been transformed into interest group organisations, which form a social movement when they participate together in collective action for a specific purpose, such as the movement for the maintenance of tax benefits discussed above. In this way, this analysis seems to confirm Diani’s understanding of social movements as networks of informal interaction (1992a, 1992b, 2003). As he stresses, “treating movements as networks enables us to identify a specific social dynamic, which differentiates social movements from cognate processes” (Diani, 2003: 300), in this case from the independent existence of the organisations of disabled people as interest groups. However, as my case study reveals, the self-contained nature of the organisations’ goals, interests and strategies often surmounts their collective existence as a social movement that only surfaces at specific moments in time. Plus, the institutionalisation of the Disabled People’s Movement over time makes the interest group component even more evident. This is most obvious in the Portuguese case where the lack of a collective ethos and of a politicisation of disability makes it extremely difficult for the movement to sustain collective action and, therefore, the interest group component of the organisations surmounts any collective call to action. This emerges in the words of some of my interviewees:

That solidarity that existed from 1974 up to the 1980s, that voluntarism, that solidarity began to fade away and today is almost nonexistent. [...] It is 'each to their own'. (Jorge, interview)

Several attempts were made, the formation of federations of... [...] There is a great division at the national level and it becomes difficult to form a structure and then ask them to respect our impairment, to respect our demands, and then we do not feel represented (André, interview)

In fact, lobbying Parliament for disability rights, and campaigning for funding and the provision of services has consumed the majority of the energy of the Portuguese organisations of disabled people since their beginnings. This is what could be described as a 'legalistic approach to emancipation' (Finkelstein, 2001a, 2007) or a 'rights based approach to disability' (Sheldon, 2005; Oliver and Barnes, 2006), where the organisations of disabled people or the Disabled People's Movement presents itself as an interest group lobbying the government. In this respect, it is interesting to compare the Portuguese and the British Disabled People's Movements.

Since the beginnings of the Portuguese movement in the 1970s a rights based approach has been pursued, for the reasons I identified in previous chapters, such as a lack of politicisation of disability and the uncoupling of this fight from the social model of disability, to use Finkelstein's terminology (2007). This trace was reinforced later on with the internationalisation of disability issues and the involvement of supranational bodies like the EU and the UN, as was analysed in Chapter 7. In the UK, this strategy was also used in the early days of the movement in the 1960s by organisations such as DIG and its successor DA (see Chapter 4), which favoured parliamentary pressure group politics (Finkelstein, 1996). However, disappointment with this type of strategy, which did not attack the roots of disabled people's poverty and oppression (Finkelstein, 1980; Oliver, 1990; Campbell and Oliver, 1996; Sheldon, 2005), i.e. the capitalist mode of production (Finkelstein, 1980; Oliver, 1990; Gleeson, 1997; Russell, 2002), led to the radicalisation of the fight and the formation of UPIAS in 1972 with its emancipatory understanding of disability, which located the source of oppression within society. This also symbolised a shift in the strategy of the Disabled People's Movement, which moved "onto grass roots work within the disabled community." (Finkelstein, 1996: 2). The 1990s, which focused on single issue campaigning for anti-discrimination legislation (Oliver and Barnes, 2006), saw the return to 'pressure group politics

campaigning' (Finkelstein, 1996), or, as I prefer to call it, to interest group politics. According to Finkelstein (2007), this strategic shift taken by the Disabled People's Movement in the UK is the result not only of the uncoupling of the fight for disability civil rights from the social model of disability, but also of an ideological turn in British politics in general, i.e. the Labour Party's move into a more centre ideological political position. This ideological shift within the movement was consummated in the hegemony of a politically centre right section of the Disabled People's Movement, the importation of USA solutions, such as independent living and a rights based approach to disability, and the surrender of care services to a capitalist market economy (Barnes and Mercer, 2006; Finkelstein, 2007).

The analysis of the Portuguese case can only confirm part of Finkelstein's (2007) argument. In Portugal, as has been argued here, the lack of politicisation of disability and of an involvement with the social model of disability left the Portuguese Disabled People's Movement adrift allowing it to be consumed by other ideological rifts. However, I cannot confirm the connection between an ideological left-wing turn in the movement and its radicalisation. In fact, my analysis reveals a detachment between political party ideologies and the disability strategy and an understanding pursued by the organisations of disabled people. Despite the Portuguese movement being ideologically dominated by a left-wing political spectrum, it has never embraced a radical vision of disability. Again, I would like to single out the importance of the historical context of each movement.

As became evident from the data, there is no teleological principle in the life-course of social movements, contrary to what Snow *et al.* (2004) suggests. Indeed, social movements are very complex formations without linear biographies. Therefore, I argue that the transformation of the Disabled People's Movement into an interest group should not be regarded as fate but as another action strategy of the movement defined, enriched and constrained by specific social, economic, political and cultural contingencies.

8.2. Beyond the old/ new social movement debate

As was analysed in Chapter 2, the 1960s represent a watershed in the history of social movements, which is characterised by the emergence of an increased variety of social

conflicts beyond the workforce. These newly emergent conflicts, which centred around 'post-material' issues (Lawrence and Turner, 1999; Melucci, 1989) gave rise to the formation of new social movements. Contrary to their predecessors, which focused on material and class issues, new social movements pushed for a multitude of issues concerning civil rights, gender, anti-war, peace, anti-nuclear, environmental, lesbian and gay, student and disability. Arguably, as was argued in Chapter 2, the changing nature of NSMs can be found in their social support base; in the values and issues that feed their struggles; in their field of operation; in the action strategies used; in their internal organisation and in the scope of their intervention. In fact, NSMs are mainly middle-class driven; are directed towards post-material issues such as culture, identity, moral issues, lifestyle; distribution, and 'grammar of forms of life' (Habermas, 1981); operate mainly within civil society; promote action strategies that involve direct action and embracing a new lifestyle; privilege a non-hierarchical and multi-headed type of organisation, which favours the creation of networks between different organisations of social movements and between different social movements; and embrace a conflict that affects society structurally.

As was discussed throughout this thesis, the Portuguese and British Disabled People's Movements are a post-1960s reality. The conditions of the movement's creation in the UK have, however, resulted in an intense discussion about whether this is a new social movement or not (Oliver, 1990, 1996; Shakespeare, 1993; Abberley, 1996; Campbell and Oliver, 1996; Lee, 2002; Barnes and Mercer, 2003). In fact, as has been analysed throughout this thesis, the emergence of the Disabled People's Movement in most countries, including Portugal and the UK, is the result of the oppression suffered by people with accredited impairments and of their exclusion from participating in mainstream society and from accessing the quality of life, living conditions and wealth as other citizens do. The material issue at the core of disabled people's demands has divided disability scholars in their classification of the Disabled People's Movement.

For authors such as Oliver (1990, 1997b), the Disabled People's Movement is definitely a NSM. Oliver anchors his argument in four main features of the Disabled People's Movement. Firstly, it has been marginalised from traditional politics, and has thus embraced alternative forms of political action, which contest traditional views of disability. Secondly, by rejecting the medical model of disability and advocating a social model, which stresses that disability is artificially created, the Disabled People's Movement presents a critical evaluation of society. Thirdly, it is concerned with the

quality of life of disabled people, which is a 'post-materialist' value. The continuous concern with material values is due to the fact that the material deprivation of disabled people continues to be extensive (Beresford, 1996; Coleridge, 1993; Ghai, 2001; Stone, 2001; Turmusani, 2001; Zaidi and Burchard, 2002; Barnes and Mercer, 2010). Finally, Oliver presents the development of this movement as evidence of its concern with international issues. Despite acknowledging some of the arguments advanced by Oliver, Shakespeare (1993) is sceptical about conceptualising the disabled people's struggle as a NSM. He questions the applicability of the label NSM to the Disabled People's Movement due to problems of identity formation, which was analysed above, and due to the newness of its forms of political action and representation. Shakespeare (1993) suggests that the concept of NSM

obscures important differences between two types of contemporary popular struggle: the 'post-materialist' tendency, on the one hand, and the 'liberation' movements on the other. (1993: 258)

He goes on to argue that the Disabled People's Movement, the Women's Movement, the Black Movement and the Lesbian and Gay Movement would be better conceptualised as liberation movements, as their fights are mostly concerned with resource allocation – "women, black people and disabled people are crucially concerned with their economic exploitation and poverty." (Shakespeare, 1993: 256). This is, however, debatable. As Sutherland (2006) and Swain and French (2000) have illustrated the Disabled People's Movement is also about identity politics and about creating an affirmative disabled identity.

In addition, I do not share Shakespeare's call for a new typology of social movements. I am more persuaded by Hoffman's argument that we need "to welcome the new, not by repudiating the old, but by enriching it." (2004: 162). Arguably, studies of NSMs tend to overlook social and economic inequalities and to overstate issues related to culture and identity. I contend that this is due to a misunderstanding of the concept of social movement. In fact, most scholars tend to see contemporary social movements as entities, as actors on a stage. Instead, social movements should be understood as processes (Melucci, 1989), as "socially constructed collective realities" (Melucci, 1995: 110). It is only by looking at the Disabled People's Movement as a process, i.e. as networks of production of collective action and of a collective identity enmeshed in specific structural conditions and particular geographic contexts, that it is possible to

capture not only its nature as a social movement, but also the changes operating in social movements over time. In this perspective, current social movements are NSMs, in the sense that they are constantly under construction and their features are the result of unique configurations of power and resistance, as well as current structural conditions. Therefore, there is no contradiction in locating the origins of the Disabled People's Movement in the eighteenth century (Gleeson, 1999), nineteenth century (Driedger, 1989; Oliver, 1990; Barnes, 1992a; Shakespeare, 1993; Barnes and Mercer, 2002) or the early twentieth century in the Portuguese case and in classifying it as a NSM. As was analysed in Chapter 4, despite some organisations of disabled people having their roots in the early twentieth century, with the formation of deaf and blind organisations, their structure, political standing, action strategies, activities and general goals has no parallel within current organisations. Arguably, the same applies to other social movements too, namely the Women's Movement (Roseneil, 1995).

Therefore, the features presented by the Disabled People's Movement at each moment in time result from the intersection between structural conditions and configurations of power and of resistance. This accounts for the changes in the focus of social movements as well as for their adaptive strategies of action over time. This has been the case in the UK (Oliver and Barnes, 2006) as well as in Portugal. In the Portuguese case, as was analysed previously, the movement did not follow a single route, or a single strategy. ADFA, a multi-impairment organisation, is a good example of this. Having been one of the most radical organisations and having presented equally radical claims and strategies during the 1970s (see Chapter 6), it then transformed itself into an interest group for impaired war veterans for the next thirty years or so, only returning to direct action in 2008 with a major street demonstration in Lisbon, which finished in front of the National Parliament (ELO, 2008). Actually, a close examination of the Portuguese Disabled People's Movement reveals the constant presence of features associated with both old and new social movements. Whilst its struggles are detached from labour and employment – a typical feature of NSMs (Melucci, 1984) – most of its claims are rooted in questions of re/distribution. For Oliver (1990), however, the distributive questions raised by the Disabled People's Movement are post-materialist in that they are concerned with disabled people's quality of life. The only reason why material values continue to populate the Disabled People's Movement's repertoire of demands is because disabled people continue to be overrepresented in economically deprived

groups (Beresford, 1996; Coleridge, 1993; Ghai, 2001; Stone, 2001; Turmusani, 2001; Zaidi and Burchard, 2002).

The agenda of the Portuguese Disabled People's Movement has also included broader issues, namely post-material concerns. These became visible in its critical evaluation of society and in its call to change representations and attitudes, a call that figures in most organisations' discourse and documents, as well as in my interviewee's discourses:

Since the beginning of the organisation the goal was to change people's mentalities. The biggest aim was to change mentalities, that was always the main objective. Because a disabled person [sic] has got difficulties, natural limitations, but these difficulties can be compensated for through personal effort. Because there are always capacities which we are able to develop [...] and that brings us great joy, great pleasure in life, because it is somehow like being born again. [...] But in order to make that possible it is necessary that mentalities change, that others accept us. (José, interview)

Perhaps this theoretical dispute between old and NSMs is of limited use to the movement if it is to be regarded from an evolutionary perspective, as Shakespeare (1993) seems to suggest. As the Portuguese case reveals, materialist and non-materialist values have become closely intertwined and the action strategies pursued result from disabled people's living conditions and structural factors within each society and from its specific political culture. Cyclical economic crises in countries like Portugal have produced a retrenchment of the state in the social sector, not only in service provision and its delegation to the third sector, but also in the constant threat to those social rights that have already been granted/won.

Therefore, the centrality of materialist or non-materialist claims should not be used to assess the social movement but, rather, to evaluate, in the case of the Disabled People's Movement, the level of disablism and of disabled people's oppression within a given society. In fact, there is a positive correlation between the level of economic redistribution and social inclusion (to the built environment, employment, family life, independent living, etc.) and the removal of disabling barriers within a given society. The higher the former, the more efficient the latter and, consequently, the greater the social movements' focus on post-materialist issues.

The role of social movements in shaping democracies leads me to the final part of this thesis, where the notion of citizenship will be considered and, within it, the role of social rights.

8.3. Visions of citizenship

Hoffman (2004: 138) distinguishes between *static* and *momentum* concepts, i.e. between what he sees as concepts that “cannot be reconstructed, because they are intrinsically repressive and exclusionary” and “concepts that are part of the human condition, and that are capable of further development”. Examples of the first case include concepts such as the state, patriarchy, sexism, disablism and violence, and of the second include freedom, equality and citizenship. In fact, what it currently means to be a citizen in Portugal is different from what it meant forty years ago. Rightly this notion has evolved from an exclusive concept: male middle class, economically active, heterosexual, to a more inclusive notion of citizenship that accommodates more people, not only women, but also children, and, more recently, disabled people, amongst other formerly excluded groups (Driedger, 1989; Archard, 1993; Qvortrup, 2002; Hoffman, 2004; Prince, 2009). I contend, however, that this progression in the notion of citizenship was only possible through the development of several other momentum concepts that cushioned and pushed forward the concept of citizenship. I identify four main interconnected momentum concepts of citizenship, i.e. concepts that have sustained and propelled the notion of citizenship: participation, empowerment, emancipation and inclusion.

The participation of civil society in the definition of its future has been fundamental to broadening the notion of citizenship. In Portugal this was done, initially, through the majority of Portuguese society acting against the dictatorial regime and in support of the new democratic regime and, in a second moment, following the political and social turmoil, through new social movements, such as the Disabled People’s Movement, the Women’s Movement or the Lesbian and Gay Movement. Empowerment is understood as the power of each citizen to rule his/her own life without any overbearing interference from or domination by other people or institutions. This is linked to emancipation, which is understood as freedom of thought and of action without sanctioning. Inclusion here is conceptualised in broader terms, and refers to belonging to and involvement in everyday life without any barriers.

Hoffman's distinction between *static* and *momentum* concepts (2004: 138), as well as my subsequent proposal, seems particularly useful in thinking about the notion of citizenship. Citizenship defines the relationship between the individual and the state, as well as between individuals within a given society. As Oliver (1996) argues, citizenship was used as a tool to resolve the crisis in the relationship between individuals and the state. In Rioux's words, "Citizenship determines the conditions for full membership and inclusion in a society" (2002: 216).

The increased variety of social conflicts in the post-1960 years led to the extension of the individual's participation in the state's activity (Turner, 1986) which was mirrored by the formation of NSMs and the expansion of the notion of citizenship. From the initial tripartite model of citizenship suggested by Marshall (1950, 1963) – comprising civil, political and social citizenship – there has been a demand for new forms of citizenship, ranging from sexual or intimate citizenship (Phelan, 2001; Plummer, 2003; Richardson, 2000) to ecological or green citizenship (Dobson, 2003, 2005, 2006; Smith, 2005). As Phelan states, "the category of citizenship seems to open up under the pressure of multiple desires to identify with its promises." (2001: 13). New groups of people have emerged claiming citizenship rights. This has been the case of disabled people in most Western countries since the late 1960s and 1970s (Driedger, 1989) including the UK (Oliver, 1990; Campbell and Oliver, 1996; Barnes, Mercer and Shakespeare, 2000; Fagan and Lee, 2001) and Portugal (see Chapters 4 and 6). In order to do this, disabled people started to coalesce into uni- and multi-impairment groups and organisations to denounce their exclusion and oppression from civil society and from the state and to call for their rights as citizens. In fact, most disabled people have been discriminated against in many areas of their lives, from the segregation they experience within the education system, the welfare services and the labour market to the segregation forced upon them by the inaccessibility of the physical environment, which leads to the curtailment of disabled people's citizenship rights (Barnes, 1991, 1992a; Barnes, Mercer and Shakespeare, 2000).

Drawing on the previous analysis, it is my contention that the Disabled People's Movement has been fighting for rights to make disabled people equal citizens without challenging the dominant model of citizenship in each society. As Drake recognises, "the adopted definition of citizenship may itself prevent equality of treatment, membership and participation for some individuals." (2001b: 121). In fact, governments promote different definitions of what it means to be a citizen, dependent on what is

perceived to be the social, economic and political problems of the time and what they address in the social policies put forward. Taking this line of argument, Emery (2009) observes that deaf people:

are marginalised in society largely due to a citizenship that assumes an idealised individual as a speaking and hearing citizen, with a social policy constructed and made in the image of hearing culture, that is rooted in a philosophy of favouring by default the instruction of deaf children via oral means in overwhelming mainstream education. These state policies have resulted in an entrenched social exclusion of Deaf people.” (2009: 31)

Moreover, Marshall’s initial take on citizenship as a status closely connected with the state and focusing on the rights of citizens, has now been modified in most countries by the idea of citizenship as not only being about rights, but also about responsibilities, participation and contribution. As has been noted in the British case:

socially approved ways of obtaining income (particularly through ‘responsible’ participation in the paid labour market) are now an integral part of New Labour’s deliberations on acquiring the rights of citizenship (Prideaux, 2005: 140)

But social movements also promote different notions of citizenship. As has been argued throughout this thesis, the Portuguese Disabled People’s Movement, for most of its existence, and the UK Disabled People’s Movement, during some periods in time, have privileged a ‘rights based approach’ (Oliver and Barnes, 2006) to citizenship, understood from a narrow statist perspective. Arguably, this rights based approach ascribes greater importance to the individual (disability and impairment specific benefits), neglecting the collective aspect of disability (social oppression and discrimination, barriers to participation). As Phelan (2001) illustrates from an LGBT perspective, this approach may lead to problems in exercising rights, that only a collective perspective would help to overcome. In fact individuals may enjoy formally equal citizenship status but then be barred from exercising these rights in their daily lives. Such has been the case for most disabled people in the UK, but also in Portugal, who, despite having been granted equal citizenship rights formally, have been effectively denied most civil, political and social rights (Barnes, 1991, 1992a; Barnes, Mercer and Shakespeare, 2000). In the UK, the Improving the Life Chances of Disabled People report from the Prime-Minister’s Strategy Unit (PMSU, 2005) and the Disability

Equality Duty, which came into force in December 2006, mark precisely this theoretical acknowledgement of a social model perspective by the government. Recent political advances in the UK, which came into force through the Equality Act 2010 (GEO, 2010) however, might lead us to question this apparent progress, as they once again present disability as a direct result of impairment. As it states in Chapter 1 of Part 2 of the Equality Act 2010:

6 Disability

(1) A person (P) has a disability if—

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities. (Equality Act 2010, 4)

As my analysis reveals, social citizenship in Portugal is based on work and on the individual's contribution to the social security system. Those people whose needs have to be fulfilled through a needs based system (Stone, 1984), i.e. most disabled people in a disablist society have, in reality, a limited version of citizenship. As was analysed in Chapter 5, the low levels of redistribution in the Portuguese welfare state, in conjunction with the lack of enforcement of disability policies and the inefficiency of the law, has made disabled people extremely vulnerable to poverty and to social and economic exclusion. I would argue, therefore, that if the problem in the UK has been mostly one of a lack of opposition between the government's and the Disabled People's movement's citizenship projects, in Portugal this scenario is aggravated by the incomplete nature of the state's social citizenship project.

In sum, disability has been almost totally neglected in the citizenship debate and disabled people have thus been constructed as passive citizens (Meekosha and Dowse, 1997). Citizenship is, however,

the result of 'the way in which different groups, classes and movements have struggled to gain degrees of autonomy and control over their lives in the face of various forms of stratification, hierarchy and political oppression (Held, 1989: 199)

Therefore, there is a need to rebuild citizenship in an inclusive and non-statist way. Arguably, we need to move beyond the state (Hoffman, 2004) or at least the type of

state that has ruled our lives. In fact, as history reveals and social movements testify, the state has been a barrier to the citizenship of certain groups of people like women, ethnic minorities and, certainly, disabled people.

Inspired by a poststructuralist (Mouffe, 1993) and reflexive (Ellison, 1997, 2000) understanding of citizenship, I am tempted to suggest an intersectional approach to citizenship, according to which fragmented identities and solidarities would become proactively engaged in tackling discrimination on all grounds. This would, indeed, take human rights as the core for democratic participation and recognition, considering each person as a valid and precious actor. However, we do not live (perhaps, yet) in such an ideal world. There are (perhaps still) striking differences that are silenced by exclusionary hierarchies and processes of prioritisation that result in disabled people being denied citizenship rights. A similar need was felt, for instance, by movements for gender and sexual equality, leading to the increasingly recognised and researched concepts of intimate citizenship (Plummer, 2003), sexual citizenship (Richardson, 2000) and reproductive citizenship (Richardson and Turner, 2001). In this context, I argue that it is necessary to push the boundaries of the notion of citizenship in order to call for a non-ableist specificity. The distinction advanced by Ellison between 'proactive engagement' and 'defensive engagement' is valuable for this purpose. According to Ellison, a proactive engagement refers to the process according to which

social actors are able to exploit a particular political 'conjuncture' to further their own interests (or those of others) through significant interventions in those dimensions of the public sphere which privilege or 'recognise' these particular types of action. (Ellison, 2000: 2).

Ellison suggests a defensive engagement, described as resulting from the

restless desire for social engagement, citizenship becoming a form of social and political practice borne of the need to establish new solidarities across a range of putative 'communities' as a defence against social changes which continually threaten to frustrate such ambitions (1997: 714)

A non-ableist citizenship would emphasise the need for 'proactive engagement' in the field of recognition and a 'defensive engagement' in the field of rights. The usefulness of reframing the concept of citizenship in this vein is two-folded. On the one hand, it abandons an exclusively statist view, suggesting instead that emphasis should be placed

on changing disablism society at the same time that it ensures the state's commitment to legal protection and enforcement of its acts. This endeavour is undoubtedly at the core of collective action and research that is informed by the social model of disability. On the other hand, it goes beyond the various 'either/or' dominant theoretical perspectives of citizenship, according to which one can invest in recognition *or* redistribution (Fraser and Honneth, 2003; Young, 1989, 2000), proactive *or* defensive strategies (Ellison, 1997, 2000), statist *or* pluralist understandings (Marshall, 1950; Young, 1989, 2000). Whilst acknowledging that the main problem resides in ableism, the notion of non-ableist citizenship aims at engaging with both state and society, claiming both recognition and redistribution, employing an array of both proactive and defensive strategies of action. Arguably, embracing a non-ableist notion of citizenship will empower activists and researchers in the field, offering them (us) a name to call their own and a legitimate category enabling equality claims to be made. Being rendered invisible, silenced and oppressed will probably be more difficult when the notion – and, perhaps more importantly, the practice – of citizenship formally encompasses the idiosyncracies of the Disabled People's Movement. This is particularly important in contexts where the movement is fragmented and non-politicised, as it is the case in Portugal.

8.4. Future directions

The welfare-state's failure of disabled persons (Oliver, 1991) has made them especially active since the 1960s. This was especially true of the UK and USA (Shakespeare, 1993), where disabled people struggled "for equality and participation on an equal footing with other citizens" (Driedger, 1989: 1). As has been analysed throughout this thesis, this groundswell of action by disabled people in Portugal was only possible in the second half of the 1970s. This action occurred via the coalescence of disabled people into single and pan-impairment organisations and the creation of the Disabled People's Movement. Political consciousness was prompted by the welfare state's failure of disabled people in the British case (Campbell and Oliver, 1996; Oliver, 1990) and by the lack of a welfare-state and the oppressive nature of traditional culture in the Portuguese case. Since then, disabled people have been at the forefront of their destinies, proposing disability policies, challenging traditional disabling culture, lobbying the government, demonstrating and educating civil society. As has been

argued throughout this thesis disabled people have partially succeeded in their endeavours. In the UK, this is visible in recent documents adopted by the government, including the Improving the Life Chances of Disabled People report from the Prime-Minister's Strategy Unit (PMSU, 2005), the Disability Equality Duty and, most recently, the Equality Act 2010 (GEO, 2010). In Portugal, this is mostly visible in the incorporation of disability issues into the government's agendas and in the state's accountability for disabled people's well-being after 1974.

In recent years the acceleration of the process of globalisation has generated an internationalisation of disability policies and politics. As was explored in Chapter 7, this created an opportunity for the Portuguese Disabled People's Movement to force the implementation of some of the disability policies and politics that had been repeatedly postponed by the national government over many years. It is my argument, however, that the internationalisation of disability policies and politics also poses important challenges to the Disabled People's Movement in countries such as Portugal and, consequently, to the lives of disabled people. First, as was examined in Chapter 7, disability politics at the international level have centred on areas of disability policy that are less likely to produce state antagonism, i.e., areas more related to issues of 'regulation', rather than those of 'distribution' (Hvinden, 2003). This is highly problematic for countries such as Portugal, where 'distribution' issues are still at the core of the exclusion of disabled people. In this case, the internationalisation of the Disabled People's Movement's agenda might increase rather than reduce disabled people's exclusion from mainstream society.

Second, the implicit loss of power of the nation-state to regional and international institutions, like the EU, transformed the state into more of a reactive, rather than a proactive, entity. This means that in the area of disability policies the state is guided by the documents and treaties issued and ratified at the international level. The establishment of a benchmark means that the state need to go no further than the international treaties and institutions requires it to. Again, this raises complex issues in Portugal and similar countries, where the attention of the state is diverted from basic social rights, which have been downplayed by the internationalisation of disability politics, onto post-material rights, including discrimination and human rights issues (Oorschot and Hvinden, 2001), before the former have been guaranteed.

Finally, due to the state's underfunding of Portuguese organisations of disabled people, and their subsequent lack of financial resources, they are extremely vulnerable to the disability agendas of supranational bodies like the EU or the UN. Despite providing extra sources of funding for the organisations of disabled people, external international funding for projects in the area of disability may take over their agendas and redirect their strategies of action. These challenges, in combination with the focus on a rights-based approach or on a legal route taken by organisations of disabled people, pose a real threat to the collective political struggles for disability (Sheldon, 2005; Barnes and Mercer, 2010), without providing the necessary eradication of structural inequalities (Hahn, 2002) faced by disabled people in current societies.

Arguably, the future of the Disabled People's Movement depends upon its ability to find an internal 'common denominator' to unite disabled people, to recognise the multidimensionality of social oppression (Young, 1990) and to create alliances with other social movements at the national and international levels. As Vernon and Swain (2002) suggest, if the lives of disabled people are not threatened by a single kind of oppression and disablism, its eradication can only be achieved by addressing and challenging all forms of oppression faced by disabled people. In fact:

disabled black people, women, gay men and lesbians, older people and those from the working-class (...), all experience oppression singularly, multiply and simultaneously depending on the context (Vernon, 1999: 395)

This is especially important in the Portuguese context where issues of ethnicity and sexual orientation have been totally absent from the Disabled People's Movement's agendas and discourses, and gender issues have been considered only occasionally and are residual. Indeed, the Portuguese Disabled People's Movement is predominantly white and male dominated. In fact the leaders of the organisations of disabled people have historically been male with one, brief, exception in the case of APS from 1999 to 2000 (the current leader of APS – 2010/2013 – is also a woman).

In the face of such a complex reality, difficult heritage and the increasing antagonism from the power holders, the only way forward is therefore to create intersectional alliances with other social movement's organisations involved in combating discrimination and social oppression and creating a new emancipatory reality for everybody.

Conclusion

The first part of this chapter focused on debates about developments in social movements scholarship, revisiting the notion of social movement and the minority groups approach. This issue informed the second part of the chapter, in which the debate over the classification of the Disabled People's Movement as an old or a new social movement was explored. As was analysed, the Portuguese Disabled People's Movement is an interesting case study, which provides new data that may steer the theoretical and political debate in a new direction. Showing features that resemble both old and new social movements, this case study underlines the difficulty and complexities of the otherwise (allegedly) clear-cut distinctions between old and new forms of collective action. As was argued, this feature of the Portuguese Disabled People's Movement reflects wider characteristics of Portuguese society and of the Portuguese state, but also mirrors trends and changes taking place internationally.

The third part of the chapter discussed the process of (social) citizenship formation and its implications for the Disabled People's Movement. It addressed issues related to the exclusive nature of the concept when associated with the state as well as the importance of bottom up pressures, i.e. from civil society, in the process of citizenship formation. Arguably, as the Portuguese case indicates, there is a need to detach citizenship from the state and to create a more inclusive understanding of citizenship.

The last part of the chapter presented a critical evaluation of the future of the Portuguese Disabled People's Movement in the context of Europeanisation and globalisation. As was mentioned, internationalisation poses the risk of erasing the more radical and emancipatory claims and demands of the movement, making it more inclined to align with the state's mainstream agenda, rather than being proactive. Plus, as was suggested, its future lies in the recognition that disability is only one form of oppression that interacts with other aspects based on gender, sexual identity and ethnicity, creating more complex forms of discrimination. The task ahead can only reach success through the development of strategic, intersectional alliances with other social movements.

Conclusion

We are experiencing a time of economic crisis that poses a threat to already oppressed groups. This has historically been the case with disabled people (Beresford, 1996; Coleridge, 1993; Stone, 1999; Turmusani, 2001; Zaidi and Burchard, 2002; Sheldon, 2005, 2009). Capitalism may not be recent in human history (Held, 2006), but it has recently acquired a fiercer ‘face’, as the current worldwide economic crisis testifies. In the case of Portugal, ‘caught in the eye’ of this economic storm, recent statistics reveal a growing rate of social inequality (INE, 2010; Eurostat, 2011). In the UK, Conservative MP Philip Davies has recently suggested that disabled people should work for less than the minimum wage as a strategy to increase the likelihood of them getting a job (*The Guardian*, 2011), showing a clear disrespect for disabled people’s citizenship rights.

In the current scenario, citizenship, despite the arguments for being sectarian (Glenn, 2000; Hall and Held, 1989; Young, 1989), emerges as a “strategy of defensive engagement” (Ellison, 1997: 713), i.e. as a tool for social and political struggles, as well as a mechanism for creating solidarity between people. More specifically, as was argued here, disabled people need to access social rights in order to be able to exercise their civil and political rights.

In contrast to Marshall (1950), I do not believe in the meritocracy of the system. I argue that any extension of people’s rights is mostly the result of their own efforts to change that system. This thesis examined, thus, the development of the disabled people’s social citizenship project in Portugal since 1974 and the role of the Portuguese Disabled People’s Movement in generating political, social and cultural change in the area of disability in contemporary Portugal.

In this venture, I have considered wider historical processes of modernisation and Europeanisation, exploring how different factors have intersected, interacted and enabled this social movement to develop particular strategies leading to specific outcomes.

Combining an empirical study based in Portugal with cross-national historical experiences from Portugal and the UK, this thesis engaged with three main bodies of literature: disability studies, citizenship studies and social movement studies.

Within disability studies, there are competing definitions and models, with variable potentials for the emancipation of disabled people. In the case of the medical, or individual, model of disability, disability emerges as a direct result of impairment. Therefore the only 'solution' for 'abnormal' bodies rests in medical treatment and rehabilitation services administered by professional experts. As such, disability is the result of a 'faulty' body and disabled people are rendered dependent and passive regarding their own biographies. As was argued here, this model was the dominant one in disability policies both in Portugal and in the UK until very recently. The increasing politicisation of disabled people since the mid-1960s and the formation of politically engaged organisations of disabled people in the UK since the 1970s, such as the Union of the Physically Impaired Against Segregation (UPIAS), laid the ground work for the emergence of an alternative understanding of disability, commonly referred to as the social model of disability. According to this perspective, disability is not created by impairment, but by society instead, which disables people with an accredited impairment through cultural, social and environmental barriers (UPIAS, 1976; Oliver, 1990, 1996). This perspective represented a reversal of the cultural understanding of disability, as well as of disability policies by refocusing attention, and the intervention on society rather than on the individual. The need to reconcile both perspectives forged a new approach entitled the bio-psycho-social or the relational approach to disability, which is advocated by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and by authors such as Thomas (1999). In this new perspective, disability, i.e. 'activity', is determined by both the health conditions and the contextual factors surrounding that person. Again this perspective has had enormous impact on the lives of disabled people and on disability policies, however, as was shown earlier, through an overreliance on health conditions and individual factors, it prevents the politicisation of disability and allows policy makers to choose their own focus.

Based on my own epistemological and ontological standpoint, I situated my study in the framework of the social model of disability. Arguably, this model enables an analytical account of disability from a social oppression perspective, at the same time as it offers emancipatory alternatives to such oppression. Within the social model of disability I have positioned myself at the intersection between materialist (Finkelstein, 1980; Oliver, 1990; Gleeson, 1997) and idealist visions of the social model (Morris, 1991; Shakespeare, 1997a; Garland, 1995; Garland-Thomson, 1996, 1997).

The second body of literature investigated within this thesis was citizenship studies. After a brief historical account of the development of the notion of citizenship, including a consideration of the still pervasive traditions – republican and liberal – I considered the works of Marshall (1950, 1963) and Rawls (1971, 1985) due to their focus on social citizenship. Important to this field of study has also been the new perspectives on citizenship, such as the pluralist/multicultural accounts of Young (1989, 1990) and Kymlicka (1998) and the post-structuralist perspectives of Mouffe (1988, 1992; 1993) and Laclau and Mouffe (2001). During this discussion, the absence of disabled people from the theoretical debates was highlighted, as was the segregating, sectarian and exclusive character of the notions of citizenship proposed. However, as was discussed here, contemporary theoretical developments have contributed to a more complex and nuanced understanding of citizenship. Within the different debates, I endorsed Ellison's (1997) reflexive notion of citizenship as a strategy of defensive engagement that constitutes a sign of solidarity and unity.

In the field of social movement studies, I offered an overview of contemporary theoretical approaches to social movements, differentiating between American and European traditions of thought, as well as between social movements and other forms of collective action. Considering the North-American perspectives of political process theory (PPT) and of resource mobilization theory (RMT), the works of Tarrow (1988, 1994, 1995) and Tilly (1993, 1995) were explored. I also engaged with the European new social movement (NSM) theory, revising the work of Habermas (1976, 1981, 1987), Touraine (1981, 1985, 1987, 2002) and Melucci (1984, 1985, 1988, 1989, 1994, 1995, 1996). As was demonstrated, the possibilities created by NSM scholarship are crucial to this research to the extent that they enable a dynamic and agentic understanding of collective action, removed from the rational and strictly planned script that other approaches seem to expect from social movements.

Methodologically, I have triangulated different data generation methods and data sources, including participant observation, semi-structured interviews, a literature review and document and thematic analyses. As was stated in Chapter 3, this is also a partisan research, i.e. it is politically committed to the study of disability through the lens of the social model.

The historical overview of disability issues in Portugal before 1974 demonstrated that disability, and disabled people as a specific category, are modern creations, dating back

to the nineteenth century. This conclusion was based on the lack of specialised institutions for disabled Portugal before the nineteenth century and their inclusion within the broader category of 'poor people' who qualified for public assistance. As was argued in Chapter 4, the inauguration of specialised 'institutes' after 1823 marked the beginning of the medicalisation of disability, of the institutionalisation of disabled people according to impairment categories and of the exclusion of disabled people from the citizenship project in Portugal. I have suggested that such exclusion was maintained across time until the reestablishment of democracy in Portugal in 1974. I have identified four main factors that account for this continued exclusion. Firstly, despite the emergence of a new concern with the education of disabled children at the end of nineteenth century and early twentieth century, this venture was compromised by biased ideas about the role and work capacities of disabled people. Secondly, newly created organisations of disabled people after the 1920s continued to reinforce the exclusion of disabled people. Thirdly, organisations *for* disabled people, formed since the 1950s, relied on a charitable ethos and the work of professionals. As such, they were unable to challenge biased ideas about disabled people in the political and social spheres. Finally, as was shown, until 1974 the Portuguese state did not take a leading role in social provision, delegating this responsibility to families and charitable organisations. This compromised the establishment of social citizenship rights for the population as a whole, including disabled people.

In sum, Portuguese disability politics and policies were shaped by a combination of Judeo-Christian ideology, the endemic economic crisis of the Portuguese state and the leading role played by the family in social provision. This context has influenced the Portuguese state's attitude towards disability issues.

More specifically, I have suggested that disability policies after 1974 were mostly characterised by their disorganised, piecemeal, unplanned and mostly inconsequential features. After the establishment of the Portuguese welfare-state in the late 1970s, disability policies have been produced in a fragile balance between a needs-based approach and a rights-based approach. However, the financial difficulties of Portugal, its position in the economic world system, the compromises between political forces after the Revolution, the dominant role of the Catholic Church and the late development of the Portuguese welfare-state, meant that a needs-based approach dominated disability policies. As such, any legislation that has been approved within the spirit of a rights-

based approach has been doomed to failure, as legal documents determining the removal of physical barriers or establishing work quotas for disabled people illustrate.

Until very recently these policies were ideologically based on medicalised and individualised understandings of disability. Such conceptualisations had an impact on disabled people's lives, seriously hindering their ability to challenge discrimination and exclusion. Nevertheless, there has been a recent shift, with the expansion of disability policies concerned with social aspects of disability – what Drake (1999, 2001a), referring to the UK, describes as the 'citizenship paradigm' or a turn to a 'rights-based' approach. In the Portuguese context, such a turn is still embryonic. This reality, as was argued, has compromised the development of the disabled people's social citizenship project in Portugal, impacting deeply on the lives of disabled people and influencing the characteristics of the Portuguese Disabled People's Movement.

I have suggested that the Portuguese Disabled People's Movement is a post-1974 reality, whose emergence is a direct result of the long-standing exclusion of disabled people from the citizenship project. I suggested that the emergence of the Portuguese Disabled People's Movement stems from a three-fold political phenomena: the re-establishment of a democratic regime in 1974; the situation of social and economic exclusion experienced by disabled people; and the return of a large number of military people impaired in the colonial war (1961-1974).

I have also identified five major features of the Portuguese Disabled People's Movement, comparing and contrasting them with the British case. The main characteristic of the Portuguese movement is the lack of a collective ethos between disabled people. In contrast to the UK, where the existence of large residential institutions to accommodate, and exclude, disabled people from mainstream society spurred on the movement and the collective identity from the 1960s (Campbell and Oliver, 1996; Barnes, Mercer and Shakespeare, 2000), in Portugal the political regime and the small number of disabled people living in similar institutions limited the creation of such a collective identity. Such a collective ethos and critical thinking was only to be found amongst impaired war veterans in military hospitals. This was the starting point for the Disabled People's Movement in Portugal. It was the impaired war veterans who challenged the old-established organisations of disabled people. The difference in relation to the British case was the fact that ADFA never led the movement as happened with UPIAS (Campbell and Oliver, 1996).

Drawing on this, the second distinctive feature is the lack of unity within the Portuguese Disabled People's Movement, which has always been highly fragmented. This fragmentation mirrors a lack of politicisation in the Portuguese Disabled People's Movement, as was previously highlighted, as well as a permanent crisis of leadership. My analysis revealed that these facts have prevented the establishment of strong alliances between the organisations and have amplified the process of differentiation within the movement. In fact, it was never possible to bring disabled people together nor to give them a sense of collective identity beyond the daily specificities of their impairments, biographical narratives and institutional affiliations, in contrast to what the BCODP achieved in the UK with the politicisation of disability.

Thirdly, most Portuguese organisations of disabled people continue to focus on rehabilitation and welfare benefits to compensate for the 'flaws' of their bodies, which reveals the influence of the medical model. Even in the cases where there is an engagement with the social model of disability (APD and CNOD), this does not imply a shift in their understanding of disability, but rather the coexistence of both philosophies. An example of this is the simultaneous demand for anti-discrimination legislation and for disability specific benefits or for rehabilitation. It was argued that this lack of political and theoretical anchorage left the movement adrift. This was partially accounted for by the absence of an academic arm in the Portuguese movement, in contrast to the UK. The British Disabled People's Movement was inspired by the social model of disability. Its absence in Portugal has contributed to the movement's lack of any unifying principles. Moreover, such an absence made the movement particularly vulnerable to the influence of the state, making activists more reactive than pro-active and resulting in an agenda that is too narrowly focused on rehabilitation and impairment-specific benefits.

A fourth characteristic of the movement is the centrality of the body in the struggle. In contrast to the UK, the Portuguese movement has focused on the body, rather than on society. A clear example of this is the impaired war veterans, whose bodies have been used as the living proof of the country's debt to them. As the analysis revealed, however, the body is not only constructed as a locus of discrimination, but is also represented as the locus of emancipation, which can be achieved through rehabilitation and employment.

Finally, I singled out the movement's investment in 'first level demands', i.e. demands that focus on basic daily-living rights. 'Second level demands', i.e. demands that

transcend the attribution of rights to disabled people and emphasise social and political issues, are less common. The most persistent 'first level demand' made by the movement up to the present day is access to rehabilitation. In contrast to their British counterparts, who have focused on controlling services rather than being controlled by professionals, most Portuguese organisations of disabled people have always insisted on the creation of a national rehabilitation policy.

In contrast to other new social movements (Melucci, 1989, 1996; Wall, 1999), my socio-historical analysis of the Portuguese Disabled People's Movement demonstrated that activists have favoured traditional action strategies, namely political lobbying and raising social awareness, instead of direct action or political protest. As was discussed, this can be partially explained by the current dependence of disabled people's organisations on the state, as well as by the existence of psychosocial and physical barriers that continue to hinder the inclusion of disabled people. Nevertheless, I have also demonstrated the importance of foci of resistance, exploring to what extent this rather fragmented movement has been able to mobilise and make demands collectively.

The difference between the movements in Portugal and in the UK, it was argued, stems from the broader contexts of both countries. The lack of a well-established universal welfare-state capable of granting disabled people a minimum standard of living, means that Portuguese disabled people have had to rely on a low level of social protection, which frequently places them below the poverty line (Santos, 1999; Hespanha, 2001). This major factor has structured the Portuguese Disabled People's Movement, whose struggle has centred on achieving basic citizenship rights, with a particular emphasis on adequate healthcare, rehabilitation and work.

As has already been signalled, the relationship between the Portuguese Disabled People's Movement and the state can be partially described as the opposition between a rights-based approach and a needs-based approach to disability policies, particularly in the field of benefits and social rights. The internationalisation of the Disabled People's Movement and the involvement of organisations such as the UN and the EU, has contributed to the affirmation of a rights-based approach to disability issues. Pushing the movement's agenda towards adopting a legalistic strategy, this global politics of disability has also had an impact on the state, but not at the level of benefits and social rights. However, this rights-based approach has not had, until now, the impact anticipated by the Disabled People's Movement. Being more interested in establishing rights rather than exposing and undermining the roots of disabled people's oppression,

this process has had little consequence for the lives of disabled people, as has been shown throughout this thesis. In fact, the Portuguese reality is rife with examples of social and political rights that have been legally defined but never actually implemented, due to a tenacious non-enforcement of the law.

I suggest, however, that a rights-based approach does not contradict the premises of the social model of disability. Despite its inability to identify and tackle the roots of disabled people's oppression, I still believe that a rights-based strategy, if properly enforced, can be valuable in tackling the civil, economic and social discrimination experienced by disabled people on a daily basis. Yet, I am still persuaded by materialist criticisms of the rights-based approach, and thus I do not endorse this approach as a long-term strategy, but rather as a short/medium-term one that needs to be combined with a materialist perspective (Finkelstein, 1980; Oliver, 1990; Sheldon, 2005).

One of the central analytical dimensions of this study was the issue of the political and cultural impact of the Portuguese Disabled People's Movement. As was demonstrated, the transformation in disability policies and politics after 1974 was remarkable, and was mostly a response to the movement's claims. However, this shift has not happened without hardship. Since 1974 the movement has faced silent opposition from the state's power holders, including resistance to legal change, coupled with the lack of enforcement of legislation. It was argued that other structural issues account for this opposition too, including economic interests, the dominance of neo-liberal thinking within social policies, as well as the economic position of the Portuguese state. All of these factors have directed and framed disability policies and their outcomes in Portugal.

The analysis suggested two major trends in the movement's political impact. The first trend – the 'period of responsiveness', which spanned from the emergence of organisations of disabled people until the end of the 1970s – was characterised by a high level of access to the state and by structural impact on the government's disability politics and policies. The second trend – the 'period of detachment', which is still pervasive today – presented low levels of access to political power and reduced political impact.

Forging connections with the government, political parties and/or MPs has been used as the main action strategy of the Portuguese Disabled People's Movement. However, despite the movement's high level of impact on the establishment of governmental

agendas, it was only able to force through some of these promises and it had no influence in the way these policies were applied.

In relation to the cultural impact the movement has had, two major outcomes have been suggested, namely the formation of a culture of rights and the conquest of public space, making disabled people visible, as well as legitimate users of those spaces. These impacts have contributed to challenging the dominant disabling culture, despite showing significant differences to its British counterpart. As was discussed, the cultural revolution initiated by the Portuguese Disabled People's Movement did not question the existing social order or the existing conceptions of disability, and pushed instead for the integration of disabled people into existing frameworks. In addition, the Portuguese movement did not attempt to identify a common source of oppression, as it lacked an engagement with the social model of disability.

Despite these hindrances to a more profound transformation of dominant culture, arguably a cultural revolution was triggered by the Portuguese Disabled People's Movement, which was largely anchored in what I call a counter-narrative of disability. By this I mean a new understanding of disability and of being disabled, which challenged traditional oppressive views that portrayed disabled people as useless and as charity cases. It was this newly crafted narrative created by the movement that provided, to a certain extent, a common ground for the organisations, steering the debate on disability issues and mobilising people into collective action.

This is what I term the 'unfinished cultural revolution', as it has neither been able to overcome the disabling attitudes of Portuguese society, nor the antagonisms of a capitalist system, which hinders the social citizenship project of Portuguese disabled people.

Arguably, assessing the impact of social movements in the field of disability has become increasingly complex with the internationalisation of disability and the involvement of international forces that shape the possibilities, strategies and resources available to think, understand and struggle within disabled people's collective action. As was shown here, after the 1980s disability policies in Portugal resulted from a symbiotic relationship between national and international forces, enabling the conditions for the changes demanded by the Disabled People's Movement.

Using the Portuguese case study, this research has also engaged in wider theoretical discussions within social movement theory and social citizenship scholarship. After acknowledging the existence of different forms of collective action, I suggested four distinct elements of social movements: continuity, identity formation, ideologically-driven action and transformative intervention. I argued that social movements, formed by organisations and activists, evidence different patterns of interaction and intensity across time. In fact, social movements operate in waves of mobilisation, alternating between periods of intense networking and periods of limited exchange. As was signalled, networks of social movements are triggered by events that prompt action, offering social movements' organisations a specific reason for mobilising at a specific moment in time. The history of the Disabled People's Movement in Portugal showed the coupling and uncoupling of organisations over time and the formation of alliances for specific time-limited periods.

In addition, I have demonstrated the need for a more flexible understanding of social movements, in order to accommodate different cases, such as the Portuguese Disabled People's Movement, with diverse historical backgrounds and, consequently, with different biographical trajectories. Otherwise, there is a risk of misreading social movements as other forms of collective action. This risk is even greater in this case, as was discussed here, due to the tendency for the institutionalisation of the Disabled People's Movement over time, which makes its interest group component more evident. As was illustrated by the Portuguese case, organisations of disabled people have been transformed into interest groups, which form a social movement when they engage with each other in collective action for a specific purpose. Arguably, there is a need to conceptualise the Disabled People's Movement as a process, as networks of production of collective action and of collective identity enmeshed in specific structural conditions and particular geographic contexts. Only this would allow us to capture it as a social movement, as well as to acknowledge the changes that occur in social movements over time.

The conceptualisation of social movements as dynamic networks, which are constantly under construction and whose features result from the structural conditions of unique configurations of power and resistance, allows us to move on from the old/ new social movement debate. Arguably, this dispute has limited use for the Disabled People's Movement if it is to be regarded from an evolutionary perspective. As the Portuguese case reveals, materialist and non-materialist values have become closely intertwined and

the strategies of action that are pursued result from seeking to change disabled people's living conditions and structural factors within each society as well as from its specific political culture. Therefore, the role played by materialist or non-materialist claims should not be used to assess the social movement but, rather, to evaluate, in the case of the Disabled People's Movement, the level of disablism and of disabled people's oppression within any given society. From this point of view, the Disabled People's Movement can be seen as a barometer of citizenship formation.

As was argued here, disability has been almost completely neglected in the citizenship debate in Portugal and disabled people have been constructed as passive citizens. Therefore there is a need to rebuild citizenship in an inclusive, non-statist and non-ableist way. In order to accomplish that task, it was suggested that an intersectional approach to citizenship be used, according to which fragmented identities and solidarities become proactively engaged in tackling discrimination on all grounds. This would, indeed, take human rights as the core for democratic participation and recognition, and would consider each person as a valid and precious actor. This understanding of citizenship would emphasise the need for 'proactive engagement' in the field of recognition and a 'defensive engagement' in the field of rights.

In Chapter 8 it was argued that the construction of an inclusive society depends not only on the state, but also on the Disabled People's Movement. In fact, the future of the Disabled People's Movement in Portugal and elsewhere is dependent on its ability to recognise that social oppression is a multidimensional phenomenon which takes many forms (poverty, disablism, sexism, homophobia, racism, xenophobia, amongst others), whose constellations may magnify the discrimination felt by disabled people (Shakespeare, 1997b; Vernon, 1999; Vernon and Swain, 2002), and will influence its capacity to create alliances with other social movements at the national and international levels. Only alliances such as these will prevent the Disabled People's Movement from being distanced from disabled people's expectations and needs, and from being neutralised by new barriers, such as the present global economic crisis, which is currently strangling welfare-states and disability policies all over the world and, therefore, challenging disabled people's citizenship rights.

Thoughts about future research

I have learnt much from the process of exploring my topic and writing this thesis. Looking back, invariably there are things I would have done differently given the chance.

In relation to methodology, in order to contribute to the emancipation of disabled people I would like to apply the principles advanced in Emancipatory Disability Research more systematically in future work. As was discussed in Chapter 3 this was not possible within this academic research. In order to mitigate this, I am planning to organise several workshops with activists from the different organisations of disabled people I considered here as well as producing a summary report in order to overcome the language barrier created by writing a thesis in English, a language which is not accessible for the majority of the disability activists, and, therefore, to share and discuss my findings.

This research has also opened up the field for future research projects which hopefully will provide answers to a number of issues I came across during fieldwork. Firstly, the Portuguese media are powerful opinion makers, who influence the social representations of disability. As such, there is an urgent need to explore the conceptions of and images of disabled people being broadcast and publicised by major TV channels and national newspapers. Secondly, a thorough exploration of these conceptions is also needed in parliamentary debates on disability issues in order to explore the dominant conceptions of disability amongst Portuguese political elites. Thirdly, it seems important to encourage disability activists, historians and social scientists in general to write about the history of organisations of disabled people in Portugal and of the Portuguese Disabled People's Movement. As I can testify, in the field most materials are still there to be collected. However, there is an urgent need to organise and catalogue these materials in order to preserve them, as well as to collect the life histories of those people who have participated in and guided the movement since 1974.

Any research project includes decisions based on planning, contingencies and accidents, even if this is rarely acknowledged. These elements have played a role in this study as well, influencing the course of the research, as well as the analysis and findings. The interpretations advanced in this thesis are therefore a result of hermeneutical exercises, for which I am the main person responsible. As such, the findings remain open to

debate, contestation and re/signification. I hope that the Disabled People's Movement will be an important part of such dialogue, without which scholarship runs the risk of being void and pointless.

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APPENDIX

Appendix 1 – Researcher’s participant observation in the following events:

- 1) **9th National Congress of Disabled People** (one day event, organised by the CNOD) (20/10/2007).
- 2) **Extraordinary General Assembly of ADFA** (27/10/2007).
- 3) **Conference “Disabilities and Incapacities in Portugal”** (one day conference in Porto included in the ‘European Year of Equal Opportunities for All’) (30/10/2007).
- 4) **Seminar “Equal Opportunities, Disability and Dependency”** (seminar organized by the Institute of Social Security in Lisbon) (08/11/2007).
- 5) **Day meeting – ‘Perspectives upon Disability: to fix actions and to raise consciousnesses’** (one day event, organised by the Portuguese delegation of the European Network Against Poverty (REAPN) with several other local disability organisations *of* and *for* (mainly ‘for’) disabled people, within the ‘European Year of Equal Opportunities for All’ (30/10/2007 – Castelo Branco).
- 6) **Day meeting – ‘European Conference Celebrating Diversity – ‘European Year of Equal Opportunities for All’** (one day event organised by APD to celebrate the International Day of Disabled People in Portugal) (03/12/2007 – Lisbon).
- 7) **Demonstration** organised by the communist workers trade union – CGTP – joined by some of the organisations *of* disabled people (17/04/2008).
- 8) **Ordinary National General Assembly of ADFA** (19/04/2008).
- 9) 25th of April March, joined by some of the organisations *of* disabled people (25/04/2008).
- 10) **Mayday Demonstration**, joined by some of the organisations *of* disabled people (01/05/2008).
- 11) **Demonstration** organised by ADFA against the government cuts in the rights and benefits of impaired war veterans and direct relatives (14/05/2008).
- 12) **Demonstration** against the new labour package organised by the communist workers trade union – CGTP – joined by some of the organisations *of* disabled people (28/06/2008).
- 13) **Seminar “Terminology in Disability: To adjust the definitions to the language of human rights. One definition of Disability”**. (one day seminar organised by APD in Lisbon) (30/06/2008).

Appendix 2 – Disabled People social protection scheme

		DP up to 24 years old	Means tested	€		DP older than 24 years old	Means tested	€
Contributory regime	<u>Right acquired through parents contributory regime</u>	- Disability Additional Benefit of the Children and Youth Family Allowance Up to 14 years old From 14 to 18 From 18 to 24	No	€59.48 €86.62 €115.96	<u>Right acquired through parents contributory regime</u>	- Lifelong Monthly Disability Benefit	No	€176.76
		- Special Education Attendance Benefit Or	Yes	Depends on family income		- Additional Complement of Solidarity Up to 69 years old Older than 69	No	€16.83 €33.65
		- Third Person Assistance Benefit	No	€ 88.39		- Third Person Assistance Benefit	No	€88.39
	<u>Right acquired through deceased contributory relative</u>	- Surviving benefit	Yes	Depends on family income and number of people in the family receiving it	<u>Right acquired through deceased contributory relative</u>	- Surviving Benefit	Yes	Depends on family income and number of people in the family receiving it
<u>By own right resulting from their contributory regime (impairment must not be caused by professional activity)</u>					- Invalidation Pension	Yes	Minimum amount guaranteed: €236.47	
					- Dependency Complement Grade 1 Grade 2	No	€90.96 €163.72	
		DP up to 24 years old	Means tested	€	DP older than 18 years old (unable to work)	Means tested	€	
Non Contributory regime	- Disability Additional Benefit of the Children and Youth Family Allowance Up to 14 years old From 14 to 18 From 18 to 24	No	€59.48 €86.62 €115.96	+ - Additional Complement of Solidarity Up to 69 years old Older than 69	- Invalidation Social Pension	No	€181.91	
		- Special Education Attendance Benefit Or	Yes		Depends on family income	- Third Person Assistance Benefit	No	€16.83 €33.65
		- Third Person Assistance Benefit	No		€ 88.39	- Third Person Assistance Benefit	No	€ 88.39
						Or Dependency Complement Grade 1 Grade 2	No	€81.96 €154.62

Adapted from INR (2009)