

# **Challenges Facing the Disabled People's Movement in the UK: An Analysis of Activist's Positions**

**Steven Dodd**

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## Abstract

This thesis explores disabled activist's perceptions of the challenges to British disabled people thrown up by changes in policy and cuts to services made by the coalition government of 2010-2015. These themes are explored through a qualitative analysis of interviews conducted with 20 disabled activists.

The thesis begins with a presentation of the history of the British Disabled People's Movement, drawing on writers such as Hunt (1966, 1981), Campbell and Oliver (1996) and Barnes and Mercer (2006). This is followed by an overview of available evidence concerning current challenges to the standard of living of disabled people. The next chapter involves a discussion of methods in the form of a narrative account of the development of the thesis. This is followed by an interrogation of prominent methodologies in disability research, pointing to the strengths and drawbacks of the emancipatory disability research approach (Oliver, 1992; Barnes 2008) by drawing on critical realist perspectives (Sayer, 1992; Lawson, 1999). Moving on to an analysis of interview data, the combination of challenges currently facing disabled people are explicated. To make sense of challenges revealed at individual, collective and ideological levels, the notion of 'enforced individualism' (Roulstone and Morgan, 2009) is drawn upon. It is argued that, taken together, these challenges comprise novel forms of disablism that coexist with older and more familiar forms of disablism associated with paternalism and oppression within institutions. Following examination of these challenges, attention turns to the political positions and responses that disabled people have adopted in reaction. To theorise such responses, Fraser's (1995: 2003) analysis of injustice and resistance is applied to the political positions taken by participants. Later chapters reflect further on injustice and resistance, drawing again on Fraser, as well as the extension of the social model of disability presented by Thomas (1999; 2007; 2010; 2012), the political theory of Holloway (1991; 1993a; 1993b; 2005) and the political economy of Polanyi (1944). These theories serve to highlight the nature of contemporary anti-disablist resistance, and also provide a novel means of conceptualising the relationship of disability studies and disability activism.

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## List of Abbreviations

British Council of Disabled People (BCODP)  
Centres for Independent/Integrated/Inclusive Living (CILs)  
Deaf and Disabled People's Organisation (DDPO)  
Derbyshire Centre for Integrated Living (DCIL)  
Direct Action Network (DAN)  
Disability Action Alliance (DAA)  
Disability Alliance (DA)  
Disability Income Group (DIG)  
Disability Living Allowance (DLA)  
Disability Rights UK (DR UK)  
Disabled People Against the Cuts (DPAC)  
Disabled People's Movement (DPM)  
Disabled People's Organisations (DPOs)  
Discretionary Housing Payments (DHP)  
Emancipatory Disability Research (EDR)  
Fair Access to Care Services (FACS)  
Independent Living Fund (ILF)  
Independent Living Movement (ILM)  
Joint Committee of the House of Commons and Lords on Human Rights (JCHR)  
Local Housing Allowance (LHA)  
National Centre for Independent Living (NCIL)  
Office for Disability Issues (ODI )  
Personal Independence Payment (PIP)  
Resource Allocation System (RAS)  
Royal Association for Disability and Rehabilitation (RADAR)  
Union of the Physically Impaired Against Segregation (UPIAS)  
United Nations Convention on the Rights of People with Disabilities (UNCRPD)  
User-Led Organisations (ULOs)  
UK Disabled People's Council (UKDPC)  
Work Capability Assessment (WCA)

# **Chapter 1: The History of the British Disabled People's Movement**

This thesis explores disabled activist's perceptions of the challenges to British disabled people thrown up by changes in policy and cuts to services made by the coalition government of 2010-2015. It also examines the political positions and responses that disabled people have adopted in reaction to these challenges. It is structured around a qualitative analysis of interviews conducted with 20 disabled activists. It was necessary to restrict the sample group to the narrower constituency of those with physical impairments (see chapter three), but some of the questions and conclusions thrown up by the research could prove relevant to other people who self-define as a disabled person. Research for the thesis began in January 2011 and writing up was completed in November 2014. Central to the concerns of the thesis are the policies implemented by the government upon its election in 2010, as it embarked on a strategy of deficit reduction, in main characterised by reducing public sector expenditure. At the time of interviews from March 2012 to January 2013, some cuts to services and benefits were still in the planning stage, and thus some interviewees were more concerned with establishing their concerns about anticipated challenges, rather than addressing prior impacts of cuts and reforms.

In this first chapter I will summarise one of the two main elements that form the background to my thesis, giving a brief overview of the British Disabled People's Movement (DPM). This serves the purpose of positioning participants within a wider social movement, and contextualises their contributions, showing why their contributions to this thesis are valued.

## **The British Disabled People's Movement**

Current activism and opposition to government policy follows a notable history of disability activism in the UK. In the past this activism has done much to challenge the situation of disabled people in British society, and it is likely to have a major role in any opposition to the policies I describe in the next chapter. Together with the impact of



austerity on disabled people, the nature of disability activism in the UK provides the primary background consideration to this thesis.

Within this chapter I could not hope to do justice to the diversity at work currently and historically within the British DPM. Omission from the following discussion should not be taken to mean that I consider omitted topics and organisations insignificant. I proceed with the modest goal of sketching some key developments and key ideas within the movement, to contextualise the rest of the thesis.

The history of the DPM reflects the development of the movement through its various strands and factions, and therefore any account of its history is inevitably partial, contentious and open to question. In writing this history I have primarily drawn upon Campbell and Oliver's interviews with key actors in British disability politics in their presentation of 'a series of perspectives on the process of self-organisation of disabled people' (1996: 17) over the preceding thirty years. Campbell and Oliver's text is of particular significance as an example of research carried out with disabled activists. To the best of my knowledge it is one of very few examples of research of this sort. Another important example of relevant research comes from Barnes and Mercer (2006). Though they do not refer to their research participants as 'activists', it is reasonable to infer that many of them could be described as such. This is because their research involved interviews with a range of staff and users of services in Disabled People's Organisations (DPOs) across the country, both in well-established and newer DPOs. Many of their participants would appear to fit the profile of an activist. The aim of their work was to 'assess the development of Centres for Independent/Integrated/Inclusive Living (CILs) and similar user-directed service organisations' (Barnes and Mercer, 2006: 63). In complement to these more recent texts, I also draw upon some notably influential texts from the earlier period of the modern movement (Hunt, 1966; UPIAS, 1976). Overviews of the more recent history of the movement are scarcer, perhaps reflecting a decline in the vigour of the movement's activity (Oliver and Barnes, 2006). Alternatively, it may be that movement actors have been more concerned in recent times with action and less with systematic reflection in written form. When I turn to very recent activist history at the end of this

chapter, the account given is primarily re-constructed from grey literature, such as blogs written by disabled activists and representatives of DPOs.

The detailed literature concerning the British DPM typically begins with reference to the efforts by those within residential institutions to increase the level of autonomy they experienced in everyday life (Campbell and Oliver 1996; Barnes and Mercer, 2006). Barnes and Mercer observe of this early activism that it 'stressed self-determination, choice (where and how to live) and control over support services (who assists, how and when), and the removal of disabling barriers in mainstream society' (2006: 33). The growth in consciousness this involved was based on disabled people forming groups and, through cooperation, learning more about what they shared in common (Campbell and Oliver, 1996). It is clear that these scholars believe something distinctive began in the nineteen sixties. This can be understood against a context in which the formation of the welfare state created new formal rights for disabled people, but by the 1960s 'many disabled people were faced with the choice of managing with little or no service input or being shut away in a geriatric ward, a Cheshire home, or the like' (Campbell and Oliver, 1996: 29). In this sense, the promise of greater equality and autonomy offered by the formation of the welfare state was not experienced by large numbers of disabled people. As the affluence of society as a whole grew, and standards of living improved for many previously impoverished sections of society, disabled people were in a stronger position to become more assertive in demanding similar levels of prosperity.

Both Campbell (1997) and Shakespeare (1993) link the growth of the DPM in this period to the emergence of other new social movements. This is to say that they link the development of the DPM in the nineteen sixties to other movements that emerged at a similar time. Such movements eschewed traditional forms of political mobilisation, seeking to address political objectives ignored by mainstream political organisations. To build on the tentative statements of Campbell (1997) and Shakespeare (1993), one might link the growth of the DPM to the post-materialist thesis of Inglehart (1971). Inglehart's basic contention is that the satisfaction of the basic material needs of much of society opened up its members to consideration of other non or 'post' material political demands. Relatedly, one could argue that changes

towards a post-industrial society (Touraine, 1974) meant that disabled people could be more included in the workforce leading to greater potential rewards for employers. Such a background may have meant the demands of disabled people were easier to bring about than in the industrial past. Arguments about the shift to post-industrial or post-materialist societies are frequently linked to the emergence of new social movements in general and may have a degree of relevance to the DPM. However, more than many other social movements, the DPM arguably has a strong class based dimension (Priestley, 1999), demanding a redistribution of resources to bring about participation on the basis of equality (Morris, 2011). Thus although the DPM grew at a similar time to many other social movements, the post-materialist thesis of Inglehart (1971) tends to overlook an economic based argument of this sort. This is not to suggest that other new social movements are exclusively post-materialist. Indeed it could be argued that the DPM shares with anti-racism, feminism and other movements a 'bivalent' (Fraser, 2003) struggle against both cultural and economic oppression (See chapter eight).

Given the significance of economic questions to the DPM, it is relevant to refer to Roulstone's (2002) exploration of the relationship of the DPM to older social movements such as trade unions. One of Roulstone's concerns is with the way trade unions have largely been unable to defend aspects of the welfare model that are of value to disabled people. This, he argues, is because they have been ill-suited to resisting the 'spatial, technological, trade, political and discursive' (2002: 634) elements of globalisation. These elements operate at a level beyond the reach of national trade unions and pose problems for the UK welfare model. Other than challenges to the welfare model, disabled people face further problems in the labour market that unions have thus far been unable to overcome (ibid). For example, Roulstone highlights the results of applying ideals of 'flexibility' and labour discipline to both public and private sector employment. As parts of the public sector have been contracted out, work in cleaning, catering and laundering has required employees take less pay for more labour (ibid). Roulstone argues that this and the process to competitive tendering has meant people with impairments have lost work due to the

way in which the relevant contractors have selected against those they perceive to be 'less fit' to work, removing many disabled people from the work force.

Roulstone was perhaps more hopeful regarding the role that new social movements could take in defending and extending disability rights, noting their capacity to use information technology to span national borders and tackle international challenges (ibid). Fifteen years after Roulstone wrote, it may be argued that new social movements have been no more able than trade unions to resist challenges to disabled people in the UK either in the labour market or welfare and social care.

To conclude this brief discussion of social movements and the DPM, it is notable that the challenges the DPM faces combine elements characteristic of those faced by both old and new social movements, incorporating economic elements that are arguably of a more recognisably traditional form than those typically associated with new social movements. Arguably, the most obvious recent challenges to the DPM have been driven by an economic commitment to shrink public spending as a proportion of GDP and to remodel the state on more streamlined neoliberal ideals (Blyth, 2013). This perhaps suggests the continued relevance of trade unions to disabled people because they represent the largest and most obvious means by which these trends may be challenged. On the other hand, greater collaboration between trade unions and the DPM would not be straightforward, particularly given a history of trade unions defending workers and jobs in cases in which professional practices are perceived to be oppressive or paternalistic by many disabled people.

To continue discussion of the history of the DPM, it is instructive to examine the essay *A Critical Condition* by Paul Hunt (1966). It is part of his book *Stigma: The Experience of Disability*, which has been described as the 'first important book written by disabled people about disability issues' (Campbell and Oliver, 1996). This text is not only of interest in its own right, but can also be read in light of the pivotal leadership role that Hunt played in the emergence of the DPM (ibid).

Hunt drew on the concept of 'the other', arguing that disabled people's position challenges and causes discomfort to the values of the rest of society because

they are seen as 'unfortunate, useless, different, oppressed and sick' (Hunt, 1966: 2).

He summarises the role of disabled people as 'the other' in the following analysis:

Contact with us throws up in people's faces the fact of sickness and death in the world. No one likes to think of such which in themselves are an affront to all things, our aspirations and hopes. A deformed and paralysed body attacks everyone's sense of well-being and invincibility. People do not want to acknowledge what disability affirms - that life is tragic and we shall all soon be dead (1966: 8).

The way in which disabled people are constituted as 'the other' underpins what Hunt saw as their oppression. Hunt records that he has 'seen disabled people hurt, treated as less than people, told what to do and how to behave by those whose only claim to do this came from prejudice and their power over them' (ibid: 6). In reference to institutional settings, Hunt makes the following observation of his experience of the oppression of disabled people:

There are administrators and matrons who have had people removed on slight pretexts, who try to break up ordinary friendships if they don't approve of them. There are the staff who bully those who cannot complain, who dictate what clothes people should wear, who switch the television off in the middle of a programme, and will take away 'privileges' (like getting up for the day) when they choose. Then there are the visitors who automatically assume an authority over us and interfere without regard for our wishes (1966: 7).

Hunt's work appears to have been a novel development in that it is written by a disabled person and characterises disabled people's political position in terms of resistance to oppression. His analysis offers a potent example of the power of taking this analytical step, and the way in which it leads to generalising from one's own experience to that of a broader group. This can be seen as Hunt goes beyond his experience of institutions to observe:

Employers turn away qualified and competent workers simply because they are disabled. Restaurants and pubs give transparent excuses for refusing our custom. Landladies reject disabled lodgers. Parents and relations fight the marriage of a cripple into their family (1966: 7).

Following from this analysis of shared oppression, Hunt articulates the challenge offered by disabled people to society as a whole, demanding of it that disabled people are included and integrated. This demand reflected a growing refusal of disabled people to be ignored and oppressed (ibid). Anticipating the later social model of disability, Hunt argues that the focus should be on the change required in society and not on the failings of disabled people. He frames this within the need to overcome the othering of disabled people and the principle that 'society is itself sick if it can't face our sickness' (ibid: 9). Disabled people are a challenge 'to values that put attributes or possessions before the person' (ibid: 10), experiencing life from a position that is 'uncomfortable' and 'subversive' to those who insist on the dominance of these values.

At the time at which Hunt wrote, an important trend in disability activism was the emergence of the Disability Income Group (DIG), dedicated to gaining disabled people a fairer share in the growing wealth of British society (Campbell and Oliver, 1996; Barnes and Mercer, 2006). Although this group was centred on the campaign for greater income, it also had a broader significance, as a forum through which people with different impairments could come together and share ideas (Campbell and Oliver, 1996). It was formed by two disabled women but, for Campbell and Oliver, it ultimately represented a 'false start [...] on the road to liberation' (1996: 63). This is because 'it promised more than it delivered' (ibid), failing to achieve its goals in part because it became subject of a schism 'between those who wanted to become a single issue lobbying group and those who wanted to become a mass movement' (ibid). Increasingly there was a divide between the grass roots of the group and a relatively small group of lobbyists who were often able-bodied. According to Campbell and Oliver, these factors ultimately meant that the income-centred approach of DIG became discredited (ibid).

Although Campbell and Oliver describe DIG as a 'false start', it may have been an instructive experience for disabled people seeking to drive forward political change. This is because the formation of the Union of the Physically Impaired Against Segregation (UPIAS) was, in the words of one of its key activists, Vic Finkelstein, based on a 'direct criticism of DIG' and the failure of DIG 'to see disability broadly'

(Finkelstein, interviewed in Campbell and Oliver, 1996: 64). UPIAS was, in contrast to DIG, dedicated to looking at disability as a totality and not as a single issue, addressing the full range of barriers and discriminations disabled people encounter (ibid). Finkelstein argued that this holistic approach to disability followed from Paul Hunt's clarification of the principles that disabled people should have 'control over their own lives' and also that 'disability is not a single issue' (ibid: 64).

The formation of UPIAS was strongly influenced by Paul Hunt (Campbell and Oliver, 1996) who instigated the emergence of UPIAS through writing a letter to the Guardian newspaper inviting others to write to him and join him in political mobilisation:

Severely physically handicapped people find themselves in isolated, unsuitable institutions, where their views are ignored and they are subject to authoritarian and often cruel regimes. I am proposing the formulation of a consumer group to put forward the views of the actual and potential residents of these successors to the workhouse (Guardian, 1972 cited in Campbell and Oliver, 1996: 65).

Hunt's letter attracted responses from like-minded individuals. What ultimately became UPIAS began as an internal circular exchanged confidentially between members of the emerging network instigated by Hunt's letter. Communications were made confidentially so as to protect the identity of institutionalised correspondents who were vulnerable to the power of institutional staff and management (Campbell and Oliver, 1996). UPIAS appears to have been a dedicated and determined organisation. In the words of Ken and Maggie Davis (quoted by Campbell and Oliver), the union was 'very committed to the political requirement facing disabled people, which was to produce a rigorous, dependable explanation of disability in social terms that enabled society itself to be seen as the focal point of disabled people's attention' (1996: 66).

This requirement led to the writing of a manifesto *The Fundamental Principles of Disability* (1976) which contained a now famous passage which firmly asserted society's responsibility for the creation of disability:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1976: 14).

This analysis inverted common sense ideas about disability and rejected the individualisation and medicalization of disabled people's situation. It separated biological impairment from the social oppression of disability. From an essentially social analysis of disability flowed a stance on political action that arguably continues to characterise much of disability activism in the UK:

The correct direction for the Union's main energies follows from our view of the cause of our oppression. We see the essential task, at this point in time, as that of helping disabled people to organise together to take a more active part in struggling for the changes in society which will ensure that we are brought into the mainstream of life, rather than being excluded (UPIAS, 1976: 14).

The social interpretation of disability that informed this strategic analysis does not deny the medical definition of impairment, or deny that impairments can cause difficulty, but seeks to separate the individual experience of impairment from the social process of oppression that those with impairments experience in a disabling society. This way of interpreting disability was subsequently popularised, firstly by Oliver (1983), as the social model of disability. By this Oliver referred to:

Nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people (Oliver, 1983: 23).

This view continues to influence debate on disability, especially but not only in the UK, both within activist groups and within disability studies. Disability studies (an academic discipline concerned with research into disability related-issues) itself grew as it pursued research informed by the social model, building on earlier work by activists based on a 'disability as oppression' perspective such as that of Finkelstein (1980). The social model continues to exert a strong influence within disability studies, and has



played an immensely influential role within disability activism in the UK (Hasler, 1993). It has also become the object of increasing criticism from some academics (e.g. Shakespeare, 2006). I refer to it throughout this thesis and explore it further in chapter nine.

UPIAS established important ideas of this sort and stated them with cogency but they did not attract mass support (Campbell and Oliver, 1996). In the view of some of those interviewed by Campbell and Oliver, this may have been because of the perception that it was exclusionary, male dominated or aggressively argumentative (ibid). Later in the early nineteen eighties, as DPOs grew in different parts of the country, the British Council of Disabled People (BCODP) was formed to strengthen local movements by bringing them together through a national forum. Varying accounts of the genesis of BCODP are given by interviewees in Campbell and Oliver (1996), including references to the need identified by members of UPIAS to build an alternative organisation with a wider constituency.

Campbell and Oliver and their contributors generally agree that the BCODP played a crucial role in the history of the DPM in the UK. Judy Hunt, quoted by Campbell and Oliver, argues that the emergence of BCODP marked 'the point at which the movement became very visible and took on board the social interpretation of disability' (1996: 80). It built on the work of those like Hunt and UPIAS in earlier decades and, through its greater scale and national constituency, pushed important issues toward a higher profile in general political debate. These issues included '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' (ibid).

The existence of the council itself was also important to its members, demonstrating the strength that could be drawn from representative members of DPOs, and offering a powerful contrast with organisations 'for' disabled people which exercised power on behalf of disabled people without their democratic input (Campbell and Oliver, 1996). In the view of Campbell and Oliver it also had definite

practical benefits, offering a powerful reminder to those in control of disability policy that they were under the watch of a nationally organised disability organisation dedicated to change (ibid). The authors also argue that it gave legitimacy to local organisations of disabled people, making it easier for them to attract resources and members, in turn allowing members of local organisations to feed their experiences of success back into the BCODP.

BCODP was not without its problems and it was criticised by some of Campbell and Oliver's (1996) activist interviewees for appearing to be too radical in its demands; too influenced by left-wing politics; dominated by wheelchair users; and wrong to act as if it represented disabled people in general. It also suffered problems due to having to compete with the 'disability establishment' of charities and private sector care providers, meaning it was often perceived to be poorly resourced and organised (ibid). Despite these problems, it is hard to dispute that the BCODP had a valuable impact on many disabled people's lives. One prominent example of this is its role in the campaign to establish anti-discrimination legislation for disabled people (ibid). Others include its role in 'creating and funding the National Centre for Independent Living (NCIL) in 1997, which became the leading organisation giving information and support to local centres for independent living' (UKDPC, ND)<sup>1</sup>. It also influenced the development of the Community Care (Direct Payments) Act (1996) and established a Research Unit at the University of Leeds (ibid). It continues to exist today as the UK Disabled People's Council and still functions as a membership organisation for various regional DPOs. Of similar prominence today is Disability Rights UK, formed from a unification of Disability Alliance, Radar and the National Centre for Independent Living on 1 January 2012.

There are few sources available which discuss the history of the DPM in the first decade of this century. This may be a reflection of a period in which comparative economic stability brought gains to disabled people as the ideas of the movement gradually gained a foothold within parts of policy making communities. Another explanation may be the increasing professionalization of parts of the movement and its integration with the state and service providers (Oliver and Barnes, 2006). This

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<sup>1</sup> <http://www.ukdpc.net/ukdpc/pages/who.php>

might mean activists had less time to dedicate to writing histories or engaging in self-conscious theoretical reflection on the practice of the movement. This could be read as a sign of success in that the decline in visibility of the movement may have signalled its achievement in gaining a platform for movement actors and the objectives of the movement. Dejong (1983, cited by Barnes and Mercer, 2006: 138) writes of the American Independent Living Movement that it increasingly sought change by working within government and through cooperation, as its grievances and policy recommendations began to be accepted. This could arguably be applied to the DPM in the UK through the late nineteen nineties and the 'noughties' as it seemed to lose some of its campaigning visibility. A process of absorption of movements into existing social structures is in keeping with social movement theory exploring the stages through which movements evolve. For example, Blumer (1951) describes a four-stage 'life-cycle' of social movements, ending with institutionalisation of a movement as it becomes an embedded and absorbed part of society and takes on professional form.

From this view, the decline of writing about and engaging in political protest may be reflective of the success of the movement had in persuading politicians of their cause. Alternatively, in a view closer to that of Oliver and Barnes (2006), this process could be seen as the co-option and professionalization of the movement. Given the apparent decline in writing about the movement until very recently, when I return to my overview of the DPM, I will be discussing the recent history of the movement and its response to contemporary challenges.

By giving this background to the emergence of the DPM, I hope to have established the field of contention with which the movement is concerned. The academic field with which this thesis can broadly be identified, disability studies, shared a similar set of ideas to the DPM at first, but has undergone significant diversification in the last two decades, expanding to embrace areas of concern such as embodiment (Loja *et al*, 2013); disability in the global south (Soldatic, 2013); disability and the life course (Priestley, 2003); and internalised oppression and psycho-emotional disablism (Reeve, 2002). Theoretical and methodological changes have also developed in disability studies, with an increased interest in post-structuralist ideas (Shildrick, 2012; Goodley, 2013) and critical realist approaches (Bhaskar & Danermark,

2005; Shakespeare, 2006). Despite this diversification, it is fair to say much of disability activism (my primary area of concern) remains informed by the principles established in the earlier part of the movement's history. Before I turn to the recent history of the DPM, I will clarify the relation of the DPM to the Independent Living Movement (ILM). In doing so I will more fully describe the field of contention concerning British disabled activists.

## **The British Independent Living Movement**

The Independent Living Movement (ILM) has emerged and grown over a similar period to the DPM, sharing many of its objectives and participants. At times the terms ILM and DPM can be referred to interchangeably, reflecting the difficulty one would have separating them in practice. The terms 'DPM' and 'ILM' can be usefully employed to denote differing emphases and tactics among disabled activists. To give an impression of the differences at work, I now give a brief overview of the history of the ILM in Britain.

Describing the origins of the ILM in the nineteen seventies, Evans (2002) notes how its emergence resulted from the disenchantment that many British disabled people were feeling with services provided for them. As he puts it 'Disabled people felt the services were paternalistic, institutional, second class, too medically orientated and out of touch with their real needs' (2002: 1). In complement to this account, Morris (1993; 1994, cited in Barnes and Mercer, 2006: 39) summarises the following failings of state and voluntary sector provision of 'care' which gave impetus to the movement:

- Low standards, with complaints of lack of respect, neglect and abuse – in the community as well as in residential settings;
- A failure to ensure equal access and opportunities to engage in everyday activities;
- The presumption of service provider control and user passivity/compliance; and
- A lack of accountability, with little recognition of the rights of service users

These failings gave additional motivation to disabled people who wished to leave institutions and instead live in the community with personal assistance. Those driven by these grievances in the UK differed from their counterparts in the American ILM whose campaign was initially concerned with gaining greater independence at university in the late nineteen sixties (Evans, 2002).

Of those demanding independent living in the UK, among the first groups to move out of an institution into living in the community were some of the residents of Le Court residential home in Hampshire. For Evans, the position they took against the institution in which they lived represented a refusal 'to accept that they were destined to spend the rest of their lives excluded from the rest of society' (2008)<sup>2</sup>. Evans and the others who comprised this group wished to apply the principles of independent living imported from the USA, including 'asserting control about the decisions of their lives, empowering themselves, taking more responsibility about what was happening to them and developing their own choice' (2002: 3). Following three years of persuasion and negotiation, the group negotiated a financial package with their local authority to enable them to move out of their institution into their community. In practice their local authority 'provided them with the amount of money, agreed through an assessment which they could then use to pay for the support they needed through employing their own personal assistants (2002: 4). At this point direct payments to users of services were illegal, meaning an elaborate alternative needed to be constructed. Barnes and Mercer describe this development:

'An innovative arrangement of 'indirect payments' was agreed. It allowed local authority funding of an individual's institutional 'care', subject to an assessment, with individual cash payments in lieu of the institutional services received. The money was paid into a trust fund (with a local authority or voluntary organisation) on behalf of the user. And was used for personal assistance to enable the disabled person to live in the community (Barnes and Mercer, 2006: 46).

Deriving huge benefit from this arrangement, the group sought to share and spread their experiences by founding the Hampshire Centre for Independent Living (CIL) in

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<sup>2</sup> <http://www.independentliving.org/25years2008evans#speech>

1984. This important development involved the creation of a centre available for all disabled people, run by disabled people (Evans, 2002). Such an arrangement was designed to develop 'expertise around Independent Living issues which could easily be passed on to other disabled people through advice, information, peer support, self-help, sharing and training' (ibid: 6). The main initial focuses of Hampshire CIL were with ensuring that independence of disabled people living in the community was made possible through suitable housing and sufficient personal assistance.

Also in 1984, the Derbyshire Centre for Integrated Living was founded. Although this shared broadly similar priorities to Hampshire CIL, Evans (2002) notes that the two centres had quite different approaches. While Hampshire CIL had a narrower focus on personal assistance, support and direct payments issues, Derbyshire CIL adopted a broader range of priorities inspired by the 5 core services developed by the first CIL in Berkley, California. These included: housing, personal assistance, mobility/transport, access and peer counselling. To this they added information and technical equipment including support (ibid). These became known as the Derbyshire seven needs, exerting great influence over incipient CILs in other parts of the country. Among the first CILs to follow in the UK were Southampton, Nottingham, Bristol, Islington, Lambeth, Greenwich and Lothian (ibid).

As a key participant in ILM, Evans (2008) stresses the central role CILs have played in the push toward independent living, arguing that they were well placed to promote further such initiatives because they were:

Endowed with an invaluable expertise, which was essential in supporting a sustainable framework to enable the movement to flourish. It was a collective approach which soon developed a dynamic network of different models of exchange, ideas and practices throughout the country<sup>3</sup>.

The number of CILs grew through the nineteen eighties and nineties, and although they have experienced increasing financial pressures and competition from private

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<sup>3</sup> <http://www.independentliving.org/25years2008evans#speech>

sector and charitable organisations, by 2008 Evans could report that there were roughly fifty across the UK (ibid).

Differences in how independent living is implemented by different CILs are reflective of the fact that independent living is both a governing approach or philosophy and a practical delivery method of supporting relationships. As a philosophy, IL is a demand that self-determination be understood as a human right and a refusal to equate physical needs with dependency. As a delivery method, IL puts these principles into practice through measures such as direct payments and individual or personal budgets<sup>4</sup>. Such mechanisms have the potential to deliver greater independence than monolithic services directly provided by the state. The extent to which IL as a delivery method will deliver on the principles of IL as a philosophy will be determined by a series of broader circumstances including the level of funding received by individuals through each of these mechanisms.

Another aspect of IL as a practical delivery method is the independent living fund (ILF). Along with the importance of the growth in CILs, Evans (2002) highlights the achievements of the ILM in campaigning successfully for the introduction of the Independent living Fund (ILF) and the legalisation of direct payments. The introduction of the ILF followed the decision of the government in 1986 to withdraw an existing benefit called the Domestic Care Allowance which had enabled some disabled people to live independently (ibid). This provoked a campaign by outraged disabled people for the replacement of the Domestic Care Allowance, resulting in the introduction of the ILF. Evans emphasises the value of the ILF because of the improvements in flexibility and funding it delivered for many recipients. He also points out that it 'helped some people who already had an Independent Living scheme, by providing more money as a supplement to their existing arrangements. This allowed them more flexibility and choice in how they operated their schemes (2002: 12).

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<sup>4</sup> An individual/personal budget is a budget held by the state but allocated by the user to the provider of their support (see Glendinning et al, 2008). A direct payment is a direct cash payment to the individual (see Spandler, 2004).

Within the successful campaign for direct payments, the BCODP Independent Living Committee took on a central role in promoting direct payments. As Evans describes, the campaign for direct payments was initiated ‘in order to change the legislation to make it easier for local authorities to establish Direct Payment schemes’ (2002: 14). Another reason behind the campaign was a disparity in how different local authorities viewed the legality of independent living schemes. Local authorities in some areas interpreted existing legislation to mean that independent living schemes were illegal, meaning they could not be provided. This lent additional determination to campaigner’s efforts to change legislation in order that all could benefit from direct payments (ibid). An important stage in BCODP’s campaign to legalise direct payments was the research it commissioned (Zarb and Nadash, 1994) into the ‘cost implications and effectiveness of direct payment schemes’ (Evans, 2002: 18). The results of the research were overwhelmingly positive, finding that direct payments offer disabled people ‘a higher degree of choice and control, and were more reliable than service provision. Service users reported much higher levels of unmet need than payment users. They were four times more likely to have difficulty in obtaining back up for regular support than payment users. They were less likely to have assistance delivered in the manner they wanted’ (Evans, 2002: 19).

Combined with extensive lobbying this research had the desired effect, as in 1996 the government legislated to legalise direct payments, which was widely seen as a success for the ILM. These positive steps toward independent living were followed by further legislation in the first decade of this century, including the commitment to develop CILs in every locality of the UK (Cabinet Office - Prime Minister’s Strategy Unit, 2005). In more recent years the principle behind direct payments of increasing the autonomy and decision making power of disabled people has arguably been extended within the push to ‘personalise’ social care through personal budgets. With the economic crisis of 2008 and change of government in 2010, the ILM is facing new challenges which I describe in the next chapter.

To close this discussion of the ILM and relate it to the DPM, it is helpful to define more carefully the concepts at work within the ILM. Most fundamentally, the ILM has challenged the dominant ideology of independence (Morris, 2014c). Rather



than the dominant view which assumes that independence and holding one's own in society requires that one be able to do everything for oneself, the approach of the ILM changed the meaning of independence. For the ILM, independence is about being in control of one's life and being able to achieve one's goals. This necessitates adequate levels of assistance and the removal of disabling barriers to bring it about. This different approach to independence shifts the focus away from the incapacities of an individual towards a consideration of what is necessary to bring about their right to independence.

Comparing the ILM with the broader DPM, Evans comments that 'it is surprising that there have been so few conflicts amongst this group [the ILM], as it is not the case with the wider disability movement and its groups where the struggle for power has often taken precedence over the main core aims and purposes' (2002: 30). It may be that the more focused priorities of the ILM lent it cohesiveness through a fairly clearly defined set of goals. However, the ILM is still subject to a tension between, on one hand, political activism, campaigning and protest, and, on the other hand, the everyday business of service delivery and promoting choice and control through CILs and helping individuals (ibid). This could be read as a tension between working towards the narrower goal of independent living, and working as part of the DPM as a whole, protesting against and dismantling political, economic and social structures of disablism. This is not to say that the ILM has been focused on a modest or overly restricted set of objectives. I return to further reflection on independent living in chapter 8.

## **The Recent History of the Disabled People's Movement**

I now return to the various strands of the DPM, moving from the earlier history of the movement to recent responses to contemporary challenges of disablism. In recent years as potential challenges to autonomy and standards of living have emerged (see chapter two), protest and opposition has grown. At the same time, degrees of disagreement and division have become apparent as differing responses to the government programme of austerity have been articulated. I now turn to some recent

examples of opposition to government policy, before detailing some apparent divisions within the movement.

## **Recent Examples of Protest against Government Disability Policy**

Among protests against government disability policy, a prominent example is the call for a comprehensive, government-funded, cumulative impact assessment on the changes I describe in chapter two. This has formed the subject of a petition and a campaign, collecting over the required number of 100,000 signatures to lead to a debate on the matter in the House of Commons. Other new political mobilisations provoked by disability policy changes are the emergence of the ‘grassroots’ organisation Disabled People Against the Cuts (DPAC) and the network of non-academic researchers collectively known as the Spartacus Network. The Spartacus Network produced two notable reports into reforms of disability policy. The first of these, titled *Responsible Reform*, was ‘a presentation of the most relevant evidence available on Disability Living Allowance (DLA) and the proposals to replace it with a new benefit, Personal Independence Payments (PIP) (Campbell *et al*, 2013: 3). In the following year the network produced another detailed research report into Employment and Support Allowance, the Work Programme and recommendations for a new system of support titled *Beyond the Barriers* (Benstead *et al*, 2014). These reports received fairly high levels of exposure and were helped in this by a strong social media presence. DPAC has also thrived through social media and blogs, making connections with other non-disabled activists opposed to the government’s austerity program. In DPAC’s case this has been combined with more traditional street-based protests.

Along with the work of the Spartacus Network, another report produced by non-academic disabled researchers was written by Inclusion London, DPAC and other unspecified DPOs from ‘across the UK’ published as the *UK Disabled People’s Manifesto: Reclaiming Our Futures* in 2013. Its stated aim is to ‘map the key principles, demands and commitments that disabled people and our allies can use in campaigning and lobbying’ (Inclusion London, 2013: 1). It is intended as a “road map’ setting out a

vision for real sustainable change and alternative approaches to every area of our lives' (ibid: 1). The document adopts an approach informed by the social model of disability and addresses the full range of current barriers to equality facing disabled people, ranging from education to housing and organisation of support.

Among the arguments in the UK Disabled People's *Manifesto* document are seven 'priority demands', including 'A Legal right to Independent Living and Self-Determination: The creation of a specific independent living law: a legal right that fully enacts and enforces, as domestic law, the United Nations Convention on the Rights of People with Disabilities (UNCRPD) incorporating the 12 pillars of independent living as its key goals and principles' (2013: 3). Later, the authors go into greater depth on this demand:

There must be extensive and sustainable funding for genuine independent living and user self-directed support that is free at the point of need, paid from general taxation with ring-fenced funding. Funding must be at levels that enable disabled people to achieve self-determined independent living, in its widest sense as defined under the UNCRPD, with the realistic option to employ personal assistants, at an adequate wage, through the provision of Direct Payments. The level of support should be one that enables disabled and non-disabled people to enjoy the same degree of control over their lives that does not involve being forced into residential, group or nursing home provision (2013: 5).

In this passage one can see the presence of a strong commitment to non-negotiable rights to independent living, resulting in the rejection of many current policy positions of the government. As an example of this wide-ranging critique, the manifesto demands 'a halt to other current welfare 'reforms' including the Work Capability Assessment, Personal Independence Payments, and benefit caps which are not working and are disproportionately impacting on disabled people' (ibid: 8).

Of dozens of other demands, I wish to draw specific attention to two which illustrate the distinctive response that DPAC and Inclusion London have given to reforms and cuts. One is the demand that government:

Stop the closure of the cost effective Independent Living Fund (ILF) and set up an Independent living task force, co-produced with ILF users, to review independent living and specifically the Independent Living Fund in order to identify how best to improve, develop and extend independent living support building on the successful model of ILF provision (ibid:6).

As we shall see later, this position is notable because other high profile DPOs have moved toward reluctant acceptance of the closure of the ILF. The other demand from the *Manifesto* I wish to highlight is:

The creation of a disabled person citizen's income that reflects the level of income that a disabled person needs to cover the additional economic, social, cultural and impairment costs disabled people experience, including costs of exclusion from employment and additional living costs. It should replace the plethora of different, flawed benefits that are currently in place (ibid: 14).

This is notable because it differs from the 'radical' approach of UPIAS and their rejection of the income approach of DIG in favour of a holistic approach to the totality of disability. That said, in many other ways, the emergence of DPAC could be seen as a renaissance in socialist disability protest and a return to the type of historical materialist, anti-capitalist disability politics represented by some members of UPIAS such as Finkelstein (1980).

## **Resurgent Socialism in the Disabled People's Movement? The Example of Disabled People Against the Cuts**

Clifford (2014), an affiliate of the DPAC network, has proposed that its growth should be understood as a response to the tendency for DPOs to 'become subsumed by a service delivery and contract culture'<sup>5</sup>. As the presence of more politicised DPOs declined, Clifford argued that 'disabled "professionals" made careers by claiming to represent us' (ibid)<sup>5</sup>. For Clifford, this backdrop meant there was an inadequate basis for organised resistance against the government's policies, meaning the birth of DPAC was a necessity (ibid). The resulting mobilisation behind DPAC has seen 'working class

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<sup>5</sup> <http://socialistreview.org.uk/391/re-forging-disability-movement>

disabled people' discover their 'own power to effect change and have challenged the authority of the disability elite' (ibid)<sup>5</sup>. Burnip (2012), also affiliated to DPAC, sounds a similar note, identifying the existence of a distant 'disability elite who have little experience of working class disabled people's lives speaking for us with little knowledge of how fearful disabled people are or what life actually is like for those living on benefits, losing care and support funding and being thrown into even greater poverty and despair' (2012: 3).

Williams-Findlay argues that DPAC has grown partly in response to a tendency within this elite toward 'a watering down of the ideas expressed by the likes of UPIAS, Finkelstein and Oliver to the extent that 'disablism' is simply reduced to the experience of discriminatory attitudes and practices found within society' (2011)<sup>6</sup>. Without a rigorous analysis of disablism, rooted in politics and economics, Williams-Findlay argues that political campaigns are led to stress the vulnerability and neediness of specific groups or individual disabled people (ibid). These campaigns, he argues, make the mistake of failing to challenge the terms of much of public discourse on disability. Rather than making arguments in relation to fundamental rights and the social context of disablist social structures, such campaigns offer 'a simplistic message via stereotyped images of disabled people and their lives. In doing so they have assisted in constructing the new contours that are being drawn around disabled people in order to divide them' (ibid)<sup>6</sup>.

Whilst not explicitly referring to DPAC, Oliver makes a similar point, finding fault with the recent tendency for the movement to be based 'upon weakness and vulnerability. It asks for special treatment, protection and dependency' (2012)<sup>7</sup>. In this light, Burnip complains that a growing number of DPOs are 'campaigning from the medical/charity model perspective and emphasising how vulnerable disabled people are due simply to their impairments rather than because of the barriers they face... this is a major threat to any disabled people's movement in the future as it reinforces stereotypical views that we need to be 'looked after and protected'' (2012: 2). For

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<sup>6</sup> <http://dpac.uk.net/2011/03/bob-williams-findlaylifting-the-lid-on-disabled-people-against-cuts/>

<sup>7</sup> <http://www.disabilitynow.org.uk/article/politics-humility>

Burnip, this is a short step away from reinforcing ideas of deserving and undeserving disabled people, which have become more prevalent in recent times (ibid).

For Clifford (2014), DPAC breaks from accommodating charitable arguments of this sort, offering a distinct position from the 'disability elite' by positioning itself openly to the left of the political spectrum, working with the 'anti-austerity movement with core principles based on an understanding of the oppression of disabled people in the context of class politics'<sup>8</sup>. In her view this strategy is driven by a necessity to engage with the issue of class, driven by 'the current political climate where attacks on disabled people can only be understood within the framework of a wider ideological agenda aimed at dismantling the welfare state and attacks on workers'.

DPAC are unusual in their adoption of class politics, but their deep questioning of the underlying assumptions of disability policy should not be taken to mean they are an extreme outlier or that their positions lack credibility. Indeed it is notable that some more 'mainstream' activists have made points that could be interpreted as complementary to those made in the *UK Disabled People's Manifesto*. For example, Morris (2011) has previously worked as a consultant to government on disability issues, and would not typically be considered a fringe or radical member of the movement. It is of note then that she adopts positions that are quite similar in tone and content to some of those taken by DPAC. For example, in summarising her argument she states that:

In campaigning for policies to tackle disabling barriers and enable equal access, we need to explicitly and vigorously promote the welfare state and the concept of social security in its broadest sense. People of all ages who experience impairment and/or illness are at a disadvantage in a society and an economy where the market is the sole arbiter of opportunities and life chances (2011: 1).

This fits closely with the position taken by DPAC; that campaigns for disability rights must be placed within a generalised opposition to cuts to public services as a whole. One notable difference is that DPAC conclude from this that they should work closely

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<sup>8</sup> <http://socialistreview.org.uk/391/re-forging-disability-movement>

with trade unions, whereas Morris does not stress this point. Another notable statement by Morris is that:

There is little room for making progress within the ideological framework driving current disability policies. We need to develop more radical challenges to the current disability policy agenda and engage in wider debates, particularly those which question the continuing pursuit of economic growth regardless of the damage done to the environment, to values and to humanity (2011: 1).

How this statement might be translated into practical political programs may vary widely, but it seems to suggest that a more general challenge to the economic model is required to make progress in realising disability rights. Again this could be seen as similar to DPAC's argument that a fundamental challenge should be made to the economic model driving disability policy. In their terms this can be understood in terms of class conflict, whereas Morris frames the issue in less conflictual terminology.

DPAC is a 'network' without a centrally agreed political position or ideology and one should therefore be cautious to ascribe the idea of resurgent socialism to DPAC as a whole. That said, it is discernible from the writing of DPAC affiliates that an explicitly socialist message is often expressed that stresses the need to address disablism in coordination with struggles for social justice in general. In some cases affiliates of DPAC argue that this means working with professionals and care/support workers is important. This point differs from much of the DPM's history in which professionals and 'care' workers have been maligned for their role in the oppression of disabled people (e.g. Davis, 1993). In other respects DPAC's explicitly socialist politics could be seen as a revival of the Marxist materialist politics of members of UPIAS such as Finkelstein (1980), consistent with historical materialist analysis of disability such as that made by Oliver (1990).

## **Tensions Surrounding the Positions Taken by Disability Rights UK**

We saw above that part of DPAC's approach is to challenge what they perceive as a distant 'disability elite'. This has been particularly apparent in the criticisms they and

others have made of Disability Rights UK (DR UK). While DPAC and others might criticise the 'disability elite' for complicity in damaging policies, an opposing point of view might suggest that failing to engage with government removes the voices of the majority of disabled people from the process of policy formulation. Arguably, without such engagement valuable innovations such as direct payments or the ILF would not have been gained in the first place. The tension around this issue of engagement/co-option is most clearly apparent in the criticisms of DR UK.

To begin discussing the criticism made of DR UK, it is relevant to cite Oliver's (2011) concerns over the merger of the Royal Association for Disability and Rehabilitation (RADAR) the Disability Alliance (DA) and the National Centre for Independent Living (NCIL) into DR UK. His concerns are rooted in the history of these organisations. In the case of RADAR, it began as the 'Central Council for Cripples and was rooted in the nineteenth century charity ethic' (2011)<sup>9</sup>. DA was also an organisation primarily conceived as an organisation 'for' disabled people 'formed when a group of mainly non-disabled academics fell out with the Disablement Income Group over the right way to achieve a national disability income' (ibid). Oliver notes that neither of these organisations has ever been controlled by disabled people. In his view, while NCIL began as the Independent Living Sub-committee of the British Council of Disabled People (BCODP), it had moved away from a form in which it was controlled by disabled people. Given the history of these constituent organisations, Oliver's concern is with the absence of control by disabled people in DR UK and the resulting positions it may take. Oliver notes that historically, the greatest successes were achieved through the activity of organisations controlled by disabled people, often against the will of non-accountable organisations for disabled people. He closes his argument by stating:

I cannot escape from the lessons of our historical and recent past; namely that when non-accountable organisations have spoken for us our issues and our lives have been sacrificed on the altars of political collaboration, policy compromise and personal opportunism (2011)<sup>9</sup>.

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<sup>9</sup> <http://www.disabilitynow.org.uk/article/old-lessons-new-politics>



Oliver is not alone in finding reason to criticise the influential DR UK. For example, members of DPAC have made strong criticisms of DR UK, finding fault in its apparent decision to accept that the ILF should be closed. As evidence of DR UK's position, Sue Bott (2014), Director of DR UK suggests that the energies put into defending the ILF could be better spent on 'a single integrated system that would assess people's needs and allocate assistance and support based on the outcomes people could achieve in their communities and contribute to society' (2014)<sup>10</sup>. Her argument is based, in part, on the reasoning that the ILF is a national scheme providing funds to cover the cost of 'care' and support and is therefore anomalous and inefficient within a system in which social care is delivered and charged for through local authorities. Activists affiliated with DPAC disagree with Bott's reasoning. For example, Punton (2014) notes that the money given to local authorities to replace the ILF will not be ring fenced, and believes that financially pressured local authorities will not provide the necessary support to those with 'severe' impairments. Therefore, DPAC activists argue that abandoning the ILF could mean that they are forced to live in institutions as they are denied the finance provided by the ILF (ibid).

Another point of disagreement between DR UK and some other activist groups has been the dispute over the closure of Remploy factories<sup>11</sup> by the government. Traditionally the existence of Remploy factories has been seen as indicative of the marginalised and segregated position many disabled people live in, and the disabling attitudes that prevail in much of society. As a form of segregation, prominent parts of the DPM support their closure, including Essex Coalition of Disabled People, Southampton Centre for Independent Living, Breakthrough UK, and DR UK (Pring, 2012b). In her report for government on disability and employment, the Chief Executive of DR UK, Liz Sayce (2011), asserts that 'In relation to Remploy factories there was a total consensus among disabled people's organisations and charities that the factories were not the model for the 21st Century' (2011:15). This is debatable given that others, including DPAC, Inclusion London, Inclusion Scotland and Norfolk

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<sup>10</sup> <http://disabilityrightsuk.blogspot.co.uk/2014/07/we-need-new-vision-for-independent.html>

<sup>11</sup> Remploy is an organisation owned by the Department of Work and Pensions. Historically it has run and subsidised factories producing a number of goods, providing employment for disabled people. Over the last two terms of government the factories have been closed.

Coalition of Disabled People, have criticised the closure, arguing that the redundancies and resulting unemployment of those concerned was not a great sign of progress in the position of disabled people in society (Pring, 2012b). In their joint letter to the Guardian Newspaper (May, 2012) these organisations stated that ‘our goal and demand for inclusive employment must not be used to justify job cuts that will push these workers into poverty, exclusion and isolation’<sup>12</sup>. According to the Labour Party, as of November 2012, only 3% of former Remploy employees had found employment (Ranmesh, 2012).

A final cause of disagreement with DR UK is the criticism made by The UK Disabled People’s Council (UKDPC) of its participation in Disability Action Alliance (DAA), an umbrella group formed by the government to produce new disability policies, consisting of DPOs, charities, and private and public sector organisations. The website Disability News Service carried the following summary of UKDPC’s response to DR UK’s participation in DAA:

Julie Newman, UKDPC’s acting chair, said the appointment had taken place “behind closed doors”, and that DR UK was clearly “too close” to the government. She said DAA would simply be another “quango”, and was certain to represent the views and interests of big business and service-providers. She said: “We will be looking at the commercialisation of independent living in a way that is in conflict with human rights. DAA will effectively be a commercial enterprise driven by government.” Newman questioned the “validity” of the government’s decision, which “excludes disabled people from setting the agenda or defining the terms of reference” (Pring, 2012a)<sup>13</sup>.

The criticism made of DR UK regarding the ILF, Remploy and the DAA demonstrate that some level of division is apparent within the movement. Arguably, this conflicts with the answer given to Disability News Service by Liz Sayce of DR UK when she commented that DR UK and groups such as DPAC “all want the same thing” but were just “different in their tactics” (Pring, 2012c)<sup>14</sup>. Sayce’s comments here fit in with the

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<sup>12</sup> <http://www.theguardian.com/society/2012/may/10/disabled-works-fight-remploy-jobs>

<sup>13</sup> <http://disabilitynewsservice.com/2012/09/anger-over-governments-new-disability-quango/>

<sup>14</sup> <http://disabilitynewsservice.com/2012/11/disability-rights-uk-fights-back-over-new-alliance-capita-and-remploy/>

approach taken by DR UK to eschew open criticism of others, generally avoiding defence of its own positions, instead preferring to stress unity with other DPOs and cooperation with politicians. As a short defence of its position, current chair of DR UK, Phil Friend, in an interview with Disability News Service, commented that DR UK would “rather be in the tent talking to the government than outside the tent chucking stuff in” (Pring, 2012c)<sup>14</sup>. In the same interview, Liz Sayce again defended the approach taken of working with government, arguing that if the DPM had not engaged with previous Conservative governments it “would never have got direct payments, we would never have got the Disability Discrimination Act” (ibid).

In noting the presence of disputes in the movement I am not seeking to stress division but to highlight important points of contestation within current approaches taken to challenging disablism. The weight of material criticising DR UK should not necessarily be seen as an indication that it is mistaken in the positions it has taken. An even-handed way of viewing these disputes may be to see them as evoking the dilemma stated by Oliver and Barnes that ‘[t]o 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’ (2006: 2).

I will not be able to resolve such disputes in this thesis, but it may be that I can throw some light on the nature of current challenges facing the movement and develop an analysis of current forms of disablism in the UK, informed by wider social theory. Hopefully, this might help to inform political activism in the field. By interviewing activists from varying backgrounds with differing views in this thesis, I can further explore the tensions within the movement. By giving voice to participants regarding current challenges and available strategies, I hope to offer an insightful account informed by varying perspectives. Such voices are divided on some aspects of their analysis but also unified to a degree by a critique of government policy. At a time when the challenges to individual disabled people and DPOs I describe in the next chapter are driving debate forward, tensions are likely to become even more apparent. This need not be seen as unhealthy as debate over both the nature of challenges and the possibilities and strategies for resistance can only help the DPM. It is with the

purpose of understanding these challenges and possible responses that I proceed for the rest of this thesis.

I conclude this chapter by giving an overview of how I will address these goals in the remainder of the thesis. Chapter 2 will provide details of the challenges to disabled people in the UK brought about by current disability policy. Chapter 3 begins discussion of methods and methodologies, describing the development of the thesis and the changes in my priorities and research questions. Chapter 4 continues methodological discussion, locating the approach I have taken in relation to prominent research traditions within disability studies and social science more generally. Chapter 5 begins analysis of interviews with activists, probing their perceptions of current challenges to the realisation of the DPM's demands. Chapter six further develops the analysis of data presented in chapter 5, broadening the analysis by drawing on relevant literature including Roulstone and Morgan's (2009) notion of 'enforced individualism' to deepen the examination of participant contributions. Chapter 7 returns to more direct analysis of interview data, analysing how participants positioned themselves in relation to different political strategies. Chapter 8 builds upon the analysis carried out in chapter 7, developing a greater understanding of the strategic positions taken by participants, in part through an application of Fraser's (1995; Fraser and Honneth, 2003) analysis of injustice and resistance. Chapter 9 turns to the perennially contentious issue of the social model of disability, arguing in favour of the 'social-relational' contribution to theorising disability developed by Thomas (1999; 2007; 2010; 2012). In chapter 10 I broaden my analysis by introducing theoretical insights from contemporary thinking in feminism and Marxism, applying them to the current situation of disability activism. The final chapter summarises the contribution of the thesis and offers some concluding thoughts.

## Chapter 2: The Challenges to Disabled People Brought About by Austerity

In this chapter I give a summary of the available evidence regarding the impact of reforms to disability policy and cuts to public sector expenditure on disabled people. I do not seek to show whether these have been effective in reducing expenditure; the scale of the national deficit; or whether such austerity measures are necessary. These broader economic questions are of great relevance to the situation of many disabled people in Britain, but addressing them adequately would overwhelm the core concern of the thesis. Instead I attempt to give an overview of their effect on disabled people.

The current Government is yet to carry out any assessment of the impact of the totality of reforms they have made on disabled people's standard of living and independence. Many suspect that the reason such an assessment has not been carried out is the fear among members of the government that it would reveal to the voting public the scale and impact of cuts endured by disabled people (Duffy, 2013). There does not yet appear to be any studies written by academics on the effect of the broad sweep of government policy on disabled people. This thesis is based on the idea that developing an understanding of the impact and perception of these cuts and reforms as a whole is a valuable exercise. Others, notably Duffy (2013) and Young (2014), appear to have reached a similar conclusion. In this context it is of note that the Government's Advisory Committee on Social Security (2014) raised the issue of the cumulative impact of welfare reform on disabled people. The committee stressed the exposure of disabled people to greater risk than others because of the increased likelihood they will be claiming multiple benefits and their comparatively restricted capacity to change their behaviour in response to reforms.

In this section I will firstly draw on Duffy's (2013; 2014) work on assessing the cumulative impact of cuts in government expenditure, providing a summary of the changes that appear likely to affect many disabled people. Duffy has been an influential voice in the reform of social 'care' over the last fifteen or more years, particularly in relation to the 'personalisation' of services and the increased availability

of personal budgets for users of services. In recent years he has become a vocal critic of the disability related policies of the coalition government. After discussing Duffy's work, I go on to explore the effect of some specific cuts and reforms in more detail, drawing principally on the work of Young (2014). Young is 'a campaigner and consultant based in the borough of Kingston in South West London'<sup>15</sup>. She has been 'involved in co-ordinating the 'We are Spartacus' grassroots movement' which is one of the most prominent examples of work produced by service users and allies provoked by government policy, concerned with offering detailed critique of policy and the suggestion of alternatives.

Duffy (2014) explains that the cuts that disabled people face fall into two main categories: cuts in social care and cuts in personal income (benefits and tax credits). This is to say that cuts may be felt through social welfare as cuts to social security benefits, or through cuts and changes to eligibility in social care such as reductions in personal budgets, direct payments or local authority managed budgets. Changes in eligibility to social care may make more disabled people 'entirely reliant on more stigmatised social welfare for the first time' (Roulstone and Prideaux, 2012: 101).

Referring to cuts to social care (2013), Duffy reports that the second highest cut of any major area of public sector spending is to local government (behind only cuts to benefits). By 2015 social care in England will have been cut by £7.5 billion, meaning a real terms cut of 33% since the election of the government (Duffy, 2014). According to Duffy, this massive cut means in practice that the following services, disproportionately (but not only) relied upon by disabled people, will bear the burden of social care cuts:

- Reductions in support, freezing of fees for service providers and the reduction of personal budgets.
- Reducing expenditure on supported housing services funded through 'Supporting People'.

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<sup>15</sup> <http://janeyoung.me.uk>

- Increasing the threshold for eligibility for social care; e.g. by 2011, 78% Councils had stopped supporting people with 'Low' or 'Moderate' needs.
- Increasing charges for social care services effectively being a direct tax on those disabled people who have the most severe needs (Duffy, 2013: 17).

Turning to the cuts to personal income, Duffy notes that the government aims to be saving £22 billion a year in cuts to benefits by 2014-2015 (Autumn Statement, 2012). To put these cuts into some historical and administrative context it useful to draw on Burchardt's (1999) typology of benefits. She divides the types of benefits available to disabled people into four principle categories:

i) Compensatory benefits.

Tax free and not means tested, these are awarded to those who have become sick or disabled serving in the military or ordinary occupational capacity.

ii) Earnings Replacement Benefits

This type of benefit provides an income for those who are unable to earn as a result of sickness or disability. They are not means tested but may be taken into account when assessing income for other benefits. They may or may not be tied to previous employment. An example of earnings replacement benefits is employment and support allowance (ESA).

iii) Extra Cost Benefits

This category of benefits has come into existence to pay for the extra costs of being disabled. This type of benefit is tax free and is not take account of when assessing income for other means tested benefits. An example of extra cost benefits is disability living allowance (DLA), which is currently being phased out to be replaced by personal independence payment (PIP).

iv) Means Tested Benefits

Such benefits exist to top up income to a minimum level. The level reached is determined by the number of people in the household, any special needs of household

members, and housing costs. Means tested benefits are not disability-specific benefits but they may be received by disabled people and disabled people may be eligible for additional premiums. Examples of means tested benefits include income support and also housing and council tax benefit.

The cuts to benefits highlighted by Duffy fall into the categories of earning replacement benefits, extra cost benefits and means tested benefits, among other changes that may affect disabled people’s income. The totality of potential cuts to an individual disabled person’s income is complex and could be the subject of an entire PhD thesis. For the sake of brevity, I again draw on Duffy’s analysis and the following summary of the cuts in benefits and tax credits that will allow such a saving:

Replacing DLA with PIP	Time-limiting of contributory ESA
Change to CPI indexation of benefits	Child Benefit freeze
Council Tax Benefit – 10% reduction and localisation	Child Benefit clawback from higher rate taxpayers
Housing Benefit cuts	Tax credit changes
Universal Credit	Abolition of the Independent Living Fund
Closure of Remploy services	Localisation of the Social Fund
Reductions in Access to Work funding	Abolition of the Child Trust Fund
Abolition of the Health in Pregnancy Grant	Abolition of the ESA youth rules
Abolition of Sure Start Maternity for second and subsequent children	Household benefit cap
Extension of JSA lone parents with a youngest child aged 5-6	Continued use of ATOS or others
Transfer of Social Fund to local government	Reductions in support for carers

**Table 1. Summary of cuts to benefits and tax credits (Duffy, 2013: 18).**

Young (2014) addresses similar territory to Duffy but chooses to highlight particular reforms in order to discuss their impact in greater depth. Her analysis is informed by the UK’s legal obligation<sup>16</sup> to realise disabled people’s right to

<sup>16</sup> Britain is a signatory to the United Nations Convention on the Rights of People with Disabilities



independent living and she notes that the Joint Committee of the House of Commons and Lords on human rights (JCHR) raised the following concern:

The range of reforms proposed to housing benefit, Disability Living Allowance, the Independent Living Fund, and changes to eligibility criteria (for social care) risk interacting in a particularly harmful way for disabled people. Some disabled people risk losing DLA and local authority support, while not getting support from the Independent Living Fund, all of which may force them to return to residential care. As a result, there seems to be a significant risk of retrogression of independent living and a breach of the UK's Article 19 obligations (JCHR, 2012: para 161).

Informed by these concerns of the JCHR, Young identifies a range of factors which may obstruct the realisation of independent living. I follow her identification of these factors to structure the following section. In doing so I will not attempt to address the full range of cuts and reforms affecting disabled people, but instead highlight a number of striking points she makes. Following Young's structure and summarising her argument, I start with her analysis of the impact of changes to housing benefit.

## **Examples of the Challenges to Disabled People Brought About by Austerity**

### **1. Changes to Housing Benefits**

Housing benefits are particularly important to some disabled people because disabled people are disproportionately likely to live in poverty and not own their own home (ODI, 2009 and Leonard Cheshire, 2008 cited in Young, 2014). Young reports several concerns of the JCHR with changes to Housing Benefits.

One risk to disabled people brought by changes to housing benefits is the restriction on Local Housing Allowance (LHA) for homes in the private sector. This relatively new benefit (introduced in 2008) was changed in 2011 so that LHA can only be paid to cover the costs of the bottom thirty per cent of market prices (Young, 2014).

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(UNCRPD). This convention contains, as article 19, 'The right to live independently and to be included in the community'.

As many disabled people have very specific housing needs, such as requiring a ground floor flat, they may not be able to find adequate housing in the restricted range of properties within the lowest third of market values. In Young's view this could constitute a risk to the independence of disabled people if they cannot access appropriate housing.

Young also identifies the under-occupation penalty (often known pejoratively as the 'bedroom tax') as another threat to the adequate level of Housing Benefit required for independent living. Beginning in April 2013, this operates similarly to restrictions to LHA, but in this case the risks relate to housing in the social rented sector (Young, 2014)<sup>17</sup>. Tenants deemed to have more rooms than they require lose a portion of their Housing Benefit, meaning they must cover the costs with other income or move to a smaller property. Importantly, this change was applied to existing tenancies unlike changes to LHA. Thus disabled people who had occupied a property for many years could be forced to move. Roughly two thirds of those affected are households in which a disabled person lives (ibid). This is unsurprising given that the vast majority of accessible homes with adaptations that promote independence are found in the social housing sector (ibid). As disabled people are less likely to be in work, they are also less likely to be able to afford the additional costs of compensating for a loss in housing benefit (ibid). For Young, this change in policy is again likely to mean that the independence of many disabled people could be placed in jeopardy. The government impact assessment of the 'bedroom tax' estimates that 420,000 disabled people would receive a reduction in their housing benefit. Disabled people with a 'spare' room are not exempt and only have recourse to apply for a discretionary

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<sup>17</sup> There are signs that the imposition of the under-occupation penalty and resulting challenges for disabled people may be reversed. BBC news reported on 5 September 2014 that: 'Liberal Democrat and Labour MPs have joined forces to defeat Conservatives in a Commons vote to partly overturn housing benefit changes' (<http://www.bbc.co.uk/news/uk-politics-29075300>). Carried by a majority of 306 to 241, the 'Affordable Homes Bill' means people who could not be found a smaller home would be exempt from the cuts, as well as disabled people who need a spare bedroom or who have adapted homes. The BBC's parliamentary correspondent Mark D'Arcy said there was now a "fighting chance" the bill would become law. He speculated that the Affordable Housing Bill could clear the Commons, but it could be 'vulnerable to death by a thousand amendments in the Lords', although 'Labour and Lib Dem peers, plus sympathetic crossbenchers may see it through to the statute book'.

housing payment (Morris, 2014a). For Morris 'Such short-term, temporary payments are an inappropriate response to long-term needs' (2014a: 20).

Young is also concerned by 'the adequacy of discretionary housing payments to mitigate the impact of proposed changes on disabled people' (Young, 2014: 39). By this she is referring to the inadequacy of Discretionary Housing Payments (DHP) designed to offset the problems caused to disabled people by the restrictions to LHA and the under-occupation penalty. Rather than simply exempting disabled people from these changes, the government has provided local government with funds with which they can make discretionary payments to those concerned. Precisely because these payments are discretionary, councils do not need to make them in a way that would offset the impact of restrictions to LHA and the effect of the under-occupation penalty on disabled people. Young argues that DHP are provided unevenly in a way that fails to protect the right to independence for many disabled people. Instead, disabled people have been expected by some local authorities to use benefits intended for other purposes to meet their housing costs (ibid).

## **2. Disability Living Allowance**

Having described challenges associated with housing benefits, Young goes on to assess the impact of changes to Disability Living Allowance (DLA) on disabled people's right to independence. This benefit represents recognition of disabled people's right to independence because it is designed to address the costs that disabled people encounter due to disability and the costs of achieving independence. DLA is of fundamental practical importance, but it is also arguably symbolically important because it embodies recognition of the need to meet additional costs to realise the right to independence (Morris, 2011). Under the Welfare Reform Act 2012, DLA will be replaced by Personal Independence Payment (PIP) for working age disabled people. This change is premised on achieving a 20% reduction in the cost of the benefit. Young (2014) notes the concern of the JCHR that the effect of this arbitrary target on the tightening of eligibility criteria for PIP would mean that 500,000 people will either lose all rights to PIP or receive a lower sum. Morris (2014a) reports that 560,000 people currently receiving DLA will be reassessed for PIP by October 2015. 160,000 of those in

this group are expected to receive a lower amount of money (ibid). The lowest rate of DLA payments for those deemed in need of assistance with care (mobility payments are the other main constituent of DLA and PIP) is not replicated within PIP (Young, 2014), meaning that those who depended on DLA for a low level of support to enable their independence may lose what independence they may have gained and ultimately end up requiring more financially costly support if their condition deteriorates (ibid).

Assessing the eligibility criteria for PIP becomes essential in a situation in which the government is committed to an arbitrary reduction of 20% in costs. Young sets out the eligibility criteria in the following passage:

They are based on a set of activities and descriptors for a 'daily living' component and a 'mobility' component. There are ten activities relating to the daily living component including, for example, 'preparing food', 'washing and bathing', 'communicating verbally' etc., and two activities relating to the mobility component: 'planning and following a journey' and 'moving around'. Each activity includes several descriptors, by which a number of points is awarded depending on which descriptor offers the best fit with the needs of the claimant. For each component, an aggregate score (across the activities relevant to that component) is derived to determine whether an award is made at the standard or enhanced rate of that component (2014: 55).

DR UK (2012 cited in Young, 2014) reports widespread concern that the eligibility criteria of PIP are too narrow and do not reflect the range of activities that DLA recognised as significant. Among the activities that are omitted from consideration in the criteria for PIP are:

- Moving around indoors, including using stairs, getting in and out of bed, getting to the toilet and other indoor activities.
- General supervision to keep disabled people safe - lack of supervision could put disabled people in danger of injuring themselves during an epileptic fit or a fall, or due to the risk of self-harm.
- Assistance at night time – under the PIP criteria there is no specific provision for assistance required during the night, the nature of which can be very

different from the assistance required during the day (DR UK, 2012 cited in Young, 2014: 56).

Along with these omissions, Young reports that the most controversial aspect of the introduction of PIP has been changes to the criteria for support with 'moving around'. DLA and other areas of government policy had used the measure of whether a person could move without a wheelchair for 50 metres to decide if they required assistance with mobility. Under PIP this has been restricted to 20 metres (ibid). This means that many disabled people receiving enhanced rate mobility component of DLA will no longer do so, including the benefits of the motability scheme<sup>18</sup>. This may risk their capacity to access community, educational, medical and commercial engagements and Young estimates that this could affect over half a million individuals (ibid).

Morris (2011) argues that PIP assessment involves a medical approach to establishing levels of impairment, rather than a social model approach centred on establishing experiences of disabling barriers. Giving a positive assessment, Morris argues that PIP's predecessor, DLA, represented a degree of acceptance of the social model of disability by recognising the need to create a level playing field to provide for the additional costs of living with disability<sup>19</sup>. PIP, on the other hand, she argues, embodies a 'corrupted version of the social model' (2011: 4). The Government replaced DLA because of its concern at the mounting costs of the benefit and the 'subjectivity' of the assessment process involved (ibid). Morris argues that this shift to PIP has led to a process based on providing funding to those who are seen as

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<sup>18</sup> The Motability Scheme enables disabled people to lease a new car, scooter or powered wheelchair, using the Higher Rate Mobility Component of Disability Living Allowance, the Enhanced Rate of the Mobility Component of Personal Independence Payment (PIP), the War Pensioners' the War Pensioners' Mobility Supplement or the Armed Forces Independence Payment.

<sup>19</sup> Morris's assessment of DLA is perhaps debatable given that it emerged as mobility and attendance allowance in the more paternalist early 1970s. Rather than being an approach close to the social model of disability, DLA is perhaps more focused on deficits than social barriers. This is apparent as Roulstone and Prideaux argue that DLA 'claimants have to emphasise what they cannot do' (2012: 157). That said, upon its introduction it was 'well received by those able to establish eligibility for the care and mobility components (formerly called the Mobility Allowance, MA) of the allowance' (ibid: 53). Although Morris may exaggerate the link between the social model of disability and DLA, changes toward PIP may still represent a departure from reasoning based on the social model of disability.

'dependent' on support. Those who use aids and adaptations are deemed to be 'independent' through the use of aids/adaptations, and therefore not in need of financial support from the state. The assumptions of the new approach, driven by the need to reduce 'welfare dependency', radically differ from the independent living approach of the DPM. The independent living approach challenges common sense ideas of independence by asserting that needs for support do not mean one cannot be independent. The point of independence is control and self-determination, and not that one has to do every task for themselves. By contrast, Morris (2014c) argues that in government welfare reform:

"Independence" is defined as not being "dependent" on benefits. The need for support is seen in entirely negative terms and the barriers created by discrimination, disabling working conditions and/or a lack of jobs are ignored. Instead, the cause of "dependency" is laid at the door of individual motivation and pathology, and the route to "independence" is to be found through "fixing" people's attitudes (Morris, 2014c)<sup>20</sup>.

Seen in this way, this departure from, and corruption of, the independent living approach is a significant obstacle in realising the goals of the independent living movement.

### **3. The Independent Living Fund**

In addition to the impact of changes to housing benefits and DLA on disabled people's right to independence, Young also argues that the closure of the Independent Living Fund (ILF) could threaten independent living for many disabled people. The ILF was intended for those with significant support needs, receiving the highest rate of DLA care component, to use to employ a personal assistant with the particular aim of avoiding having to live in an institution rather than living independently in the community. From 2010 the ILF was closed to new applicants. The Government has proposed to close the ILF for existing recipients and devolve the resources to local authorities, causing consternation to many disabled people who are aware that local

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<sup>20</sup> <http://jennymorrisnet.blogspot.co.uk/2014/09/independence.html>

authorities face a struggle to fund their existing social care services, and fear they may be forced into living in institutions (Young, 2014). John Evans (2014), a leading pioneer of independent living, added his voice to those concerned at the closure of the ILF, arguing that users of it are ‘understandably scared by the prospect of having to move back into residential care’<sup>21</sup>.

In 2013 five ILF users applied for judicial review of the Government’s decision to close the fund. The court of appeal found in their favour, noting that the then Minister for Disability had failed to uphold the legal obligation of the government to promote independent living. This legal finding only concerned the legality of the decision-making process, and at present the Government intends to proceed with the closure of the ILF in 2015. However, Young notes that the legal decision raised the issue that the closure of the ILF ‘would constitute impermissible retrogression in relation to UNCRPD Article 19’ (2014: 65). Thus Young believes the future outcomes of those no longer in receipt of ILF funds should be monitored to ensure that local authority funding is sufficient to enable independent living. According to Young, if this is not the case, further legal challenges could be brought with reason to believe they could be successful given legal obligations under UNCRPD Article 19. The Government’s *Equality analysis of the closure of the Independent Living Fund* (DWP, 2014) accepted that the value of budgets allocated to service users formerly in receipt of ILF funds is likely to fall short of their former award in most cases. If Young is correct, this outcome is likely to result in further legal challenges.

#### **4. Social Care**

As a final set of challenges to independent living, Young (2014) observes that tightening eligibility criteria for the provision of adult social care is limiting the number of those who are eligible for support in a way that prevents many disabled people from receiving social care. She cites evidence (Brawn *et al*, 2013) to show that since 2006/07 (before the financial crisis) 69,000 working age disabled adults with moderate needs

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<sup>21</sup> <http://www.theguardian.com/society/2014/jul/16/independent-living-fund-closure-disabled-people-residential-care>

and 8,000 with substantial needs have lost eligibility for social care<sup>22</sup>. Survey research produced by a consortium of charities (Brawn *et al*, 2013 cited by Young 2014) revealed that disabled adults:

- Are failing to have their basic needs met: with nearly four out of ten (36 percent) unable to eat, wash, dress or get out of the house due to underfunded services in their area.
- Are withdrawing from society: with nearly half (47 percent) saying the services they receive do not enable them to take part in community life and over one third (34 percent) being unable to work or take part in volunteering or training activities after losing support services.
- Are increasingly dependent upon their family: with nearly four in ten (38 percent) seeking support services saying they experienced added stress, strained relationships and overall decline in the wellbeing of friends and family.
- Are experiencing isolation, stress and anxiety as a result: with over half (53 percent) saying they felt anxious, isolated, or experienced declining mental health because they had lost care and support services (Brawn *et al*, 2013, cited by Young, 2014: 68).

Complementing these findings, Morris (2014a), drawing on Fernandez *et al* (2013), presents evidence that reductions in social care funding have led to a 'widespread increase in eligibility thresholds: almost nine out of ten councils now only support people with 'substantial' or 'critical' needs. It has been calculated that this has led to 69,000 working age disabled adults with moderate needs and 8,000 with substantial needs losing their eligibility for social care' (2014a: 11). These potentially significant challenges to independent living and quality of life are combined with the move by an increasing number of councils to increase their charges for social care services (Young, 2014). Councils are allowed discretion in how much they charge and are permitted to take social security benefits into account when assessing the ability to pay, provided

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<sup>22</sup> Local Authority eligibility criteria banding for social care make use of four bands indicating different levels of need. Of these four bands, local authorities are increasingly only granting social care to those who are classified within the top two bands ('critical' and 'substantial').



they take account of essential disability-related expenditure. However, Young reports that there is wide variation in how councils define 'disability-related expenditure'. In some cases this can result in local authorities demanding a portion of the individual's DLA to meet their social care charges. This removes part of the DLA which is intended for the separate purpose of meeting additional costs of achieving independent living other than social care.

## Overview of Cuts/Reforms

As the cuts described above take hold, Young and Duffy are strongly of the view that many disabled people's independence and standard of living could be compromised. This could be exacerbated by interactions between the changes noted above, particularly for individuals receiving multiple benefits and using services that are cut. Young (2014) uses the example of the interaction of DLA reform and the introduction of an overall cap on total benefits available to an individual to demonstrate the challenges posed by the cumulative impact of different policy changes:

If a family member claims DLA, the family is exempt from the overall benefit cap, but if that family member loses entitlement following an assessment for PIP, the family's benefits will be reduced to the level of the cap, despite no other change in their circumstances; the loss of DLA (and carers' allowance, if anyone in the family claims that benefit) will also have an impact on their ability to meet disability-related expenses. This may mean the family has to move to a different area, separating them from the informal support of local friends and neighbours (Young, 2014: 75).

This is only one example of the way independent living could be compromised by the interaction of policy changes. Duffy argues that the overall impact of the combined changes will be to lead to 'growing numbers forced to use food banks... growing crises in health care services as social care diminishes...increased personal debt...increased mental health problems...increased family breakdown...growing inequality (2014: slide 19)<sup>23</sup>.

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<sup>23</sup> <http://www.centreforwelfarereform.org/library/by-az/counting-the-cuts.html>

Duffy concludes from his analysis that, contrary to the Deputy Prime Minister's insistence that "those with the broadest shoulders should carry the heaviest burden" (Clegg, 2012)<sup>24</sup>, the combined impact of cuts in public expenditure has been to disadvantage and impoverish many disabled people. The cumulative impact of these changes, Duffy calculates, will total a cut equivalent to £4,410 per disabled person, or nine times the burden of cuts endured by most citizens. This means 'as a group, disabled people, 8% of the population (1 in 13 of us), [will] bear 29% of all cuts' (Duffy, 2013: 22). Duffy finds that the situation for the subset of disabled people with severe impairments, qualifying for social care provided by local government, is even worse (ibid). His calculation is that the total burden of cuts on disabled people with severe impairments is £8,832 per person (ibid). People in this situation form 2% of the population but bear 15% of all cuts. If Duffy's analysis is correct, the opposite of the government's rhetorical commitment to fairness is occurring.

Morris (2014a) reviewed the extent to which the targets of the 2008 *Independent Living Strategy* are being jeopardised by welfare reform and cuts to public service funding. She found 'no evidence of significant progress in disabled people's experiences of choice and control' since 2008 (ibid, 5). Among other negative findings, Morris also states that 'large numbers of disabled people have experienced a reduction in their household income since 2010 (ibid: 6). Morris makes the general conclusion that 'disabled people who need support in their daily lives are experiencing diminishing opportunities to participate in family and community life' (ibid: 5).

I believe the data referred to above suggests growing risks to many disabled people's independence and standard of living. I am unaware of any specific criticisms to date of the work of Duffy and Young. Generally the approach of the government has been to question if genuine cumulative assessments of this sort are possible due to the complexity involved. This may be questioned given that the Government's own Advisory Committee on Social Security (2014) has recommended further analysis of the cumulative impact of welfare reform on disabled people. Furthermore, senior

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<sup>24</sup> [http://www.libdems.org.uk/nick\\_clegg\\_s\\_speech\\_to\\_spring\\_conference\\_march\\_2012](http://www.libdems.org.uk/nick_clegg_s_speech_to_spring_conference_march_2012)

economists Reed and Portes argue that ‘modelling cumulative impact assessment by equality group is feasible and practicable (2014: IV).

Other studies in this area such as Wood and Grant (2010) involve monitoring case studies of people and families facing fears of forthcoming cuts. In follow up studies Wood and Grant (2011a; 2011b) and Wood (2012) explore the impacts of cuts and reforms as they are experienced in varying ways in individual lives. Research of this sort can add to understanding of the interaction of different cuts and the differential impact upon disabled people of differing identities, backgrounds and characteristics. In the cumulative national scale research of the sort carried out by Duffy and Young, the fact that not all disabled people will be affected equally can be obscured. Qualitative research can hint at issues of intersectionality and how discrimination, inequality and oppression associated with disability can combine with other forms of political oppression and privilege.

As well as the challenges to individual disabled people noted above, DPOs, including CILs, are also arguably facing problems. DPOs are vital parts of the DPM, and could be classified as ‘social movement organisations’, carrying through the aims of the DPM. I will now discuss the challenges facing DPOs. This is important, not least because, through their expertise and knowledge of the needs of disabled people, DPOs could mitigate the impact of some of the changes noted above.

### **Current Challenges to Disabled People’s Organisations**

The challenges facing DPOs has been the subject of less scrutiny in recent years. However, as we shall see in later chapters, participants interviewed for this thesis felt the situation of DPOs were an important part of the picture of evolving current challenges to disabled people. It is then worth noting the research carried out by Inclusion London, a pan-London Deaf and Disabled People’s Organisation (DDPO), involving a survey in 2012 with 54 London-based DDPOs about their experiences of the funding cuts. Their key findings include that one in five of the organisations they surveyed were facing closure in the forthcoming two years. Further findings included that 40% of those surveyed had experienced cuts in funding in the preceding year.

More than half of those surveyed (31/54) expected further funding cuts in the following year. The falls in funding were mainly caused by cuts in local authority expenditure.

The authors of this report fear that personalisation and choice and control for disabled people will become increasingly difficult to achieve without the presence of DDPOs able to provide 'independent, accessible information, advice, independent living services and peer support networks' (Inclusion London, 2012: 2). Overall, the authors of the report were concerned that:

The reduction in user engagement, campaigning, advocacy and peer support activity provided by DDPOs greatly undermines the Government's aim of positively changing attitudes towards Deaf/disabled people and supporting greater participation by Deaf and disabled people in the wider community (Inclusion London, 2012: 2).

The challenges facing DDPOs are such that they could add further to the possible failure to meet obligations under the UNCRPD (ibid) (highlighted by Young above).

Having discussed in detail the challenges of cuts and reforms to individual disabled people, and having briefly touched upon challenges to DPOs, I will now turn to the related problem of high levels of prejudice and cultural demonisation directed at disabled people. This means moving from discussion of material disadvantages to analysis of challenges at the cultural and/or ideological level. This is an important area because cultural and ideological challenges to disabled people could arguably serve to justify regressive policy changes and distract the public from the denial of independence that many disabled people will experience. To better understand current challenges to disabled people, I now turn to this cultural element.

### **Current Cultural Challenges to Disabled People**

Changes in disability policy and cuts to benefits and services can only be carried out in the longer term if the voting public are willing to accept them. The way in which disability and issues such as social security benefits are portrayed and culturally constructed will play a role in how the policies described above are perceived, as well

as the esteem in which disabled people are held more generally. In this light, some have noted an apparent shift in the manner in which disability is portrayed in the mass media.

Briant *et al* (2013) tried to test if this is the case by comparing the output of five newspapers in 2004/05 against their output from 2010/11, using a 'comprehensive content analysis'. Briant *et al* found that media coverage has shifted toward a politicisation of disability, characterised by 'increased discussion of disability as a benefit problem, and of disabled people as a burden on the state' (2013: 878). This occurred within the context of an overall increase in discussion of disability, represented by a 43% climb in the total number of articles concerning disability (*ibid*).

To give more detail, in 2004/05 there was still a large number of articles concerned with disability benefit claims as a problem, but they tended to differ in finding the fault with government policy and professionals rather than disabled people themselves. Notably, while 9.5% of articles from this period about disability were critical of government policy on disability, there were none that defended government policy. By contrast, in 2010/11 most of the papers were supportive of government policy and particularly its attempt to reduce spending on welfare. At the same time, articles that expressed sympathy with disabled people (albeit usually in stereotypical reference to triumph over adversity) fell from 29% of all tabloid articles to 22%, reducing the overall number of positive depictions of disabled people. This is consistent with falls in the number of articles about disability in which discrimination against disabled people was the main story. In tabloids this was a fall from 19.5% to 14.4%.

Briant *et al* go on to argue that the media portrayal of disabled people amounts to a process of demonization. They base this on factors such as an increase in the total number of articles describing disability benefit recipients as 'undeserving' (127 in 2010/11 compared with 81 in 2004/05). To illustrate their case further the authors cite indicative examples of the demonization of disability benefit recipients such as an *Express* story which claimed that 75% of incapacity benefit claimants were 'skiving' and a *Sun* headline which included the claim that the 'Work-shy are Largely to Blame for

Deficit Crisis'. These perhaps extreme examples are arguably consistent with a pattern of increases in the overall use of pejorative terms such as 'scrounger' or 'cheat', climbing from '12% of tabloid articles in October– January 2004/05 (63 occurrences) compared with 18% of tabloid articles (144 occurrences) from October to January 2010/1' (Briant *et al*, 2013: 880).

Briant *et al* explored the impact of these changes on the public through holding five focus groups with non-disabled people and two with people who self-identified as disabled. Asked to describe a typical story on disability in the media, 'by far the most common' answer given by non-disabled focus group participants centred on benefits and benefit fraud. Such participants nearly always drastically over-estimated levels of benefit fraud when compared to official government estimates. The result is that a large amount of participants believed changes in government policy are justifiable because they target undeserving benefit recipients who are not genuinely disabled.

Briant *et al* do not specify or speculate upon any causal link connecting the cultural shifts they document to reforms/cuts. However, one can conclude from their research that any attempt to address potentially harmful changes in disability policy will need to address the public support that has grown for these changes, and the mistaken beliefs this support is based upon.

## Summary

The end of this chapter draws to a close the presentation of background information within this thesis. An overview of the history of the DPM was given in the first chapter, and in this chapter some of the challenges currently facing disabled people have been highlighted. Among the challenges discussed have been those related to housing benefit, including restrictions on LHA and the impact of the under occupancy penalty. I have also discussed the replacement of DLA by PIP, the closure of the ILF, changes to social care eligibility and challenges to DPOs. These are combined with the cultural challenges described by Briant *et al*. I have only been able to summarise some of the more prominent current challenges to disabled people and have not referred in any depth to a significant number of further challenges (see table 1, p24).

Although I have detailed many reasons to believe that disabled people are facing considerable challenges, I do not wish to have depicted disabled people as if they have no agency, or as if they are in a position deserving of pity or charity. In the remainder of the thesis I rely heavily on the anti-disablist accounts of disabled activists. It is my belief that structuring the thesis around such accounts can counteract any impression given in this section that disabled people are increasingly 'vulnerable' or deserving of charity.

In the next chapter, I turn to issues of method, with particular stress on the way in which the thesis has developed.

## Chapter 3: The Development of the Thesis

In this chapter I present the steps through which the thesis developed, detailing how I have responded to the views of participants and other factors as the thesis evolved. This will provide a greater sense of the choices I was presented with and the reasons that the research developed in the way it did. To do this I will begin by explaining how I arrived at my area of research interest. This is followed by a discussion of why I chose to research disabled activists and how I went about identifying and accessing participants to interview. Subsequently, I discuss my chosen method of data collection, my experiences of carrying out interviews, and my method of data analysis. In closing, I discuss ethical considerations, including the issue of anonymisation.

Throughout this and the following chapter I hope to portray a sense of the reflexivity and co-construction that marked the research process. In chapter four, I will discuss in depth how I conceived of the role of the researcher within my approach to research. In this chapter I will reflect on the way in which pre-judgements suffuse the entire process of research design, data collection and data analysis. I will not seek to downplay or ignore this in the hope of presenting findings that appear uncontaminated by researcher-influence, but seek to be as honest as I can about my conscious and possibly even unconscious influences. Precisely because they are my pre-judgments, it is of course possible I will be unaware of their influence. Through a frank discussion I hope to minimise this possibility. Acknowledging the role of pre-judgment is consistent with the critical realist perspective presented in chapter four, which acknowledges the 'concept-dependence' of all observation. To reflect this, I will describe the strength and limitations of my chosen methods and how I might have done things differently.

### How the Focus of the Thesis Developed

As is often the case in qualitative research, the concerns of the thesis have undergone successive revision as I have moderated my initial preconceptions in response to what I have learnt in interviews and from surveying the relevant literature.



The thesis was initially conceived as an inquiry into the apparent contradiction between individual forms of empowerment promoted by the 'personalisation' of social care, and collective forms of political empowerment that provide a platform for campaigning for greater independence. In particular, I was interested in whether the pursuit of individual empowerment in personalisation could come at the cost of collective political strength, undermining the collective contexts/spaces which can promote solidarity and mobilisation. As I began to carry out interviews and continued to follow the written output of disabled activists and disability studies scholars, it became increasingly clear to me that this concern with individualism versus collectivism could be a crude and reductionist lens through which to view personalisation. Indeed, from my perspective as a non-disabled 'outsider' to the movement, one of the continually fascinating aspects of the anti-disablist struggle was that it seemed to combine collective and individual empowerment in a relatively harmonious fashion, as de-institutionalisation and resulting gains in independence could allow participation within forms of collective mobilisation. This could create a virtuous cycle through which collective mobilisation would feed into further individual empowerment, and so on.

There was another problem with my relatively narrow concentration upon personalisation in a thesis based upon learning from disabled activists. As I began interviews, talk of "personalisation" was rarer than I expected as participants tended to frame developments such as personal budgets and direct payments within the DPM's longer standing principle of independent living. Demands for conditions that would bring about independent living for British disabled people had long preceded the government's policy rubric of personalisation. In the context of activism, independent living had commonly been successfully combined with other more collectivist aspects of disability activism. As evidence of this, the prominent activist and disability studies academic Michael Oliver maintains that the possibilities for social change fomented by the DPM had been 'based upon the bedrock of three big ideas which have emerged exclusively from our movement and have been based entirely on our own experiences; the ideas are, of course, the social model of disability, independent living and civil rights' (1999a: 17).

If the abstract ideas of personalisation and independent living are similar or overlapping, the contention that there could be a tension between the individualism of personalisation and the collectivism of activism might appear alien to participants and my reading audience. In sum there appeared to be two problems. Firstly, I had based initial interview invitations and interviews upon the idea of personalisation, rather than the more familiar and meaningful language of independent living. Secondly, divorcing the mechanisms of personalisation (or what participants knew as independent living) from other aspects of disability activism, and presenting it as if it could be in tension with them, failed to reflect the manner in which activists assumed such mechanisms were part of a complementary whole, augmenting and mutually reinforcing collectivist practices and mobilisation.

My concern with personalisation's potential to weaken collective mobilisation flowed from my prior work experience. My earliest experiences of the term came as a support worker in a large housing association as I became familiar with praise for "personalisation" and its purportedly huge potential to change the organisation. This fed into a degree of scepticism on my part as I noted how a wide range of practices (including closing homes/projects) were seen as justifiable through the discourse of personalisation and endowed with unquestionable status through their association with this term. I felt these practices were questionable and this informed my initially sceptical and one-sided attitude to personalisation.

My initial reading into the subject was premised on my understanding that "personalisation" was an important term. My concentration on this term in particular filtered the range of literature I encountered. This led to a narrower range of literature than could have otherwise have been the case, as I was led toward material in the Guardian newspaper, the community care website and social work practice journals. It was only later with my introduction to disability studies journals and interview participants that I began to understand more keenly that the DPM had its own analytical frame through which to conceive of individualised funding mechanisms. This was brought home to me further during initial interviews carried out for the thesis. In a sense this validated my decision to interview activists, in that through interviewing

them I was prompted to reflect and change my initial interpretation of the topic at hand.

In addition, while I planned the project and did my best to immerse myself in the relevant literature, my initial concern with the tension between collective mobilisation and individual empowerment seemed self-evidently important. On paper, this had seemed like an obvious and important theme for investigation, but my interviewees did not directly refer to this as an important theme.

It may have been an error to begin the study with a research interest that failed to reflect participants' concerns. However, I can look back more positively upon my decision to change course in response to their priorities. The process by which I altered my topic illustrates the principle of fallibilism (Sayer, 2000); the point being that our ideas are consistently shown to be wrong or mistaken, meaning the objects of knowledge cannot be reduced to different linguistic constructions of them. Rather than seeing different views of the world as incommensurable and free-standing constructions, accepting the potential fallibility of one's views can encourage one to accept when we may have been wrong, misguided or simplistic.

With the benefit of increased engagement with participants, I chose to reflect the way in which participants construed personalisation as one part of a greater whole, encompassing other complementary goals. This caused me to revise my topic to allow other concerns to be discussed in the context of my central concern with personalisation, meaning I could minimise constraints on the range of factors participants felt were relevant to discussion. This resulted in a second version of my primary research question, as it shifted from 'what is the relationship of personalisation of social care to the collective political mobilisation of disabled people' to a more general concern with 'to what extent does personalisation realise the demands of disabled activists for the reform of social care?' This revised question went some way to address the broader range of issues that participants wished to discuss.

At this stage I still felt a central focus on personalisation remained important, continuing my belief that it encapsulated important dilemmas for the movement. In part this continued stress on personalisation was because I was reluctant to broaden

the scope of the thesis to such an extent that it became unfocused or vaguely defined. My choice at this stage to retain an integrating focus on personalisation was not purely an a priori judgement of its importance, but followed other researchers with more experience of disability activism and the demands of disabled people for change. They, for example, had noted the potentially problematic issue of the lack of collective contexts/spaces in a landscape of support provision based on individual empowerment, or even atomism (Roulstone and Morgan, 2009; Ferguson, 2007). In this sense there was good reason to initially premise the thesis on this tension. Whilst I realised that positing a dichotomy between collective and individual empowerment could be misleadingly simplistic, I did not want to rule out instances in which it remained an important issue. Indeed, later in the development of the project I drew on the notion of 'enforced individualism' (Roulstone and Morgan, 2009) to show how many current challenges to disabled people could be conceptualised.

Even as I broadened my focus in this way, I was still concerned that I was imposing an excessively restrictive lens onto the full range of responses that participants wished to give. My second revised question was still principally concerned with the defined boundaries of social care and personalisation, but in light of my interviews I started to believe this was also narrow and restrictive. This was confirmed to me by reading about the forms of disablism that exist and how they interact with one another (Thomas, 1999). For example, the area of social 'care' and personalisation I had focused on could not be easily divorced from cultural patterns of disablism, or from economic exclusion and subordination of disabled people. This was most obviously the case during interviews as participants invariably sought to go beyond the discussion of personalisation to address the restrictions imposed by cuts to benefits and services that disabled people relied upon. This may not have meant that concerns with personalisation had gone away, but rather that other issues were considered to be more pressing and worthy of urgent discussion. There was an ethical and political need to adapt to the concerns of my participants, especially as my thesis was based on articulating activist accounts of anti-disablism, implying an endorsement of anti-disablist politics on my part. As well as the ethical and political case for changing topic, I would also argue it was methodologically sound to adapt to what I was learning. In an

inductive process of theory generation in which one builds hypotheses or theories from the data, it is best to flexibly adapt one's theoretical framework to track what participants find most important. Similarly, an informal type of inductive analysis takes place as researchers revise their focus in response to new information and ideas. The way in which the topic changed, in response to participants concerns during the interview stage of the thesis, can thus be seen as part of the broader process of theory generation.

Eventually I decided upon a third and final focus of the thesis, changing to a more general concern with 'activist perceptions of contemporary disablism and the prospects for resistance'. This allowed me to follow what was most important to participants: the subject of their campaigning, and the means by which they could achieve their objectives. This final development meant I was no longer centrally preoccupied with personalisation. It did not end my interest in it, but it meant I could explore participants' perceptions of disablism and anti-disablism against a backdrop that included personalisation.

As well as adapting the topic for the reasons described above, another reason was my exposure to accounts of disabled people's current struggles, particularly through the flourishing online oppositional culture that had emerged in resistance to the impact of the government's program of austerity on disabled people. I could discern from this oppositional culture and from interviews, less stress on personalisation and more on the general scenario of a government program of austerity and the impact this was having on the standard of living of individual disabled people and the survival of DPOs. Although this represented a shift from my focus on personalisation, it was inclusive of challenges to the potential of personalisation such as cuts to the levels of personal budgets that disabled people received.

Adapting to participants predominant concerns is an advantage of evolving qualitative research in general, and in particular of semi-structured interviews which allowed me to follow participant concerns and to revise the focus of my questions and the subsequent focus of my analysis. From an experimental, positivist point of view, adapting to participant concerns and changing my research objectives could be seen as

a sign of under-specified research goals, and of an interview technique which does not adhere to pre-defined questions with sufficient rigour. I argue to the contrary that by adapting to participant concerns I could better track the evolving nature of disablism in general, following the present trends considered most important by my well-informed participants. If I was to illicit 'thick' data (Lincoln and Guba, 1985) from my participants, it was logical that I explore what they considered important, reflecting the value of *their* interpretation within my thesis. It was therefore a methodologically sound choice to widen my research question. To gain the most revealing insights from my participants and maximise the space available for their valued perspective to be heard, I decided to respond to the aspects of disablism they considered most important.

Even though my focus changed, the reason I was initially interested in personalisation was the extent to which it would empower or disempower disabled people. There was, therefore, no great jump or break in my underpinning motive. It might be argued that placing the political priorities of participants above a previously more policy-orientated concern with personalisation reflects a degree of partisanship on my part. I would openly concede that my politics have played a role in choosing to change topic, although I would also argue it is methodologically sound for the reasons stated above. If participants considered personalisation to be an increasingly abstract concern in the face of mounting cuts, I was willing to shift my research focus accordingly. The overriding goal of representing anti-disablist perspectives was more implicit at an earlier stage when I was concerned with personalisation, but it was still present through my preference for interviewing activists. As I adapted my topic, this overriding goal became more explicit.

After adapting my overall research question for the third time, I could still rely to a great extent on the sub-questions that had guided me from my second formulation of the question. These questions formed the loose structure I used to guide interviews. The interviews frequently touched on other subjects than those I reproduce below. They could be seen as 'guided conversations', in that I tried to follow what participants considered most important, rather than following a rigid schedule. That said, the following questions are a good summary of the topics covered:

- What ideas and principles and priorities have motivated participants to engage in activism?
- What do participants understand by personalisation?
- What variations exist between the approaches of different activist groups and how do their views on personalisation vary?
- Can personalisation work for everyone?
- What are the strengths and weaknesses of current government disability policies?
- Do personal budgets and the promotion of the idea of personalisation mean activist goals have been achieved?
- What goals remain for disabled activists?
- What role do participants perceive Centres for Independent Living or User Led Organisations to have had in the development of independent living? What do they believe their current and future role to be?

By asking what participants understood by personalisation, I gauged the extent to which they felt it was a pressing issue and then chose whether to follow these up with further questions on the matter or jump to other questions. Broader than personalisation, if participants did not wish to discuss 'support' or 'social care' and preferred to dwell on other arenas of disablism and resistance, I could adapt to this by asking about the strengths and weaknesses of government policy more generally. Using my questions in this way allowed me a useful degree of flexibility.

The way in which I could retain the questions above, even after I had shifted focus for a second time, demonstrates some continuity in my focus. Indeed, there is a danger with the above presentation of it appearing as if there were abrupt and discontinuous changes in topic as I realised the restrictive effect of my initial concerns. The actual process was more of a gradual evolution over the course of twenty interviews. For example, between the three changes in research question, there were moments where I had come most of the way to changing focus, even if I had not yet formally changed course. Given the degree of continuity between my research concerns, it should not be underestimated how much my initial concerns must have continued to influence my later findings and readings of the interview data.

My shift in focus may have just reflected my growing level of clarity about what it was I was aiming to investigate. The general motive for the research (to represent activists' perspectives) was always apparent, and one of the most difficult decisions was the breadth of the disabling factors that were under consideration. My initial concern with the individualism of personalisation versus the collectivism of activist mobilisation was excessively narrow and excluded too much of participants' experience, serving to 'fence off' so much of participants' experience of disablism from my analysis. As I continued to revise my focus to reflect the complexity and breadth of contributions I opened the door to consider more factors I had previously excluded. With my final focus settled, the opposite drawback was apparent to the one I had begun with. Exploring the totality of contemporary disablism and resistance in Britain risked framing my research in such a general way that detail would be lost and subsumed under broader theorisations. Broader theorisations could be built on uncertain foundations if I failed to give due attention to the micro-dynamics of disablism in the pursuit of broad theorisations.

Therefore, another potential drawback was that my questions might appear to lack specificity or direction, and this was apparent in one or two occasions when participants were unsure what type of answer I was trying to illicit from them. Overall, these drawbacks were a price I was willing to pay for the ability to better reflect the full range of relevant factors which participants wished to reflect upon. To have imposed a primary concern with personalisation onto participants could have divorced the realm of 'care' and support from more structural dimensions of disablism. This would have represented an unsustainable division between private and public politics. My conviction, informed by relevant literature, was that the everyday politics of support should not be separated off from the rest of disablism. An insight of the social model of disability, and of the 'social oppression paradigm' (Thomas, 2012) in disability research is that disabled people face multiple disabling barriers and relations of oppression. Everyday life is highly politicised for many disabled people as they negotiate disabling relationships of care and support. I did not wish to separate such forms of disablism from others. In this I was motivated by a holistic picture of anti-disablement such as that promoted by Derbyshire Centre for Integrated living



(Priestley, 1999). By joining more 'personal' aspects of disablism in the realm of support and personalisation to the others considered relevant by participants it was also more possible for me to probe the intersection between individual biographies and social structures (Wright Mills, 1959).

## **Why I Chose To Interview Disabled Activists**

Although the choice of focus for this thesis shifted, the choice of participants remained constant. In the earlier focus of the thesis on personalisation, it was thought that disabled activists could put forward an especially revealing insight into the development of it. The DPM had done the most to push for previous developments associated with independent living, achieving successes such as direct payments (Morris, 1993; Bornat, 2006). Personalisation could be seen as comprising an element of independent living, along with other influences (Needham, 2011). Although at any earlier stage, my knowledge of independent living was low, I already thought it important to find out from activists how much they perceived the principles of personalisation to be consistent with their earlier campaigns. From an early stage I felt it was necessary to limit the group of participants I worked with to those with physical impairments, rather than other groups who could be defined as disabled such as people with learning difficulties or people with mental health issues (these groups can overlap in cases in which people have multiple impairments). I believed that interviewing people with physical impairments was advantageous because of the long trajectory of activism this group had in the UK through campaigning for independent living. Their narrative in relation to the reform of social care and changes in disability policy was rich and could contribute much to an understanding of how disability policy had changed in the UK. Restricting my sample in this way also had the practical benefit of keeping my attempts to find participants within a relatively focused sample group. Finding participants from every group that could possibly be included under the description of 'disabled people' could have become very challenging, requiring that I work through multiple organisations at the same time.

As I note above, the overall theme of the thesis changed to encompass more aspects of disablism and better reflect the views of activist participants. This is

methodologically sound because the thesis is premised on the value of activist interpretations. As a justification for this contention, I argue that the views of activists are to be valued because their insight and consciousness has been raised through political activity, challenging disabling oppression, and learning how disablism responds to opposition. Activists have learnt from confronting disablism how successful resistance can best be achieved. They are also likely to be informed about the internal challenges within disability activist groups and the dilemmas and problems associated with collective mobilisation among diverse disabled individuals. This group included activists involved in academia, particularly in the field of disability studies. I sought to interview disabled activists, rather than disability activists. 'Disability activists' refer to a broader category of person who may not themselves be disabled, but are engaged in anti-disablist politics. I decided to interview disabled activists rather than disability activists for a number of reasons. Firstly, I wished to foreground the views of disabled activists because I believe that they often have the longest and richest history of activism in this area. I also argue that disabled people's awareness of disablism and anti-disablism is often greater because they experience disablism first hand. A final reason is my position as a non-disabled researcher and the way I can avoid an excessive influence of my own views by working with disabled activists.

To fully justify my preference for activist contributions, it is useful to contrast the knowledge typically produced by academics with that produced by 'movement intellectuals' with activist experience. The term 'movement intellectuals' refers to members of social movements who produce their own distinctive form of knowledge. While the knowledge of academic intellectuals is to be valued for some reasons, the knowledge produced by movement intellectuals is typically to be valued for other reasons (Barker and Cox, 2002). In particular, the strength of academic theorizing is the development of 'a broad conceptual armoury' that tends to 'treat what are, precisely, movements as static 'fields', to embed their understanding in an uncritical acceptance of the givenness of those institutions which movements often set themselves against, and to marginalize the position of the actor' (ibid: 2). Movement intellectuals share this interest in developing a 'conceptual armoury', but only in service of a set of arguments for the purpose of 'formulating 'case propositions' of a very definite and

practical nature. These take the form, in essence, of practical proposals, i.e. propositions that 'This is what we should do' (ibid: 2). I follow Barker and Cox in that I believe activist views can contribute something distinctive to academic discourse owing to the differing needs of movement intellectuals. Their interest in 'case propositions' of a practical nature may be of particular interest in that they are likely to drive forward practical insights into what activists consider to be the most detrimental and urgent forms of current disablism. Activist accounts offer a practical analogue to the political theory of Holloway (2005) (see chapter ten), in that they focus on the instability of disablism and how to end it, and not an academic consideration of why it persists. In this sense their theory may differ from typical disability studies academic production which may tend toward a static and reified depiction of disability.

The distinction between the knowledge produced by movement intellectuals and the knowledge produced by academics could be overstated in the case of disability studies because the paradigm of disability studies has its roots in the work of organic intellectuals such as Hunt (1981), Finkelstein (1980) and Oliver (1990). By use of the term organic intellectual I refer to Gramsci's (Hoare and Nowell-Smith, 1998) distinction between traditional and organic intellectuals. The application of Gramsci's class-based analysis may not map onto disability precisely, but the distinction can highlight the role of disabled activists in analysing their situation and laying much of the groundwork for disability studies. In Gramsci's distinction between traditional and organic intellectuals, 'traditional' refers to professional intellectuals 'literary, scientific and so on' whose position 'derives ultimately from past and present class relations and conceals an attachment to various historical class formations' (Hoare and Nowell-Smith, 1998: 4). In the case of disability, traditional intellectuals are equivalent to the generations of academics and professionals who worked in the broad field of disability and depended upon it for their income, in the same way that Gramsci's traditional intellectuals ultimately derive their status and income from existing class formations. In the area of disability research, traditional intellectuals would profess neutrality and objectivity while failing to challenge oppression and disablism (e.g. Miller and Gwyne, 1972). 'Organic' intellectuals by contrast are the 'thinking and organising element of a particular fundamental-social class' (Hoare and Nowell-Smith, 1998: 4). Disabled

activists fit this role as those who emerge from disability activist groups to articulate the demands of the wider movement. For Gramsci, the working class was perfectly able to produce its own organic intellectuals of this kind, and in disability activism this also has proved to be the case. Organic intellectuals are motivated by a self-conscious knowledge of their role in change and would absorb valuable ideas from 'the more advanced bourgeois intellectual strata' (ibid). This is evident in the work of disabled activists such as Finkelstein (1980) who draws on work from outside disability activism to make his case.

Disability studies, particularly in its earlier phases, was marked by the strong influence of writers and campaigners who can be considered as organic intellectuals. Beginning with activists such as Paul Hunt, they were conscious of the way in which traditional intellectuals had failed disabled people (Hunt, 1981) and understood that they would need to drive change, in part through their own production of knowledge. Later, activist accounts proved insightful in the accounts given of disability rights and activism in an important book that reflected upon the struggle of the DPM (Campbell and Oliver, 1996).

Viewing disabled activists as organic intellectuals is a way of viewing the development of disability studies, and of locating my work within it. It could be argued that some of the more intractable debates in the discipline are representative of an underlying gulf concerning the extent to which activist knowledge production can sit alongside that of academics. Writers such as Watson (2012) and Shakespeare (2006) suggest that knowledge produced by activists, such as the social model of disability, is 'too simplistic and is better suited to the political arena as radical rhetoric for a movement than as the basis for an academic model' (Watson, 2012: 193). On the other side of the debate, Oliver suggests that the academisation of disability studies and the 'declining influence of the disabled people's movement' makes it harder for the discipline to maintain a focus upon 'the disabling society' and for it to produce work that is relevant to non-academic disabled people (2009: 179). For Oliver, this can be attributed in part to the increasing tendency for work to be 'academic articles to promote the individual's career' (ibid). This critical take on much of disability studies could be seen as a concern with the growing control over disability studies by

‘traditional’ intellectuals, who by virtue of their position in the disabling society are less driven by the need to urgently challenge disablism.

By choosing to interview activists for this thesis I am taking the side of the debate that places great value on the contribution of activist knowledge within disability studies. As I suggested in chapter two, many disabled people are currently facing acute problems brought about by changes in government policy. Activists with experience of past challenges are well placed to contextualise the extent and nature of current challenges. They can also provide a snapshot of how disabled activists currently conceptualise these challenges and how they believe successful activism may best take place. These qualities of activist accounts can also balance out the limitations of my own perspective. I have some limited observational experience of disablism as experienced by people I have worked with and in the life of a family member, but I lack the first-hand experience of anti-disablist struggle that my participants could contribute. Being a non-disabled person does not mean one cannot have experience of anti-disablist struggle, but clearly there is a difference between this and being a disabled person with first-hand experience of disablism.

This relates to my earlier distinction between disabled activists and disability activists. It may be that disability activists who are non-disabled have a more extensive knowledge of the political struggle than some disabled people. However, it is only disabled activists who can combine knowledge of political struggle with experience of disablism. There is an important link from experience of disablism to knowledge of how best to challenge it. This is why I chose to try to interview disabled activists in particular. In my own case, I am non-disabled and lack extensive experience of anti-disablist activism, but believed that I had some research skills and knowledge of social theory that could aid in understanding how to challenge current forms of disablism. By working with disabled activists I felt I could limit the risk that I produce a static, academic exercise in theorising the stability of disablism and domination of disabled people.

As it becomes embedded in academia, there is arguably a tendency for disability studies to become detached from activists and their organic knowledge of

their struggle, contemplatively and uncritically accepting the givenness of aspects of disablism which disabled people may oppose. In another arena, Holloway (1991) has made the point that structuralist political-economists can slip from analysing what is necessary for exploitation and injustice to occur, to prescribing what is necessary for this to happen, as if resistance had no role in the reproduction of domination. This problem is arguably present in disability studies when academics use disability as a vehicle for tenuously related theoretical contemplation in the production of 'academic articles to promote the individual's career' (Oliver, 2009: 179). By drawing upon the insights of activists, I hope to avoid this and contribute to what has been called 'movement relevant theory' (Bevington and Dixon, 2005), meaning theory produced for the movement, not just theory produced about the movement.

This completes my argument for having chosen disabled activists as the sample group for this thesis, but it leaves the issue of how precisely to define and identify activists to interview.

## **Defining Disabled Activists**

To identify participants I required a conceptualisation of what constituted a disabled activist. It was my view that self-identification was the primary criteria for this, although I did impose some limits on who could participate. To see why self-identification is important, it is worth recalling the way in which the emergence of disability studies and the DPM rested on the self-mobilisation of disabled people against disabling conditions. They self-identified as disabled activists and campaigned for equality. This involved a re-definition of disability as oppression, most clearly stated in the social model of disability. Disabled people had thus seized the power to define disability and who could be considered disabled. This took the power away from medical or other professionals to define disability and enabled disabled people themselves to define it. As disablism is essentially seen in a negative light, as a process of oppression, it is for disabled people to self-identify if they see themselves as disabled or not. Hughes makes the point that 'for the DPM it is the social processes of discrimination and oppression that create the material circumstances out of which solidarity and politicisation arise' (2009: 679). He goes on to quote Oliver (1990: 120)

who argued that one of the key objectives of the disability movement is to create 'new solutions to problems defined not by health professionals but by disabled people themselves'. For me to have insisted on some confirmation of an individual's impairment would have been to utilise a medicalised model of disability, and I was not inclined to do this.

A collective dynamic of oppression means there is arguably a degree of commonality to the oppression that is experienced by disabled people (Priestley, 1995). This implies a shared identity formed through a common experience of oppression. Such an argument is not without problems, and the discussion concerning the extent to which there is a common identity among diverse disabled people is a recurring theme within disability politics. For the purposes of this chapter, I want to argue that the commonality of disablism means that people with diverse backgrounds and impairments should be equally able to claim for themselves the identity of a disabled person. This provides a means of defining who disabled people are and, I believe, much of the means of defining activists for my purposes as well.

To define disabled *activists* more specifically I needed to consult the relevant literature. Although there is a large amount of literature concerning the complexities of disability identity and the ways in which people may be defined as disabled, I found relatively little has been written about the identity of disability activists in particular. Of those works I found on disability in Britain from a social movement perspective (Beckett, 2006; Campbell and Oliver, 1996; Hughes, 2009; Shakespeare, 1993), there tends to be a presupposition of an unproblematic category of 'disabled activist' and little explicit discussion of the identity of disability activists, that is, who is, and who is not, defined as such.

Within the literature I found two more elaborate discussions of this issue. According to Kelly (2010) much can be inferred about activist identity, and what it excludes through the identities which are implied by the campaigning activity at hand. For example, she argues that groups of disabled activists campaigning for personal independence schemes presuppose that 'disabled people' equates to the identity of that smaller group of disabled people who are most likely to benefit from such

schemes. Another useful source on disabled activist identity is from Hughes (2009). Following Shakespeare and Watson (2002), he notes the lack of a 'mass movement' of disabled people and observes that most disabled people do not wish to be identified as 'disabled'. He states that the exclusion of impairment from the mobilising idea of the DPM (the social model of disability) creates a divide between disabled activists. He identifies activists he terms 'biological citizens' who see medical professionals as potential allies, believing they are better served by engaging with medicine, to expose it to critique, drive it to reform, and to make it more accountable. He argues that biological citizens differ from other disabled activists in actively identifying with their diagnostic category, thereby engaging more actively with the medical profession. He distinguishes these activists from what he terms 'social model stalwarts'. Such individuals tend to have little faith in scientific or technological progress, and even have dystopian views of scientific research (Hughes, citing Shakespeare, 2006).

I return to the topic of identifying disabled activists when I discuss the practicalities of finding participants later in this chapter (p66-67).

## **Access Issues**

I began trying to find activist participants by approaching the National Centre for Independent Living (NCIL) to request details regarding the number and geographical distribution of Centres for Independent Living (CILs) and the contact detail of an individual within each CIL who could serve as a primary contact. CILs had become synonymous with the DPM in my mind and this seemed like an obvious place to start. I also felt that they occupied an important collectivising role in a support landscape increasingly characterised by reforms that could fragment sources of collective identity for the DPM (Roulstone and Morgan, 2009). Choosing to begin searching for participants through CILs may have been an imposition of a pre-conceived notion of disability activism on my part and also reflected my initial focus on personalisation and the valuable role CILs can play when uptake of personal budgets is growing.

I did not have as much success contacting CILs through the NCIL as I had hoped, even after repeated attempts by phone and email; perhaps because it was going



through significant changes at the time as it merged into being part of DR UK. Instead I researched Centres for Independent living online and began to build up a picture of their spread. I sent out an information sheet and invitation to these organisations, asking if they could circulate my information sheet to anyone who they thought could be interested in participating.

I began to receive a small number of replies but generally struggled to garner a great deal of interest in my research. Of course I cannot know why people did not find it an enticing prospect. Possible explanations include that there is a great deal of research carried out with and 'on' disabled people. Part of the critique of standard disability research I shall discuss in the next chapter is that it mirrors wider social relations as relatively powerful academics research disempowered individuals (Oliver, 1992). This occurs while the most powerful and influential members of society are rarely researched in the same depth. Other grievances disabled people have felt with research on disability are that the language and concerns of academics are frequently irrelevant to disabled people (Oliver, 2009). These reasons, along with the exploitative and parasitical history of unethical disability research (Hunt, 1981) mean many disabled people may be disinclined to participate in research projects on disability, particularly when carried out by a non-disabled researcher. The frustration of many disabled activists with such research may explain why they were uninterested in my research. More prosaic reasons may also have been responsible for my difficulties in accessing research participants such as the alien language of personalisation (as opposed to independent living) used in my information sheet, the relatively low profile of my academic institution in disability research, or simply a failure of persistence on my part, meaning that my information sheet did not reach enough potential participants. It is also possible that the challenges to disabled people and DPOs that I document in this thesis may have contributed to difficulties finding participants, as individuals and organisations found themselves involved in more pressing personal and political challenges.

Regardless of the reason for the difficulty in accessing research participants, it presented me with a need to change my strategy to find more participants. Through the initial progress I made with establishing some contacts in centres for independent

living, and the small number of interviews that followed, I conducted a form of 'snow-ball sampling' as initial interviewees put me in contact with their contemporaries. I also benefited from two contacts at my university who put me in contact with colleagues who, in turn, were willing to make contact with suitable participants on my behalf. As I conducted more interviews, four more interviewees made contact 'out of the blue' reporting they had recently been given my information sheet. I can only assume that awareness of my research had percolated through networks of friends, colleagues and fellow activists, and eventually found its way to more prospective participants.

As I made progress with finding potential participants I was faced with the need to decide if they were suitable as participants. Whilst I did not believe I should have the power to define activism, it would be absurd not to use any criteria at all. The first opportunity to enter the research process was in response to my advertisement; the phone call that followed was therefore the first opportunity to gain any idea of who I was likely to interview. I did not question potential participants too closely at this stage, but sought to gain some confirmation that they could be considered disabled activists (see below). Generally this did not present any particular dilemmas. One exception was in the case of two individuals without a physical impairment. One was recommended by other activists, deeply steeped in the anti-disablist struggle and proved to be a very informative interviewee. The other had worked as the support worker of a prominent disabled activist in Scotland. The individual assured me she could be considered a disability activist, and I accepted this on the basis that her values were as important as if she had impairment. Although I had my doubts if the person should be considered as a disability activist and stressed to her the purpose of my research and my interest in speaking to disabled activists, I accepted her argument and proceeded with the interview. In the event I felt the interview was less successful with little reference made to the wider movement against disablism. This may of course have been a case of an overly restrictive view on my part of what should be considered activism, but I chose to omit her interview data from the analysis stage of the thesis. In other cases some individuals had more and less involvement in activism 'writ-large',

and in some cases I needed to be mindful that my own pre-conceived idea of activism could be mistaken, and could potentially exclude important experiences.

When potential participants made contact, I wrote to them by email to confirm my interest in interviewing them and to confirm or suggest a time and place for the interview to take place. I attached to my email a formal invitation to participate, a consent form, and another copy of the information sheet they had initially encountered. I sent the email in large font size in the belief this would be accessible to more participants. In the same email I checked if the participant had any needs that I should be aware of prior to interview.

## **Summary of Participants**

I eventually interviewed twenty individuals between March 2012 and January 2013. I did not inquire into the precise nature of the physical impairment that participants lived with, but it was evident that nineteen participants had a physical impairment. Eleven of them were female and one was from a BME background. Interviewees were spread across England and Scotland, with three in Scotland and seventeen in England. I did not gather data on the age of participants but I believe participant ages averaged at roughly fifty. Fifteen participants were active in working for a DPO, and some others were 'retired' from activism or were primarily involved within academia.

## **Strengths and Limitations of Sample**

By accessing participants with physical impairments through established organisations of disabled people, I ran the risk of excluding those who did not share the views typical of individuals associated with CILs. By contacting individuals from these organisations, I may have been mobilising a research strategy that confirmed my pre-existing beliefs about disabled people's priorities. Although I did consciously choose to interview people with physical impairments rather than just assuming they equated to disabled people in general, this decision may have meant that I excluded potential participants who could easily be defined as disabled activists. In this I may have operationalised what is presupposed as the typical disability activist within disability studies literature.

The narrowness of the group commonly assumed by the label 'disabled activist' has also been said to frequently equate to disabled man (Morris, 1991). I did not have to grapple with this issue in depth in relation to my sample because eleven of twenty participants were women. Another criticism of the mainstream disability movement has centred on its exclusion of those from ethnic minority backgrounds (Priestley, 1995). This was replicated in my study as I was only able to interview one person with a non- white/British heritage. The age of the participants I interviewed was slightly younger on average than I had envisaged. I was seeking discussions with older activists who could place the current state of disablism and anti-disablist resistance in a historically grounded account and present their views on areas of progress and decline in challenging disablism. Due to the problems I experienced in accessing participants, I decided to interview a few younger activists, although twelve of the activists had been active since the nineteen eighties and were over fifty years of age.

Again due to the difficulty in accessing participants, I needed to look as far and wide as I could to interview informed and experienced activists. In the end I interviewed individuals from South East England, the West Midlands, Humberside, North West England, North East England, Glasgow and Edinburgh. I do not wish to discuss the specific location of each participant for fear of compromising anonymity. The choice to interview participants from Scotland introduced some challenges owing to the different system of social care provision in place. In the event, two of the three interviewees from Scotland had experience in campaigning south of the border. They also emphasised the commonality of many of the challenges that they shared with their English counterparts such as the limits imposed by the control of taxation in Scotland by Westminster. A final means by which I needed to be flexible in order to secure elusive interviews was to agree to carry them out over the phone rather than in person in nine of twenty cases.

My sample was narrow in some respects, mirroring the stereotype of the British disability movement as consisting of white wheelchair users. This narrowness had its own advantages. For example, the individuals I interviewed were typically involved with DPOs, and many had long histories in disability activism. They were thus part of relatively cohesive group of people with a degree of shared history and

identity. What I would have gained from interviewing a more heterogeneous and diverse group of activists might have made it more difficult to draw any meaningful inferences and could have left me with fragmentary, contradictory data that was more difficult to interpret. As I argue above, the opinion of my sample group, however 'unrepresentative' it might be of disabled activists in general, is of particular interest for those seeking to understand disablism and anti-disablist resistance. This is appropriate for qualitative research of the type I have developed in this thesis, in which qualities of thickness or depth is more important than breadth or comprehensiveness.

Retrospectively, I see my definition of this group as being informed by certain tacit criteria I absorbed from the literature and discussions with supervisors:

- Has the person been the subject of disablism?
- Do they campaign against disablism?
- Do they express a theory of disability (including tacit)?
- Do they have a physical impairment?
- Do they have ties to the DPM?

I did not formally gauge the extent to which potential participants matched up to these criteria, but they came close to expressing the picture of a disabled activist I had imagined. Each of these criteria seems to express an important aspect of disability activism, but it is also hard to operationalise any of them in practice. For example, how could I conclude with any reliability whether someone had endured disablism? Even if one could accurately operationalise these criteria, there still remains the ethical problem of imposing a definition of activism onto self-identifying disabled activists. As I note above, self-identification as an activist, and self-definition of what constitutes disability, is itself an important moment in the anti-disablist struggle. If I were to impose a restrictive definition of disabled activist I could be guilty of the type of unethical power dynamics which marked earlier disability research by non-disabled researchers (Stone and Priestley, 1996). Refusing to impose excessively restrictive criteria also has the advantage that it could lead to a more diverse pool of interviewees than would otherwise have been the case, balancing out some of the exclusion I may

have been guilty of by basing my recruitment strategy on a restrictive picture of what constituted a disabled activist.

## **Use of Semi-Structured Interviews**

The wide ranging and mutable nature of my subject lent itself to qualitative methods of inquiry. Qualitative methods are open to participants discussing a wider range of experiences and are less likely to predefine areas out of consideration that may prove important. In the Emancipatory Disability research (EDR) approach I discuss in chapter four, the preference has generally been for qualitative methods (Priestley and Stone, 1996). This followed strong criticism of national disability surveys by Abberley (1992) for creating a divide between 'expert' non-disabled researchers and the lay-person perspective of disabled people. Barnes also notes that quantitative research was generally marginalised by EDR because 'up to now large scale surveys and detailed quantitative analyses have never captured fully the extent and complexity of the oppression encountered by disabled people' (2003: 10).

Other disability researchers not allied to EDR such as Shakespeare (1996) have also spoken out in favour of qualitative methods in researching disability because they can allow participants to exercise a greater degree of control over the expression of meaning and the direction of the research process. Morris (1991 cited in Priestley and Stone, 1996) also values the qualitative approach in disability research, particularly because of the role of oral tradition in the emergence of social movements.

Overall, I felt that one-to-one semi-structured interviews would do least to restrict the range of factors that participants could refer to when discussing contemporary disabling forces and modes of resistance. This is in keeping with my argument above that giving voice to participants' perspectives was the motor force behind the approach I adopted. In contrast to alternatives such as group interviews, carrying out semi-structured interviews could better allow participants to move between discussing disabling social structures and more 'personal' and smaller scale experiences such as 'psycho-emotional' disablism (Thomas, 1999) that are equally important. Disability politics is intertwined with the individual struggle of many

disabled people to secure independence in their everyday lives, and collecting data at the level of the individual allowed me to probe the relation of these forms of disablism.

Quantitative methods inevitably exclude dimensions of experience; this could be unhelpful given that disablism constitutes a complex and multi-levelled phenomena, comprised of challenges at different levels. My choice of semi-structured interviews is also in keeping with an ethical requirement that participants determine what they consider to be relevant to discussion of contemporary disablism. An opposing approach of using more strongly structured interview schedules would involve a greater risk that I could, as a non-disabled researcher, exercise an unwarranted degree of control over the topics discussed and themes to emerge. In this respect it may have been better if I had exercised even less control through using a more loosely structured interview schedule.

I chose to stop formal data collection after I had completed twenty interviews for a combination of reasons. Firstly, I had struggled to carry out as many interviews as I had hoped and continuing to try to find as many interviewees as possible meant I might risk using up time that I might be better advised to use writing up my thesis and analysing the interviews I had collected. This factor was particularly acute given the need to complete the thesis according to a particular schedule. Second, although there was a great deal of variation among interviews, there was also a degree to which I was encountering repeated themes and my categories of analysis were becoming 'saturated' (Mason, 2010). As I tried to gain more interviewees the energy and time expended on securing the interview started to appear excessive in proportion to the likelihood I would encounter many new insights through carrying out the interview. Stopping to collect further interview data at this point accords with Strauss and Corbin (1998) who argue that saturation is reached when further research would be 'counter-productive' and the discovery of new themes would not necessarily add anything to the overall analysis. I also needed to consider that what I could bring to the process of analysing data is an important aspect of carrying out an insightful analysis (ibid) and that time spent learning more about the field in question and repeatedly analysing the existing data may be time well spent. I felt that many of the interviews I had carried

out were richly detailed and could stand by themselves as adequate sources for my data analysis. I was also in the fortunate position of being able to access the written output of many other disabled activists through 'grey' literature such as online blogs, meaning I could gain further insight and knowledge into disabled activist views without interviewing more people. It might be that a more experienced researcher than myself would have been aware of gaps in the analysis of disablism and resistance within interview data, but I felt I had gained the foundations of a strong analysis.

## **Ethical Considerations**

I gained ethical approval in my first year of study from the University of Central Lancashire to proceed with my research.

To give greater context to ethical dimensions of my research, it is important to note that there is a history of exploitative research carried out by non-disabled people with disabled people. In response to this, the emancipatory disability research approach (EDR) was developed. I discuss this more in the next chapter, differentiating and locating my work in relation to it. I am aware that there is more I could have done to have included disabled people in the production of my thesis, particularly at the earliest stages of its development. This could also have benefited me in bringing me to a settled research question more quickly. There were time and resource limits which stopped me from doing this. With more time and awareness of the history of disability research, I would also have attempted to gain more advice from disabled people through a consultative forum to address the issue of being a non-disabled researcher working with a supervisory team of non-disabled people. It is a cause of regret that I did not do more to include disabled people at stages other than interview, particularly as I have little sense of how my research will be received, other than through the large amount of writing by activists I have read.

A more positive ethical aspect of the research is that by interviewing disabled activists I was likely to encounter challenging and politicised voices who would forcefully make their perspective known to me. There was a difficult balance to walk between theorising their contributions and saying something original without



distorting or misrepresenting these important contributions. I tried to carry out interviews in a collaborative manner, allowing participants to guide interviews within the broad themes I had pre-determined. I stressed the opportunity to withdraw from the research process at any stage, and emphasised that there would be no consequences to this. I carried out a pilot interview and gained some feedback on my performance as an interviewer. When the thesis is submitted I will send it to all participants, asking for their feedback.

With more time I would like to have had the opportunity to get feedback from participants before submission of the thesis. I will be emailing and/or phoning every participant quoted in this thesis to ask them if they would be willing to read and provide feedback. When I have done this I will reflect on their feedback and possibly incorporate their feedback into analysis in resulting publications.

## **Anonymisation of Participants**

Initially I offered participants the opportunity to be anonymised or known in the completed thesis. Participants were more interested in being anonymised than I had expected for activists, the majority of whom wishing to be anonymised. Some worked in organisations that depended on government funding and they did not wish to be public in their criticism of government. Some participants wished to read the excerpts of their interview before they would approve use of their interview transcript within the thesis. This meant I had to weigh up the balance of harms from anonymising all participants or leaving some participants as named. The harm that could result from anonymising someone who wished to be named seemed relatively slight. The harm that could arise seemed greater if someone was named and, through association, identified someone who wished to be anonymised. I therefore elected to anonymise all participants, use pseudonyms to refer to them and edit out any identifying features such as explicit reference to local organisations. Having made this conclusion, however, I raise the danger that it could diminish the visibility and profile of the participants and remove their voice, while I, as a non-disabled non-activist, benefit from their contributions and can increase my profile and voice.

## The Process of Data Analysis

I was informed predominantly by narrative analysis in the analysis of interviews. I was initially drawn to narrative analysis because I had noted how, outside of disability studies, narrative analysis has been used as a lens through which to view political issues. For example, Andrews (2007) explores narratives both for how people view struggles for power, but also for how they locate themselves within this process. In her words, she is interested in:

what kind of stories people tell about how the world works, how they explain the engines of political change, and the role they see themselves, and those they regard as being part of their group, as playing in this ongoing struggle (ibid: 8).

Narratives are well suited to these purposes, partly because they are, paradoxically, both larger and smaller than individual lives. They are smaller in only ever being a snapshot of a given moment and partial because of this (ibid). However, they are larger than individual lives by functioning as 'windows onto political movements and times which are not reducible to individual human beings. They derive their very meaning from being part of a larger whole' (ibid: 205). Without reference to this larger whole, it would be difficult to make any sense of what is said in an individual narrative. Narratives are, for these reasons, a vehicle for insights into the political.

This point by Andrews seems to say a lot about the political interest in narratives, because it tends to diminish the strong contrast that is sometimes drawn between the individual and society. Narrative draws attention to the dynamic at work between the two and is useful in disability studies in which critics of theorising personal experience have expressed concern about the depoliticising consequences of research into personal lives (e.g. Finkelstein, 1996).

In the process of analysis, the power and influence of the researcher inevitably exerts a degree of influence. To place some limit on the extent to which I could read whatever I chose into the data, I used a relatively rigid method of narrative analysis. Through my reading on the subject of narrative analysis, I was drawn to the method of Williams (1984) cited by the scholar of narrative methods Riessman (2008). Here, as

Riessman describes: 'the investigator works with a single interview at a time, isolating and ordering relevant episodes into a chronological account' (2008: 57). Applying this meant turning each transcript into a series of narratives each in chronological order. After this had been done for every interview, I followed Riessman's guidance that the researcher 'zoom in, identifying the underlying assumptions within each interview and naming (coding) them' (ibid). Analysis comes from keeping the story intact and analysing from the individual case (initially), and not 'by fracturing the biographical account into thematic categories' (ibid: 57). When this process was completed for each interview, I began to trace similarities and differences between accounts. Particular cases can then be used to 'illustrate general patterns, and the underlying assumptions of different cases can be compared' (ibid: 57).

The themes that emerged from my analysis reflected pervasive themes in the majority of accounts. Although not all of the central themes I derived from interviews were referred to by most or all interviewees, the mention of some arguments even by a small number of participants made them significant. For example, participants who stressed the challenge of isolation facing many disabled people were making what I saw as a significant contribution because the DPM has generally sought to stress the independence, risk taking, and individual flourishing that could occur through individualised funding. As individualised funding of social care interacted with cuts to personal budgets, this produced the possibility of individual isolation, meaning participants would broach the topic. In other cases, themes were referred to more frequently, but they were not invoked explicitly, rather implied or suggested by the arguments at work. An example of this is the challenge I identified from interviews of obstructively individualistic conceptions of empowerment that lack a grasp of structural disablism. In interviews it was rare that language of "structural disablism" was ever used even though some of the participants were very aware of the terms of debate in disability studies. Part of the role of the social researcher is to theorise and this necessarily involves some transformation of the language at work and a degree of subjective judgement. In constructing such theorisations some of the fine complexity of individual accounts is inevitably lost. Within the analysis chapters of this thesis

(chapters 5-9) I hope to minimise this by providing counter examples in an attempt to avoid an overly reductive account of what was discussed in interviews.

To give more practical detail regarding the form of narrative analysis I have used, I refer to Riessman's typology of forms of narrative analysis. I have practiced something close to the form of narrative analysis described by Riessman (2008) as thematic narrative analysis. In essence, this differs from other forms of narrative analysis (performative or structural) in placing emphasis on the told and not the telling. Although the main focus is on content, and on societal context rather than local context, I have also tried to use elements of the performative form of narrative analysis. As I am in the position of being an 'outsider', it would be misleading to represent data as if this had no influence on the interview process. I have tried to avoid this and to indicate when I think my outsider status could have altered what was said.

In analysing the data for narratives I have sought to understand how participants' stories account for the fluctuating degree of success gained by the DPM and the forces and actors that have impeded and facilitated the achievement of its goals. This involved trying to understand what sociological concepts and power relations they have invoked within their explanations. This is part of the process of developing 'thematics' from the data, which is influenced by 'prior and emergent theory, the concrete purpose of the investigation, the data themselves, political commitments and other factors' (Riessman, 2008: 54).

In the next chapter I discuss the significance of broader methodological paradigms such as emancipatory disability research and critical realism to my approach. I then explain how this relates to my choice of narrative analysis as a method of data analysis.

## Chapter 4: Methodology

### Introduction

In the last chapter I explained the development of the project and gave details of the research process and the choices I made. In this chapter I will discuss in more depth, and with more explicit detail, the epistemological and methodological positions which underpin the thesis. Doing so will require that I locate the approach I have taken in relation to other research traditions, and particularly to other traditions in disability research. I will not be able to offer an exhaustive overview of the entire corpus of disability research, but will highlight some important traditions that are of particular significance to my work, situating my approach in relation to them. First, to place my research in a historical context, I will discuss the critique of conventional disability research made by disabled academics and activists. Following this I will detail the principles of Emancipatory Disability Research (EDR). EDR is perhaps the most well discussed and developed methodological framework to have emerged from disability studies. I then discuss the influence of critical realism on my approach and the relevance of narrative methodologies to my analysis.

### The Critique of Disability Research by Disabled Activists and Academics

To situate disability research historically and politically, Oliver (1992) argues that the way in which the ideological category of disability is 'produced' is increasingly contested by disabled people. He describes how the production of disability has passed through stages in which it was first produced as a medical problem, and second as a social problem, in both cases requiring the intervention of relevant professionals (ibid). It is a cause of frustration for Oliver that research has nearly always 'operated within these frameworks and sought to classify, clarify and map and measure their dimensions' (1992: 101). As disabled people have organised and subjected the conventional production of disability to critique, a crisis in the production of disability occurred in which conventional productions are increasingly displaced by the DPM's production of disability as oppression (ibid). Through this process, the ideological

production of disability becomes a critically important political domain. It is within this charged political climate that disability research unfolds. For Oliver, the question facing disability researchers is simple: 'whose side are you on?' (ibid: 101). He relates this to the model of disability mobilised in the research process - social models of disability are associated with political commitment to disabled people's emancipation, while individual models of disability are connected with oppressive productions of disability (ibid).

Oliver's analysis is coupled with a concern with the role of the outsider researcher who may impose alien views of disability onto their 'subjects'. To correct the production of disability in medical or individual terms by 'outsider' researchers requires a consideration of 'the social relations of research production' (1992: 101). By this Oliver means the way in which researchers are typically seen as specialist, skilled and legitimately powerful, while the researched are assumed to be passive and relatively ignorant. Experts, lacking democratic control by disabled people, occupy an elite role in which they decide the subject, method of investigation and conclusion of research into disability. Stone and Priestley liken this role of expert to that of a rehabilitation professional who assumes they are best placed to 'define the self-concept, goals and inner motivations of disabled persons and determine their 'real' wishes and potential' (1996: 703). Casting themselves as an expert, such researchers implicitly assert that the knowledge and experience of disabled people does not count. Stone and Priestley argue that research produced by such 'experts' is constructed as if it is removed from the structures which produce disability, but it is implicated in their reproduction (ibid).

Oliver (2009) finds fault with most research into disabled people's lives in three other ways. Firstly, it does not adequately reflect the experience of disability from the perspective of disabled people. Secondly, it fails to provide any useful information that could influence policy formation in a way that would improve disabled people's lives. Thirdly, and perhaps most revealingly for the purposes of this thesis, it fails to acknowledge the struggle of disabled people, or to recognize the political dimension of disability. Thus for Oliver, as disabled people become aware of the discriminatory and

oppressive constitution of disablism, their alienation from research about disability grows as it becomes increasingly irrelevant to their needs.

These failings can be seen in both interpretive and positivist research. Both of these research traditions have been the subject of criticism by the DPM and are perceived by many to have failed the cause of disabled people (Barnes, 2008). The positivist tradition has been typified by large scale national surveys, aiming to collect data concerning the prevalence of different impairments and the difficulties of living with such impairments in daily life (ibid). Such research was designed to be directly relevant to policy in social 'care' and the social security system (ibid). In the case of interpretive research, there was a large amount of small scale research into chronic illness and disability by sociologists and psychologists, the latter approach focusing on adaptation and coping with impairment (ibid). Both types of research can be criticised for inadequate involvement of disabled people and an operationalization of 'individual deficit models of disability' which ignored the impact of disabling structures (ibid, 2008: 466).

In the case of positivist informed research, many disability scholars lament its dominance in disability research (Oliver, 1992; Barnes, 2003; Stone and Priestley, 1996). Such critics believe the influence of positivism in disability research has resulted in the distortion of the experience of disabled people. For them, positivism assumes that researchers can access the truth of the social world as it really is, without reference to participant accounts of disablism as oppression. Yet, it is argued that it would be difficult for oppression to be researched in an objective way. Insofar as positivist research denies the need to take sides, it is implicated in disablement because detached objectivity is not possible in a situation characterised by oppression (Oliver, 1992). Rather than committing to political change, positivist research assumes that positive change can come about through a 'social engineering approach to the policy making process' (ibid, 1992: 107). Oliver argues that, contrary to much of history, such an approach assumes that the necessary level of social change will take place if sufficient evidence is provided to policy makers.

As well as positivist research, the other dominant approach to disability research is through interpretive inquiry. This too has been seen as failing disabled people (Stone and Priestley 1996; Oliver, 1992). Although it is radically at odds with the epistemology of positivism, and at least in some cases takes disabled peoples' views of their situation more seriously, it is not perceived to have done much to serve disabled people's interests. According to Oliver (1992) this may be attributable to the hierarchical relations embedded in the research process. As he puts it 'interpretive research still has a relatively small group of powerful experts doing work on a larger number of relatively powerless subjects' (ibid: 106).

The potentially harmful impact of interpretive research can be seen in a particularly notorious example of disabling research from the nineteen seventies. Miller and Gwyne's (1972) research was perceived to reinforce existing prejudices and discrimination against disabled people and continues to serve as an exemplar of disabling research (Barnes 2008). Their qualitative research investigated the lives of disabled people living in five different residential institutions. Barnes (2008) reports that the research was initially instigated by disabled residents of Le Court Cheshire Home, who requested that academic researchers at the Tavistock institute research their living conditions. These residents had been engaged in a long struggle to democratise their institutional lives in order to gain a greater degree of control over the patterns of their daily existence (ibid). Their attempts to change the practices of the institution were met with resistance by staff and management. It was into such a divided institutional environment that Miller and Gwyne entered to conduct their research.

The researchers based their research on the assumption that it would be best to adopt a balanced and objective viewpoint and to avoid taking sides. This approach could not conceal that the researchers had effectively sided with the staff of the institution, arguing that the limitations of having an impairment meant that the demands of the residents were unrealistic (Barnes, 2008). Instead of the institution changing to meet the demands of residents, the researchers advocated that staff adopt an 'enlightened guardianship' approach that took greater account of the resident's needs and desires. Residents perceived this to be an act of complicity in



oppression. Paul Hunt condemned the researchers as ‘parasite people’ trapped within an individual understanding of disability that assumed it was the biological restrictions of impairment that were the ‘whole root cause of the problem’ (1981: 41). This condemnation of research ‘on’ disabled people was to become ‘a central reference point for later writers exploring a new direction for disability research’ (Barnes, 2008: 5).

## **Emancipatory Disability Research (EDR)**

As described above, disabled activists have long been critical of much research into the lives of disabled people. The critique of existing research ‘on’ disabled people is the foundation upon which Emancipatory Disability Research (EDR) is built. In 1991 a series of seminars funded by the Joseph Rowntree Foundation provided a forum for the development of an approach informed by ‘critical social research’, ‘action research’ and the social model of disability (Barnes, 2003). This followed the development of the social analysis of disability (Oliver, 1990) and the need to develop an understanding of how this could be operationalised within social science research.

EDR can be seen as building on the criticisms of previous disability research to develop a new approach. In a thesis such as this, which is based upon working with disabled activists, discussion of EDR is almost unavoidable. If I were to ignore the powerful arguments and proactive demands made by proponents of EDR, I believe it would be an evasion of the challenging points made by advocates of this approach. This does not however mean that I must agree with all of EDR, or adopt it wholesale. Engaging with it is a reflexive act, forcing me to be honest about the status of my approach and its relation to the critique of conventional disability research by disabled activists and academics.

In order to do this I will outline the five fundamental principles of EDR identified by Stone and Priestley (1996) and then discuss how far my own research meets these criteria. It is worth bearing in mind that although the structure I borrow from Stone and Priestley presents EDR as a fairly static, agreed-upon approach, EDR is

really 'more a set of principles-fairly loosely defined rather than a set of rules for doing disability research' (Zarb, 1992: 127).

## **The Five Principles of EDR:**

### **1. Choosing an Epistemology**

For Oliver EDR requires a 're-definition of the problem' (1992: 112) such that research is re-framed to focus on the disabling structures of society rather than individual disabled people. The research agenda for EDR that follows is not concerned with 'the disabled people of the positivist and interpretive research paradigms but the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society' (ibid: 112). To the extent that research can respond to the need for such an agenda, it can play a role in challenging disablism. To do so requires that it break with individual models of disability and work within a social model of disability framework. This means that EDR is built upon a fundamental shift in the ontological position regarding disability (Barnes and Sheldon, 2007). For Stone and Priestley, this first principle of EDR represents 'a radical epistemological shift from the models adopted by positivists and interpretative perspectives' (1996: 674). Overall, proponents of EDR are quite clear that EDR 'must adhere to the social model of disability' (Barnes and Sheldon 2007: 240).

In many ways the emergence of EDR is intertwined with the emergence of the social model of disability. The social model, according to Barnes has 'stimulated the adoption of a more justifiable emancipatory research paradigm that draws explicitly upon disabled people's collective experience and so challenges directly the widespread social oppression of disabled people' (2008: 458). Adoption of the social model can then be seen as a prerequisite for working within the EDR paradigm. For Finkelstein (1999), EDR suffers when the social model is accepted in principle without enough thought given to how it is to be put into practice within research that challenges disabling social structures. This means that EDR must be practically inclined toward investigating what 'can be transformed, has to be transformed, or that we want to transform in the process of confronting the exigencies of the disabling society'

(Finkelstein, 1999: 859-860). This causes Finkelstein to criticise much of research for its distance from the objective of dismantling disabling barriers. He questions if many projects are as informed by the social model as they claim to be, and doubts if the removal of all reference to 'the social model' from such research outputs would make any difference to its findings.

## **2. Surrendering Objectivity**

As we saw above, research which aspires to detachment and objectivity, such as that conducted by Miller and Gwyne (1972), has been strongly criticised. Instead, advocates of EDR propose openly committed, politically engaged research. Following Hunt (1981) many writers take a partisan view of this matter, arguing that researchers will either be part of the solution, through politically engaged research, or part of the problem by failing to condemn the existence of oppressive structures (e.g. Oliver, 1992; Barnes and Sheldon, 2007). For Priestley (1997) the critique of positivism is particularly relevant when social movements (such as the DPM) are the subject of research. He draws on Touraine (1981) to argue that it is necessary to identify with a social movement in order to gain understanding of it. 'Committed research' is the ideal to aim for, in which research contributes to the development of the movement and provokes permanent change in the movement effected by the research. This can allow research to go beyond superficial analysis as the researcher adopts an 'agitator's function' (Stone and Priestley, 1996: 5), assisting the group's analysis of its situation.

A requirement for 'commitment' and partisanship may open up proponents of EDR to accusations of bias, particularly from the medical and positivist traditions (Barnes and Sheldon, 2007). Colin Barnes has done the most to fully justify this position. He argues that all information can be interpreted in multiple ways and that those who do the interpretation are subject to myriad social pressures and forces (Barnes 2003). For him, this is reflected in the commonplace conviction of social scientists that 'all judgements are coloured by personal experience' and that 'all propositions are limited by the meaning implicit or explicit in the language used in their formation' (ibid: 11). He argues that the reason much disability research is not sufficiently informed by these insights and aware of the theory-ladenness of

observation is that it has been dominated by medical and academic interests (ibid). As the social model and EDR have gained ground, proponents of EDR are less often seen as biased and medical/individual views enjoy less dominance (ibid).

In addition, Barnes and Sheldon (2007) dispute that adopting a position of political commitment must mean advocating a subjectivist politics where one's view is wholly determined by political allegiance. Their reasoning here follows Oliver who argues that disablism is not only a result of 'the thoughts and actions of individuals or groups' but is 'objectively structured by the social and material relations of capitalism' (1999b: 184). Oppression can then be examined as an objective reality, meaning it is 'difficult to support the notion that those involved in disability research should put aside any claims to objectivity' (Barnes and Sheldon 2007: 10). This perspective is not typical of accounts of EDR in general which tend to reject positivism whilst assuming this requires no justification. Barnes (2008) argues that a more explicit discussion of methodology should take place within EDR. I return to the issue of objectivity and EDR below.

### **3. What's In It for Participants?**

Politically committed research within the EDR paradigm demands that the researcher consider the relevance of their research to improving the lives of disabled people. For example, Barnes (2008) holds that political gains are 'centre stage' for EDR. This can take the forms of 'removing social barriers, changing perceptions of disability, and generating political action' (ibid: 467). Relevant research would identify forms of discrimination and propose the removal or disabling barriers or the transformation of social structures. The researcher is active in challenging oppression rather than merely reporting oppression and resistance from the side-lines (Oliver, 1992).

Unlike conventional research which has been implicated in the existence of disabling social structures through reproducing dominant individual models of disability, EDR must represent a 'confrontation with power which structures the social relations of research production' (Oliver, 1992: 110). Such a confrontation mirrors the need for similar processes to occur in other domains of social research in which

research is carried out by those who have power on those who do not (ibid). The point of EDR is not 'attempts it might make to study the other end of existing power relations but attempts it might make to challenge them' (ibid: 110). The requirement for practically relevant research is so strong that Oliver is critical of his own work (1988) for its failure to deliver tangible political gains.

This need for research of immediate political relevance is a demanding test, and it can be that good research is rejected for reasons beyond the foresight of researchers. As a supporter of EDR, Barnes (2008) recognises this and accepts that the reason why research may or may not have an impact is usually beyond the control of an individual researcher.

#### **4. Reversing the Social Relations of Research Production**

Oliver (1992) focuses his presentation of EDR primarily on 'changing the social relations of research production'. This means overturning the divide between expert (usually non-disabled) researcher and the disabled researched, allowing disabled people themselves to set the agenda for research. It is central to this view that research is part of the wider web of social relations and cannot be separated from the social relations which underpin disablism.

Following Oliver's (1992) extensive and seminal contribution on the topic, Stone and Priestley argue that the failures of prior research can be attributed in great part to the relationships which underpin the research process. If research is to be relevant and anti-oppressive it must build solidarity and collaboration into research designs and put the skills of the researcher at the disposal of disabled people and their priorities. Changing research relations in this way would challenge socially prevalent patterns of inequality, privilege and oppression. It would also reverse the tendency in prior research to treat disabled people as passive subjects who cannot express themselves properly, requiring researchers to assess their needs instead.

In practice, changing the relations of research production means addressing questions such as who controls the research process as a whole, what it will be about, and how it will be conducted (Barnes, 2008). It also means questioning the

opportunities that exist for disabled people to criticise research outputs and influence further research (ibid). Changing the relations of research production may be the most frequently discussed and fundamental aspect of EDR, but Finkelstein (1999) warns that it is dangerous to assume that control and participation is equivalent to working according to the social model of disability.

## **5. Personalising the Political and Politicising the Personal**

Unlike the other principles I have listed here, the extent to which research should encompass personal experience is disagreed upon by advocates of EDR. For Barnes and Sheldon (2007) this represents the 'hotly contested' issue of EDR. They argue that the issue can be seen as a manifestation of the tension between, on one hand, the privileged expertise of disabled people on their experiences of disablement, and, on the other hand, the conviction that it should be disabling structures and not individual disabled people that are the subject of EDR. They note that the politicisation of the personal has been a key aspect of politicising disability for many disabled people. For this reason and others, they endorse research that considers 'personal experience', so long as it highlights the way in which disabled people frame issues in a distinct way from their oppressors. Presenting research of this sort is a political act which serves to critique the frames and constructions of disablism (ibid). This must be balanced with awareness of the danger that an excessive stress on personal experience can diminish the knowledge of collective disablement as a form of shared social oppression. Experience can be a starting point, but not an ending, and should be analysed primarily for what it can tell us about disablism (Thomas, 1999).

The most strident criticisms of including individual experience within EDR were made by Finkelstein (1996). He expressed concern that focusing upon the subjective attitudes and feelings of individuals could risk undermining the valuable shift that has taken place toward viewing disability as a form of oppression. Without a strong focus on disabling barriers, he feared the movement might lose 'an objective, practical and 'hands on' approach towards the struggle for social change' (ibid: 2) focused on the disabling barriers 'out there'. Finkelstein bemoaned the tendency towards what he considers to be an apolitical stress on personal experience: 'Gone is the original social

interpretation that the reality of disability can be most appropriately understood by focusing on the disabling barriers out there. Now insight is to be obtained by focusing on the subjective reality of our disabling experiences' (ibid: 2). The concern here is that the stress is not on removing disabling barriers but the way individuals experience disabling barriers. For Finkelstein, this risks putting action behind contemplation and passivity. He goes further and argues that a focus on subjective experiences is a short step away from re-introducing the focus on impairment that characterised individual, medical models of disability. This means that the theorisation of individual experiences could displace knowledge of objective social structures, in favour of 'subjective realities' that are promoted as if they were a reality for all disabled people.

Contrary to Finkelstein, Stone and Priestley (1996) endorse the arguments of those such as Morris (1991) who identify 'the importance of differences in the personal experience of impairment and disablement and the primacy of such experience as research data' (Stone and Priestley, 1996: 707). Such writers wish to combine a representation of the subjective realities of individual disabled people with a commitment to a social model of disability. This means attempting to balance both commonality and difference of experience (of disablement) in research design. This would give voice to 'the personal as political whilst endeavouring to collectivise the political commonality of individual experiences' (ibid: 710). Stone and Priestley appear to acknowledge that this puts them in a position of tension with advocates of the social model who tend to stress collective processes of disablement and can be suspicious of individual stories, especially in reference to impairment. The tension can also run in the other direction as writers such as Morris (1992) have questioned if models of any sort can tend to objectify and obscure individual experience.

## **Constraints on the Potential of EDR**

Those who have done most to elaborate the EDR approach freely admit that they were only able to partially realise the goals of EDR in their own research (Oliver, 1997; Priestley, 1995; Zarb, 1992). In different ways these writers recognise the constraints which limit the degree to which EDR can be fully realised in practice. For example, Zarb (1992) believes that there is only so much progress that can be made toward EDR

through research involving collaboration and genuine partnership, without far more fundamental changes being made to the social and material relations of research production. Until such changes can be made, it is misguided to suppose that EDR can be spoken of as a practical reality or even to suppose that what it would involve can be fully understood (ibid). Among the most stubborn constraints upon the development of EDR is that there is a 'clear relationship between the level of participation of disabled people in decision-making about the research, the extent of consultation during and after the research, and who instigated and funded the research' (Zarb, 1992: 129). The majority of funding of large-scale research has been for work based on the individual models of disability and this constrains changes in the social relations of research production (Zarb, 1997). Oliver sums up the constraints of material relations of production by arguing that challenges to existing power relations are 'unlikely to be funded by institutions located within existing power structures' (1992: 110).

For Zarb (1997), this should not lead to despair but instead serve to provide a more accurate picture of what can be immediately achieved, and the important choices that are available within these constraints. A decade later, Barnes and Sheldon report that the funding situation has improved for EDR, but that 'it is clear that the emancipatory research paradigm is still not fully supported in the current market-led academic environment' (2007: 249). Even when the material relations of research production allow the conduct of EDR, many disabled people lack the 'time or inclination, even if politically aware to take control of research' (Barnes, 2008: 470).

## **The Relationship of my Research to EDR**

I will now discuss the extent to which my own approach fits in with the principles of EDR described above.

In the first instance of 'choosing an epistemology' I share with proponents an agreement on the importance of the social model of disability. That said, I do not believe this should mean that researchers cannot consider aspects of disabled people's lives other than those concerned with oppression. I endorse a pluralist approach, while



also wishing to articulate the tensions between different approaches to disability research. I return to my reasons for supporting pluralism below (see p.64).

The second principle of 'surrendering objectivity' is the one that is perhaps least characteristic of the approach I have taken. As I understand this principle, the point is that the impossibility of objectivity means research should be based on an open political commitment to the emancipation of disabled people. Although I agree with Barnes (2003) that researchers judgments are unavoidably coloured by their preconceptions and existing theoretical frames, the rejection of the notion of objectivity in accounts of EDR seems under-theorised and articulated in insufficient detail. More specifically, I find the substitution of objectivity with political partisanship problematic.

The first problematic aspect of this is that developing research built on political allegiance to disabled people is not as straightforward as it might appear. Trying to realise this in practice could be criticised for assuming a homogenous group of disabled people with interests and priorities akin to those expressed in the principles of EDR. Contrary to the claims of Barnes and Sheldon (2007) that partisanship need not mean subjectivism, it could be argued that the interests and goals attributed to disabled people in EDR are only one of a variety of subjective views on the nature of disability and appropriate political goals for disabled people.

A second problematic consequence of this principle is that 'surrendering objectivity' in favour of partisan pursuit of political goals leaves uncertain grounds on which to base the claims made in research informed by EDR. 'Surrendering objectivity' and substituting it with political allegiance is a response to the impossibility of pure objectivity and the necessarily theory-laden nature of social-scientific knowledge. This involves a 'flip' from the rejection of naive neutrality and objectivity to an endorsement of the opposite extreme, assuming this is the only alternative. What follows is a privileging of a particular view and the claim it has advantage in terms of understanding society. This outright rejection of any version of objectivity assumes an over-demanding conception of objectivity which is far divorced from the version of it defended by critical realists. Sayer (2000) referring to this approach more generally,

argues that this sort of privileging can lead to a new form of foundationalism, replacing a faith in direct observation and pure foundations of truth with a strong privilege of a singular perspective as it serves as a replacement foundation. This is what seemed to be the problem with EDR, as it responded to critiques of pure objectivity by substituting it with political partisanship as an alternative ground for knowledge claims. Although social science cannot claim objectivity for what it asserts this does not mean that the value or preferability of claims should be reduced to the political allegiances underpinning them.

Like Sayer (2000) and other critical realists I do not believe that subjective preference or political allegiance is the only valid way to arbitrate between claims. When views clash, they can be assessed for their explanatory power or 'practical adequacy' meaning the extent to which they 'generate expectations about the world and about results of our actions which are realized' (Sayer, 2000: 43)<sup>25</sup>. Practical adequacy of this sort does not mean practical adequacy in relation to one set of questions or referents will be the same as in another. Something may be practically adequate in some situations but judged to be dangerous or undesirable for its general effect. From this perspective, substituting flawed claims to true objectivity with political allegiance can undermine the claims made on these grounds.

This is not to advocate a return to foundationalist claims to pure objectivity. Reflexivity is always required to increase awareness of researcher's situatedness and to ward off projections and selections which can lead to misrepresentation. The requirement in EDR that one openly admits political allegiances is thus to be valued. However, political allegiances should not be seen as rigid codes which determine the

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<sup>25</sup> Sayer clarifies his notion of practical adequacy: 'If truth were purely a matter of convention, we would be able to live by any convention we cared to invent: we don't because we can't. We can drop the idea of truth as absolute but we can't ignore the relationship between discourse and the world. We can act more successfully on the basis of some conventions than others because their relationship to the structures of the world is different' (1993: 326). Later he further clarifies his argument: 'The fact that language itself is constitutive of knowledge (though not uniquely so), need not prevent us distinguishing discourses which do provide a successful guide to action in the social and natural worlds from those which don't. But though sometimes two or more kinds of discourse or knowledge may perform equally well in this respect, not just any discourse or convention will be practically-adequate. We can't get outside discourse to see how it compares with real objects, but it is evident from observation and action within a particular world-view or discourse that some conventions about what is the case hold and others don't' (ibid: 330).

conduct of the research process. The principles of EDR and those of the DPM are as fallible as any other claims to knowledge, and are equally as subject to revision. Requiring subordination to political allegiance is therefore problematic. Proponents of EDR are right to criticise claims to neutrality and objectivity and to recognise the situatedness of knowledge. Recognition of this situatedness must be balanced by a conception of the possibility of error and misrepresentation, requiring acceptance of an independent reality about which both researchers and participants may be mistaken.

Tacitly, some proponents of EDR seem to accept that there are limits to their rejection of objectivity and endorsement of academic partisanship. For example, Barnes (1991) has drawn upon extensive empirical evidence to make the case for anti-discrimination legislation. This work was not simply a reflection of political allegiance but a marshalling of evidence about a shared object of knowledge that was used to persuade others, including those who may have begun with quite different allegiances and values to supporters of EDR and the DPM.

Following from my doubts regarding the substitution of objectivity with political subordination, the principle of 'surrendering objectivity' is not characteristic of how I conceptualise my role in the research process. Rather than subordinating my research to an allegiance to a pre-defined politics, I wish to maintain a degree of independence in formulating my own view. I take this position because I do not wish to assume that I should always refer to an allegiance to a pre-defined politics or defer to the expertise of participants.

Moving on from the second principle of EDR to the third; 'what's in it for participants', I am ambivalent on this issue. I agree that much disability research has failed to benefit disabled people and has even been actively damaging. While disablism persists, the political impact and benefit of research will always be relevant. However, the call for disability research that practically benefits disabled people may tend toward an instrumental view of knowledge that construes 'benefit' too narrowly. For example, Shakespeare (1997) notes that Oliver himself had a beneficial impact on many disabled people with his sociological and theoretical text *The Politics of*

*Disablement* (1990). It was not policy orientated or of direct political significance, but it had an important indirect impact on politics 'because it gave intellectual credibility to the social model and validated the analysis and direction of the disability movement' (Shakespeare, 1997: 187). This example shows that it would be unwise to adopt an overly instrumental view of what constitutes useful research. I follow Shakespeare on this point and have written my thesis in the hope that it could be of interest and use to disabled people, even if it is not a detailed program for political action or a practical policy prescription.

I am largely in agreement with the fourth point about changing the relations of research production, and in practice I could and should have done more to incorporate the views of participants during the planning of the thesis and the process of data analysis. I can truthfully claim that I was less aware of the significance of this issue at an earlier stage of research and that I would change the level of participation of participants and other disabled people at every stage if I carried out similar research again. For example I could have attempted to work with an advisory group of disabled people or activists to develop questions and analyse my findings. In later stages of analysis I would like to have engaged more with participants to discuss my analysis, but time and resource constraints, and the unexpected length of time required to conduct data analysis meant I lacked the time to do so. If I had fostered more contacts at an earlier stage, it may be that they would have helped by clarifying issues in analysis, reducing the length of time required to conduct analysis.

Regarding principle five and the need to theorise personal experience, I am strongly in favour of those who take the view that personal experience and private issues should form part of the subject of disability research. In my research regarding politics 'writ large', I did not set out to probe this type of issue and I did not expect that participants would be comfortable with me doing so. I may have been mistaken in this regard because the micro-level of personal experience may be exactly where many current challenges of disablism are most keenly felt. By planning a thesis based on public politics and national government policy, and advertising the opportunity to discuss these issues in particular, I may have been guilty of putting into practice exactly the public/private divide for which some disability research has been criticised

(Thomas, 1999). That said, in carrying out my research I did not anticipate that those who had volunteered to participate and had self-identified as an 'activist' would expect to discuss their private lives. I may have been wrong in this but I did not wish to appear disrespectful or over-familiar.

## **The Necessity of a Pluralist Outlook in Disability Research**

To further contextualise my approach I now draw upon Priestley (1998) who provides a useful description of the varying academic approaches at work in disability research. This gives a different and broader way of locating my approach than that offered by EDR. He draws a contrast not just between individual and social models but also materialist and idealist explanations. Priestley argues that these two distinctions should be seen as inter-related rather than the subjects of separate debate. This is observable in individual models of disability which can operate materially through a medical or biological focus, or in a form of idealism in the focus upon the psychological negotiation of living with impairment. Equally, social models can also be more skewed toward idealism or materialism. In the case of materialism, social models would lead to the study of structural and material conditions, and in the case of idealism, culture and representation. The research that results from materialist or idealist social conceptualisations of disability will lead to divergent conclusions, either stressing structural and institutional disability or disabling attitudes and representations.

Priestley's central case is that disability research should be pluralist in outlook. While individual research projects may be concerned with only one dimension of disability, researchers should not be closed to research and experience at work in other dimensions of disability (ibid). Priestley develops this analysis to show the four basic combinations of idealism and materialism, and social and individual models of disability. He presents this in the tabular form I have reproduced below:

	Materialist	Idealist
Nominalist	Position 1 <b>Subjective Materialism</b> Social phenomena have no real existence beyond material individuals  Social phenomena may be shaped by biology  Variate empiricism and biological determinism	Position 2 <b>Subjective idealism</b> Social phenomena have no real existence beyond the experience of voluntaristic individuals  Social phenomena may be shaped by attitudes and beliefs  Symbolic interactionism, phenomenology and interpretative paradigms, feminists psychologies
Realist	Position 3 <b>Objective materialism</b> Material society exists beyond the individual  Social phenomena may be shaped by political economy, structural patriarchy, etc.  Historical materialism, structural feminism, social creationism and Marxist analyses	Position 4 <b>Objective idealism</b> Idealist society exists beyond the individual  Social phenomena may be shaped by social values, culture etc.  Positivist sociology, social constructionism and cultural relativism

**Table 2: Four paradigms for the study of social phenomena (Priestley, 1998: 77)**

I will now discuss the four positions in more detail and examine their relation to my research. Position one is commonly referred to as the ‘medical model’. In this case disability is seen as biologically determined and located within the material condition of the body. The research that follows may concern physical rehabilitation, drug development or surgical intervention (ibid). Although the effect of much research in this tradition has been oppressive, because it can involve applying bio-medical solutions to social problems, it does not have to be oppressive. The key point is that this analysis can only accommodate consideration of impairment and cannot attend to disablism. Although this position is of limited significance to my work, I will also want to avoid the crude denial of the significance of impairment for which the social model is sometimes criticised (Shakespeare, 2006). Through a pluralist outlook I would also want to resist the criticism that the social model can leave medicine and the body solely to medics and remove it from the realm of politics (Paterson and Hughes, 1999).

Position two again is an individual model, but it focuses on ‘cognitive interaction and affective experience’ (Priestley, 1998: 80) rather than biology and views disability as the ‘product of personal experience and negotiation of social roles between individuals’ (ibid). Concerning itself with the analysis of identity and experience, relevant methods reflect a grounding in subjective idealism. These could include ‘phenomenology, interpretative psychology and symbolic interactionism’ (ibid). There is a great deal of research of this type, typically concerned with psychological adjustment to impairment, or attitudes of non-disabled people to impairments. A famous example is Goffman’s study of stigma (1963). This position can also refer to a quite separate tradition of mainly feminist writers who have sought to introduce a greater emphasis on personal experience in disability studies (Morris, 1991; Thomas, 1999). These writers try to reconcile this argument with a political commitment to position 3 or 4 (see below).

As I note above, I strongly endorse approaches which aim to synthesise anti-disablism and analysis of personal experience. My work has not predominantly been characterised by work that considers personal experiences and it could be argued that my framing of the thesis in terms of activism and politics writ-large reflected the absence of an appreciation of this dimension of disability in my formulation of the project. My ideal would be to follow the lead of writers such as Thomas (1999) and Morris (1991) who seek to transcend the public/private dualism that often separates ‘private’ aspects of politics from consideration of politics in general. In practice, however, this position does not characterise my analysis very well because my interviews tended to focus on the public domain of shared challenges, shared campaigning and modes of organisation.

Position three is commonly referred to as ‘the social model’ but it only refers to one possible social model which views disability as the product of material relations of power within a specific historical context. The subject of analysis and investigation are disabling barriers. This analysis has underpinned much of the work of the DPM, and has informed seminal works in disability studies (Oliver, 1990; Barnes, 1991). This position excludes consideration of impairment because it is a social rather than an individual materialist position. Yet it is also consistent with the analysis of Thomas

(1999) who develops a materialist feminist approach to disability, incorporating an analysis of 'impairment effects' within a relational concept of disablism rather than a conception of disabling barriers.

This position is the one that I accepted most intuitively and I found it to be capable of yielding insights of impressive depth in the work of others. My intuitive preference for this position may in part be a consequence of my prior knowledge of the historical-materialist framework that informs it. I continue to endorse this position, although not to the exclusion of others. Where I try to make original contributions in this thesis they can normally be identified with this position. I could not hope to make original contributions identified with all of the positions. My preference is in part pragmatic in that, in my judgment, 'material relations of power' seem to be a very salient feature of disability in the UK currently.

Position four could also be described as a social model of disability, but it is not commonly known as such. It would more likely be known as social constructionism, and has more recently been associated with 'critical disability studies'<sup>26</sup> (Shildrick, 2012; Goodley, 2013; Vehmas and Watson, 2014). This philosophically idealist position differs from position three in viewing disability as formed through ideas, or in other terms, as a social construction of a given cultural community. It is therefore primarily concerned with cultural representations. Priestley notes of this position 'the characterisation of disability as a social construct is premised (implicitly or explicitly) upon the notion of cultural relativism. That is to say, it assumes that the construction of disability is a product of specific cultural conditions' (1998: 81). The extent to which 'people of difference' are included or excluded from social life is determined by cultural perceptions of difference. Research of this type might highlight the variation in how attitudes to disability are constructed in different cultures. Proponents of this approach understand disability as determined by social labelling and role expectations,

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<sup>26</sup> Drawing on Meekosha and Shuttleworth (2009) Goodley argues that critical disability studies denotes the following: 'a shift in theorizing beyond the social model; the influence of disciplines previously on the outskirts, such as psychology, entering the field; attempts to challenge the dogmatic tendencies of some theories and theorists through reference to eclecticism; and the merging of Marxist accounts with those from feminism, queer and post-colonial studies. The word 'critical' denotes a sense of self-appraisal; re- assessing where we have come from, where we are at and where we might be going' (2013: 632).



and for the purposes of research projects exclusively characterised by this approach, do not require that material factors are invoked.

I recognise the importance of this position for what it can tell us about the cultural dimensions of disability. It characterises my approach insofar as I have been led to conclude that cultural forms of disablism are a powerful force at work in contemporary disablism. I would object to cases in which this approach is used to argue that biological impairments and economic relations of power can be reduced to artefacts of language or culture<sup>27</sup>, as Vehmas and Watson (2014) claim. In such cases adopting this position in an exclusivist mode works against the pluralism that Priestley argues is necessary for disability research in general. If the position is adopted pragmatically, without reducing non-discursive factors to discourse or denying the importance of other modes of inquiry, I see no reason to object to this position.

Whilst the above positions are, in Priestley's words, 'over-simplified' and 'very generalised' they do explain much about 'underlying differences between contemporary disability theorists' (1998: 79). They are not mutually exclusive, although there are differing degrees of tension between them. Because they are not mutually exclusive it is possible to combine elements of some or all of them in an analysis of disability. The main inference I take from them into my presentation of

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<sup>27</sup> Critical realism shares with weaker versions of social constructionism the belief that reality is necessarily interpreted, that is, we cannot perceive from a neutral or mind-independent position. The critical realist therefore has no issue with a weak form of social construction which holds that there is a 'necessarily interpreted element in the construction of any theoretical understanding and any social object' (Bhaskar and Danermark, 2005: 284). Critical realists object when it is argued, or assumed, that the phenomenon under investigation is just an interpretation, idea or belief. Strong social constructionism collapses the objects of knowledge into what is known about them, or conflates 'existence of social objects to the participating agents' concept or understanding of them' (ibid: 284). Critical realists hold that social constructions pertain to our knowledge of nature and non-human reality, not to nature itself. This is the reason that we are continually shown to be wrong in our observations and predictions about the objects of our knowledge. If there was no difference between constructions of the world and the world itself, we would never be wrong. Strong social constructionists who ignore this reduce explanation to the cultural level only, excluding consideration of extra-discursive factors such as biology.

The view that there is an equivalence between what is known about something and the existence of the thing itself is known by critical realists as the epistemic fallacy. It involves a conflation of the ontological and the epistemological. In the case of disability, the ontological existence of the biological body is conflated with the epistemology of what is known or believed about bodies (William, 1999). This does not rule out inquiry into the ways in which the body is represented or conceived of, only the claim that 'representations are constitutive of the reality that portray' (Williams, 1999: 814).

critical realism is that they suggest pluralism is an important aspect of any research approach into disability. Each of the positions represents important aspects of disabled people's lives and researchers should be aware of what is excluded in research that mobilises one of these positions at the expense of the others. Researchers may make the methodological and pragmatic decision to bracket dimensions of disability out of consideration in a given research project, but this does not mean the dimensions excluded are necessarily any less important.

## **The Relevance of Critical Realism to my Approach**

Another means of showing the importance of pluralism to the study of disability is to draw on the work of critical realists in the field. I also use critical realism to show how it can be reconciled with a social analysis of disability and to augment my decision to base my thesis around the views of activist participants.

Like Priestley (1998), applications of critical realism to the study of disability have stressed that disability research must be pluralist. The critical realist demand for pluralism reflects a view of disability as a multifaceted phenomenon, in which mechanisms from differing strata of social and biological reality interact. In the terms used by Bhaskar and Danermark, disability may involve 'physical, biological, physiological or medical/clinical, psychological, psycho-social, socio-material, socio-cultural and normative elements' (2005: 288). One of the useful aspects of this understanding is that it directs attention to the ways in which mechanisms at different levels interact.

For Bhaskar and Danermark it is a mistake to conceive of disability as meaning the political aspect of disabled people's lives, because it excludes consideration of other factors. Their justification is that all 'types of determination may play a role in the onset or maintenance of a particular disability' (ibid: 281). This later point seems to assume what it sets out to demonstrate: namely that disability is, at least in part, a biological phenomenon, which has an 'onset'. This differs markedly from accounts of disability and disablism which view disability as one means by which the experience of impairment can be socially realised within a society (Gleeson, 1997). In such accounts

disability is seen as social and variable, meaning it could be replaced by another more positive social experience for those with impairments.

Although I value the pluralism in Bhaskar and Danermark's approach, I disagree with their assumption that the category of disability must refer in part to a biological fact that has 'an onset' or 'maintenance'. Bhaskar and Danermark assume throughout their discussion that disability refers to a totality of factors which always includes impairment. Advocates of the social model of disability, including pluralists such as Priestley (1998), accept the extra-discursive reality of impairment and recognise the value of diverse research approaches into disabled people's position in society, but use 'disability' to refer to the oppressive relations those with impairments can experience. In this sense, advocates of critical realism and the social model can talk past each other, using differing terminology. In my view this is regrettable because it alienates proponents of the social model from the valuable means of conceptualising the need for pluralism provided by critical realists. The opposition of proponents of the social model to the approach of Bhaskar and Danermark is bound to follow from their insistence that disability is in part biological.

The critical realist argument here is meta-theoretical, establishing what disability research should investigate in the most general terms, rather than what the content of the interaction of those mechanisms will be. The advantages of maximal inclusiveness and complexity of such an approach has much to recommend it. However, when it is combined with a rejection of disability as a political and social category, it tends to negate the political urgency this lends to research. Analysis of disability as a political category brackets or abstracts from other factors, such as impairment, but need not deny them. This is not to say there are no potential dangers related to the social model such as social reductionism of biology into social factors. Through the impairment/disability dualism, crude and one-dimensional versions of the social model of disability may also concede too much ground to the biological and medical domain, when medicine is also in part a political arena (Paterson and Hughes, 1999). This latter point may be a genuine problem with the social model but adopting critical realism without the political category of disability could also have its disadvantages, such as taking the political urgency out of disability studies.

Perhaps a way out of this conflict would be to suggest that Bhaskar and Danermark's use of the term 'disability' could be changed instead to refer to 'disabled people's lives' which would be less contentious. If this were the case, the advantage of Bhaskar and Danermark's approach is that it does not assume the prevalence of a given mechanism in any concrete example of a disabled person's life. It would instead be the subject of concrete investigation into which mechanisms are most significant in a given example. What it seems is required is a way to reconcile the pluralism of critical realism with the urgency and focus lent by the social model. I would also now like to suggest that the social model may not be as incompatible with critical realism as is often assumed.

Initially, it can be said that, contrary to Williams (1999) and Bhaskar and Danermark (2005), the social model, or at least an analysis inspired by the social model (Thomas, 1999; Gleeson, 1999), does not have to mean reducing the biological body to social constructions, or reducing the ontology of the body to the epistemology of what is known about it. For example, the analysis of disablism in Thomas (1999) and Gleeson (1999) proposes that disablism is a category that emerges from how impairment is socially realised in a given context. It is difficult to see in these cases how the social model can be said to reject a role for biology. The assumption in these accounts is that the separation of impairment and disability is a useful basis for analysing their interface. Impairment can itself cause pain and difficulty, and this need not be denied by those who make a social analysis of disability. Impairment is always a prerequisite for disability, but disability is only one possible social form that the lives of people with impairments may take.

Thomas (2004) believes that criticisms of the social model, such as those of the critical realists, are in part caused by the simplified version of social relational thinking that can be manifest in writing on the social model. Supporters of the social model and critics of it both need to grasp that 'disability only comes into play when the restrictions of activity experienced by people with impairments are socially imposed, that is, when they are wholly social in origin' (Thomas, 2004: 580). To critics of the social model who assume that the social model denies the non-social causes of restrictions of activity, the supporter of the social relational view can say 'Yes, of

course impairment causes some restrictions of activity – but these are not what is of interest in studying and combating disability’ (ibid: 581). This circumscribed definition of disability fits in well with my specific interest in this study in the political activity of disabled activists.

From a critical realist perspective, when we have defined that our area of interest is disablism, it may be that such a concern can fit in within a critical realist framework more comfortably. Within the open systems<sup>28</sup> that are theorised by critical realism, disablism can be seen as one of a number of interacting mechanisms that intersect in the lives of disabled people. As a meta-theoretical, philosophical position, critical realism is quite right to stress the multi-faceted nature of the influences on disabled people’s lives. However, it is quite defensible that disability studies concerns itself primarily with the social mechanism of oppression that is defined as disablism (or for some as ‘disability’). Another way of reconciling this view with critical realism is to refer to the critical realist theorisation of the stratification<sup>29</sup> of reality. This philosophical argument states that reality is stratified into irreducible levels at which distinct but interacting mechanisms operate. In this light, disablism could be seen as concerning one specific strata of the reality of disabled people’s lives, referring to the political domain. In the lived experience of individual’s lives, mechanisms operating through different strata will interact, but in the case I develop above, it is the seperability of disablism from other aspects of disabled people’s lives that allow it to be elaborated in full and understood as distinct in its interface with other mechanisms.

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<sup>28</sup> An open system must be understood in contrast to closed systems. Closed systems are defined as being ‘cut off’ from external influences (Collier, 1994: 128) and unaffected by outside influences. A closed system is typified by a scientific experiment, which have the value of closing the open systems of nature and allowing predictions. The critical realist view is that such closure is impossible in social science because societies are open systems. Open systems lack the features of a closed system and only feature regularities that are short-lived, or feature no regularities at all (Sayer, 1992).

<sup>29</sup> Stratification refers to the way that our knowledge of the world is necessarily ordered into distinct disciplines. Thus physics is ‘more basic than chemistry, which is more basic than biology, which is more basic than the human sciences’ (Collier, 1994: 108). An important caveat is that mechanisms in operation at the level of one strata cannot be reduced to the mechanisms of a higher strata. Thus while everything in the humans sciences must operate according to the laws of physics, it would make no sense to try to explain emergent social processes such as disablist oppression through physical laws.

## Using the Notion of Contrastive Explanation as Support for Drawing Upon Disabled Activist's Views

I will now draw again on critical realism as an epistemological justification for my endorsement of activist views in this thesis. In discussing my ambivalence towards EDR, I argued that it could go too far in subordinating the judgment and independence of researchers to political allegiance to the emancipation of disabled people. At the same time, my project is built upon an appreciation of the interpretative value of disabled activist's contributions, particularly when exploring the themes I set out to investigate. Critical realism offers a way to conceptualise the value of particular perspectives and positions without requiring that one subordinate their approach to a pre-defined political allegiance (Sayer, 2000; Lawson, 1999), as seemed to be the case in EDR.

Lawson's (1999) analysis is of value here in his attempt to demonstrate the value of critical realism to standpoint feminism through the concept of contrastive explanation. Contrastive explanation is concerned with questions such as "why this rather than that"? It can highlight what type of questions we might concern ourselves with by highlighting important contrasts. This concept figures in my thesis as a way of highlighting the unusual and revealing perspective of activists as a group who are more rarely involved in disability research than might be the case, and who experience society in a distinctive and different way from others.

To give some context to the case made for the importance of contrastive explanation, it is important to note that Lawson follows other critical realists in arguing that society is an open system meaning that it is difficult to produce the closed experimental systems characteristic of natural science. As an alternative epistemology for use in social science he proposes the theory of contrastive explanation. Lawson describes contrastive explanation in the following way:

When phenomena in an open system are generated by a multiplicity of causes, the particular one singled out for attention depends upon the contrast identified as puzzling, surprising, unusual, undesirable or of interest in some other way. And this in turn will reflect the

interests and understandings of the individual or group of researchers or interested onlookers involved (2003: 233).

He goes on to clarify further that:

The task of detecting and identifying previously unknown casual mechanisms seems to require the recognition of surprising or interesting contrasts, and the latter in turn presupposes people in the position of being able to detect relevant contrasts and to perceive them as surprising or otherwise interesting and to want to act on their surprise or aroused interest. The initiation of new lines of investigation requires people predisposed, literally prejudiced, to looking in certain directions (ibid: 234).

Contrastive explanation focuses the attention of the social scientist upon observed differences or contrasting views, rather than demanding of the researcher that they explain everything relevant to a particular phenomenon. In my case, the views of activists can be contrasted with those of politicians, academics and others, highlighting the differing social situation that disabled people find themselves in from non-disabled others.

Lawson suggests that different standpoints can allow one to find interesting contrasts, and that standpoints are therefore an unavoidable and indispensable aid to explanation. They can aid in formulating contrastive explanation because people in certain positions may be better placed to recognise interesting or surprising contrasts. Lawson puts this point as follows:

science, or the knowledge process more generally, can benefit if undertaken by individuals who are predisposed in different ways, who are situated differently [...] the endeavour to attract diverse voices into the scientific community or any prominent (or other) discussion can be supported on grounds not just of democracy or fairness but also of good methodological practice (1999: 41).

Through this argument, critical realism gives further grounds to place value on the contribution of the participants in this thesis because disabled activists are well placed to make surprising contrasts. One reason among many for this is that their

point of view seems to be absent from dominant representations of disability and policy.

Lawson does not only use contrastive explanation to argue that the process of knowledge production can benefit from the inclusion of perspectives that are predisposed in differing ways. He also argues that it can augment the claim of standpoint feminists that marginalised positions are privileged for the insights they can provide. Here marginalised perspectives are to be privileged because of their capacity to recognise contrasts of importance. Lawson believes marginalised perspectives are well-suited to yielding contrastive insights because they denote 'both an insider and an outsider position. To be marginalised you are outside of the centre. But equally to be outside you first have to belong' (2003: 234). In Lawson's view the 'duality of belonging yet being constrained from the centre [...] facilitates an awareness of contrasts of significance. For unlike the dominant group, the marginalised are forced to both be aware of the practices, values and traditions of the dominant group as well as to live their own' (ibid: 235). This means that those in marginalised positions are well placed to detect contrasts between themselves and dominant groups, how each functions and how they are interrelated.

This way of privileging marginalised groups corresponds well to my interview group who are part of a group who are marginalised from British society to the degree that it provokes their political mobilisation. They are also an insider in that they are seeking to mobilise to change the politics of the society. Disabled people are aware both of the practices and values of non-disabled people and of disabled people (in as far as there is any difference). This enables them to better perceive differences between the two, enabling them to analyse the structures that separate them and that they share with non-disabled people. This way of valuing participant positions does not have to assume they are truer than others, or that they should be beyond doubt and scepticism. A position may be preferred over another for the differing contrasts it can throw up, potentially leading to important new lines of enquiry.

Contrastive explanation does not mean marginalised positions are valued because they can offer truer accounts, but that they can lead to important and novel



lines of inquiry through interpretive insights. Nor does using the notion of contrastive explanation mean having to endorse judgemental relativism in which any basis for arbitrating or discriminating between claims is rejected. As Lawson puts it 'the prevalence of many different voices, even if all are considering the same phenomenon, may merely reflect a focus on differing contrasts' (ibid: 236).

Lawson believes the concept of contrastive explanation can be useful to feminists because it can avoid the judgmental relativism he detects in some standpoint feminism. Contrastive explanation avoids this, and is consistent with critical realist arguments for practical adequacy and explanatory power, meaning using it as an invitation to diverse perspectives does not lead to a relativist refusal to discriminate between these perspectives. In the context of this thesis this is important because it means I can argue for the importance of participants' point of view, without having to accept EDR in full as the justification for doing so. Activist views represent a marginalised and alternative view to those who produce the culturally dominant narratives of austerity and disabled people. From their position disabled activists can produce novel accounts of the contrasting fortunes of disabled people compared to others in the current political-economic conjuncture. .

Just as Lawson's argument can serve to highlight the value of activist interpretations, so too can it be used to theorise the value of the roots of disability studies in activism. This is to say that the politicised origins of disability studies and many of its participants can be seen as a source of insight and strength. Contrastive explanation gives a way of valuing an interpretation without construing it as an 'objective' point of view or mistaking it for a reason to devalue other views. It is of note in this context that Vehmas (2014) criticises the tendency in disability studies toward the conflation of the value of an argument with the background of the person making the argument (the ad hominem fallacy). One would clearly wish to avoid this fallacy, but within Vehmas' case against it, his attempt to decouple one's background from academic debate tends to undermine any means by which one could value particular interpretations, such as those with experience of disablism. Here the notion of contrastive explanation can enable us to value the politicised perspective of activists

without any implication that those with differing background experiences should be devalued.

## **The Relevance of Narrative Analysis to my Approach**

In chapter three I described the importance of narrative analysis to the way in which I analysed interview data. I believe that narrative analysis can help fill a gap within both EDR and critical realism, created by a tendency to write out personal experience and the production of intersubjective meaning from research. In the case of EDR, as I noted above, the influential activist Finkelstein asserted that one of the drawbacks of researching individual experiences of disability is that it is similar to a 'return to the old 'case file' approach to our oppression' (1996: 2). To justify his view, he quotes the UPIAS policy statement from 1976:

We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to far better than any able-bodied expert. We as a Union are not interested in, descriptions of how awful it is to be disabled. What we are interested in, are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us (UPIAS, 1976).

This view has continued to be represented by some among disabled activists and writers in disability studies (Oliver, 1996) who argue that impairment is irrelevant to social disablement, and that theorising impairment and personal experience could let individual models back in and distract from dismantling disabling barriers.

Critical realism, according to Fairclough *et al* (2004), has also paid too little attention to semiosis, meaning the intersubjective production of meaning. Although critical realism is open to the influence of discourse, alone it is unlikely to help in overcoming a need within disability studies for consideration of personal experience and intersubjective meaning. Fairclough *et al* criticise critical realism for taking 'symbol systems, language, orders of discourse, and so on for granted, thereby excluding central features of the social world from its analysis' (2004: 39). These factors are interpenetrated with other types of social relations and institutional orders, and for critical realism to achieve a more comprehensive analysis of the social world, they

argue that analysis of semiosis and related issues must be integrated into critical realist analysis (ibid). This would allow one to consider when semiotic factors are over determined by extra-discursive factors and vice versa (ibid). As a route to achieving this goal, Fairclough *et al* recommend the integration of critical discourse analysis with critical realism because it can provide 'explanatory contextualisations of the production, communication and reception of semiosis, and provide a means of thinking about the articulation of the semiotic and extra semiotic in social transformation' (ibid: 23). They are also open to other approaches concerned with meaning and semiosis that could contribute to critical realism.

In this context I propose that narrative analysis may be a useful complement to fields in which personal experience and semiosis have been under-theorised. I agree with Fairclough *et al* that critical realism has to acknowledge that social science is also about interpreting meanings and not only about identifying causal mechanisms. Narrative analysis can be consistent with critical realism if it is granted that narratives are construals<sup>30</sup> and not constructions of reality (Sayer, 2000). Given this assumption, critical realists can agree with Riessman (1993) that narratives do not give direct unmediated access to life experiences. Narratives are representations involving interpretation and selection, just as my own readings of narratives will be similarly interpreted and selected.

This is also consistent with the work of writers such as Morris (1991) and Thomas (1999) who have argued that disability studies and anti-disablement cannot exclude consideration of individual experience. Thus narrative analysis can 'fill a gap' in both critical realism and disability studies. Thomas (1999) argues that narratives are a form of situated account that can challenge the purported neutrality of individual model representations of disability. The personal is not only about impairment and can be an arena in which disablism operates, particularly through 'psycho-emotional

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<sup>30</sup> Sayer argues that strong social constructionists make the error of reducing 'construal to production or construction' (2000: 34). By this he means that our concepts and theories do not exhaust what there is to the objects of our knowledge. He writes 'although all observation is conceptually mediated what we observe is not determined solely by concepts, as if concepts could anticipate all empirical question, or as if theories were observation-neutral' (ibid: 41). While it is essential to understand construal, meaning the mediation of observation by our pre-existing conceptual frameworks, this does not amount to what is often understood by the term 'construction'.

disablism' (ibid). The separation of disability and impairment in social analyses of disability does not mean that personal experiences need to be considered as equivalent to non-social impairment. Disability studies thus needs to explore experience and the intersection of personal biography with politics, exploring narratives 'principally, though not exclusively, for what they can tell us about disablism and other forms of social oppression' (ibid: 151). In this respect narrative analysis is relevant to my work. The interviews for this thesis were principally concerned with public political issues, but participants would also join individual experiences to political structures. In this way, narrative was a good way of linking the two.

Narrative is also of interest to understanding the background against which participants expressed their thoughts. Although participants preferred to frame personal budgets and direct payments in terms of independent living rather than personalisation (see chapter 2), personalisation is the dominant narrative through which these policies have been promoted in recent years (Needham, 2011). Writing on personalisation, Needham argues persuasively that it, and associated policies, have spread through its narrative power rather than any 'harder' form of evidence concerning outcomes for disabled people. Its fluid and contestable nature cannot be defined in a way that evades the different ways in which actors frame it. As she puts it 'personalisation has spread because it is a potent story about public services, with all the discursive advantages that stories have over other forms of communication' (ibid: 13). The view of personalisation that emerges for Needham is of 'a set of stories that were being told about public services and the people that use them. The process through which personalisation was spreading was by telling compelling stories about the personal, about the individuals whose lives had been transformed through new ways of thinking about public services' (ibid: 4). This view influences my analysis in later chapters. Narrative is thus doubly significant for my analysis, informing the way I analyse participant contributions and the way I understand the policy and political background informing reforms to support services.

Together with critical realism and aspects of EDR, narrative analysis forms one of three core methodological elements in the approach I have pursued in this thesis.

Within the next four chapters these ideas inform my approach as I turn to analysis of interview data.

## **Chapter 5: Challenges to the Disabled People's Movement**

This chapter uses my analysis of interviews with activists to identify three significant current challenges to the realisation of the DPM's demands. I use the term 'challenge' to reflect the way in which participants made predominantly negative evaluations of recent developments, but frequently balanced this by noting positive co-developments. This ambivalent analysis of challenges mixed criticism of unwelcome developments, and prescriptions to overcome these challenges, with the need to not undo welcome developments in the process. The first challenge I identify below is the exposure of individual disabled people to increasingly high levels of social isolation. The second challenge discussed is the deterioration in the conditions facing DPOs. Thirdly, the ideology underpinning policy development is discussed with attention given to the ambiguous and limiting construction of 'choice' involved. These challenges intersect and interact but they are operating at different levels: individual, organisational and ideological. In the concluding discussion, I begin to explore how these challenges intersect, overlap and are mutually reinforcing. Firstly, I present a detailed examination of data regarding each of the challenges in turn.

### **The Challenge to Individuals: Isolation and a Loss of Autonomy for Individual Disabled People**

As we saw in chapter two, there is growing concern at the cumulative impact of central and local government cuts to the funding of social care and support for disabled people. For example, the end of the ILF and changes to disability benefits could negatively impact on the security and autonomy of many disabled people. In this light, it was common for participants to detail the growing danger of isolation and alienation for individual disabled people. A key theme was that cuts to the funding of personal budgets and valuable services were restricting the range of activities that disabled people could engage in.

Being involved with a high-profile DPO, 'Roger' is in a good position to give an overview of the impact of budgetary cuts on disabled people. For example, he explained how new applicants for care were facing the likelihood their application would be rejected:

"Most people who are now coming into the situation of applying for care are having their care support request rejected."

Even those who are 'fortunate' enough to receive care funded through the state may find that, without the level of budget required to do more than have basic and personal care, engagement in social and community life beyond one's own home is increasingly limited. The quote below from Roger illustrates the isolation and lack of social interaction that this can breed; showing how individuals can be forced by an absence of adequate funding to live very individualised and isolated lives:

"Now with care cuts, it tends to be about the very most basic things in life; getting yourself out of bed and getting fed, and that's not independent living that's about surviving."

Roger chooses to dramatize the extremity of the situation by referring to the way in which many disabled people are only "surviving", stressing the low levels of support and limitations imposed on the people he works with. Later, he contrasted this isolation with the potential for disabled people to be engaged in their communities:

"Independent living should be about whether you can engage with your local community, and part of that is being able to go to your local shop, go to your local library and find out what's on the local information board, and to see people that live in your street and your community and get involved with that, and that is quickly disappearing; its more and more about the basics."

Here Roger is drawing a comparison between the increasingly restricted situations he perceives many disabled people to live in, with the rights of disabled people as asserted by the independent living approach. In the excerpt above "independent living" refers not only to self-determination, but also to active participation in, and contribution to, a community. When this is compared to "surviving", the depth of the

problem is made vivid and apparent. A version of independent living that includes active social participation evokes citizenship discourses (Morris, 2005). If disabled people are denied the resources to do much more than “survive” clearly they will be a long way from being able to exercise anything like citizenship rights.

Another participant in a similar role, ‘Andrew’, went even further in describing the restrictions faced by disabled people he had encountered through his work in another prominent DPO. In his experience, current challenges did not only concern restrictions on accessing the community, but also on basic support around the house within an isolated existence at home:

“There was a time when community care legislation recognized that a social life was pretty good for people’s health, and would recognise that having a clean house and a clean body is probably quite a good idea too. Those days are long gone; we talk about existence and support that keeps people alive rather than support that gives people a life, and at the risk of sounding a bit dramatic, that’s pretty close to where we are and have been for some time.”

Suggesting that even a clean house and clean body may not be possible for those already living isolated lives, Andrew indicates the depth of the problem. Referring to “existence and support that keeps people alive rather than support that gives people a life” Roger makes a distinction between support that merely ensures the preservation of the body in some degree of cleanliness and health, and support that enables people to engage in social participation and recreation. Support that “gives people a life” goes beyond the physical basics to facilitate activities that provide the stimulation characteristic of an independent life. In the case of both Roger and Andrew, they use notably dramatic language such as “surviving” and “support that keeps people alive”; clearly feeling such language is justified to express the degree of challenge to disabled people’s independence.

Another individual to speak out strongly on these issues was ‘James’ who felt that his dignity and independence could be undermined by the abolition of the ILF, pointing toward the probable isolation that may result:



“In two thousand and fifteen the ILF is actually going to close for all disabled people, and that means that even people like myself who have had independent living support throughout their whole lives will have to go back cap in hand to our local authorities and ask them to top up our budgets to the standard. And they can’t afford to provide the part that they’re doing at the moment, so we fear that once this happens, disabled people are going to be isolated alone in their communities because they’re not going to have the amount of care and financial support to enable them to go out in their local communities. Local authorities will just say they want to provide the minimum support; basically making sure you get bathed, toileted, so disabled people are going to get isolated, institutionalised, not just in big organisations, but become isolated and institutionalised in their own homes.”

The phrase “go back cap in hand to our local authorities and ask them to top up our budgets” speaks to the anger provoked by his situation. A key demand of the DPM has been ‘rights not charity’ and having to ask for what is required to live independently may be experienced as an attack on one’s dignity. Anger is to be expected if a regressive move occurs away from the guarantee of disabled people’s right to independence, requiring them to plead for adequate support from a council which has no duty to provide it. James’ last phrase, in which he warns of disabled people becoming “institutionalised in their own homes”, says a great deal about the evolution of challenges to disabled people’s autonomy. In the early days of the DPM it would have been assumed that the starkest oppression of disabled people occurred through segregation in institutions, whereas now this older challenge coexists with an increasing tendency toward isolation and ‘institutionalisation’ in one’s own home. The meaning of ‘institutionalisation’ here seems to suggest that whilst disabled people live in the community, the level of support they receive only allows them a degree of autonomy, choice and social participation equivalent or similar to life in an institution. In this context, it is significant that James refers to “minimum support” restricted to being bathed and toileted and allowing little choice. This supplements the testimony of Roger and Andrew in their references to “surviving” and “support that keeps you alive”.

Offering further evidence of the challenge of isolation resulting from reductions in funding for social ‘care’, ‘Vera’ is again in a very good position to judge the extent of

the problem through her work in a large DPO. For Vera, the issue demands particular attention is given to the way in which recipients of individualised funding can have their budget reduced without the attention or uproar that might meet the closure of collectivised support services. This adds a further aspect of individualism and isolation as reductions in funding are often faced and challenged alone:

“I’m fully in support of direct payments; absolutely fantastic, but I can see some dangers, and I can see the danger that people can get very isolated and they’re very easy to pick off, and funding starts to get reduced, you know and that’s precisely what’s happened in lots of ways, I mean we get endless calls from people with direct payments who’ve had their payment reduced. “

The strengths of direct payments and personal budgets can partly derive from the sensitivity of individually negotiated agreements, designed to be more responsive to the needs of the person than a collective institution could be. However, for Vera, it is the very individualised nature of these negotiations that opens up the possibility of individuals being ‘picked off’ as they face reductions in their budgets without solidarity from peers facing the closure of a shared service. In this sense, the apparent virtues of tailored and individually negotiated funding can be turned against recipients to reduce their budget. These individuals will often lack the collective resources of day centre contemporaries or strong local DPOs to challenge the decision. Reacting to this dynamic did not raise doubts for any participants about the validity of direct payments or personal budgets as a means to bring about independent living, but instead brought into question the context in which the personal budgets are made available. I develop this topic in greater depth in the third section of this chapter.

The direct impacts of isolation described above can be combined with a more indirect psychological impact felt by others as a result of changes in the wider climate of expectations. These effects seem to go beyond those directly affected. For example, ‘Mary’ expressed her frustration that less than the very most minimal support is being made available, and went on to explain the psychological impact of this on her friends and, indirectly, herself:

“I’ve had a couple of friends who’ve applied for direct payments and the assessment process has been quite traumatic and at the end of the day all that they have received, to be quite crude about it, is support to go to the loo four times a day. Full stop, end of story. And I just think for those people who have substantial physical need, it’s ridiculous, almost to the point where I feel guilty that I do have substantial support, it’s like survivor guilt.”

The example of only having support to “go to the loo four times a day” exemplifies the inadequacy of support received by many and the loss of dignity that may result. It is not surprising that distress can result from a process in which one is denied the means to live a fully social life. In some cases this is likely to further diminish the quality of life of those concerned as other problems are compounded by resulting psychological difficulties. By referring to her ‘substantial support’ in this contribution, Mary is also suggesting differences in the degree of challenge faced by herself and her friends. It may be that individuals like Mary with a background in activism, high social capital and assertiveness are less likely to suffer from the isolation described by many interviewees. However, at the same time, there still appears to have been an indirect impact on Mary, perhaps derived from her identity as a disabled person, feeling solidarity with those experiencing isolation, and a degree of what she refers to as “survivor guilt”. Knowledge like this of differential awarding of resources, has the potential to politicise larger numbers who identify with the challenge to disabled people in general, or, more pessimistically, to lead to division as those with more resources hope to not fall into the same situation as those less fortunate than themselves and withdraw further, potentially leading to greater isolation.

Many of the interviewees had campaigned for independent living and disability rights for over a decade, and some expressed a degree of shock and “fear” at a direction of travel which many felt was unethical. Some felt that progress toward greater autonomy for individual disabled people had been reversed. As Mary stated:

“It feels to me like it was someone who was active during the nineteen nineties, who achieved changes that really benefited people’s lives, that those changes are being eroded hugely, and it feels today like there are lots of fears for the future. I mean thinking about the potential closure of the independent living fund, hearing about things like the potential move from DLA to PIP.”

This type of view was not uncommon. We saw above that Andrew contrasted recent developments with community care legislation, noting that it had “recognised that a social life was pretty good for people’s health”. This reference to older legislation in a superior light suggests he, like Mary, perceives a backward trend in the level of support currently experienced by disabled people. Whilst the view that the degree of support available to most disabled people was deteriorating was only unequivocally articulated by a minority of the participants (five interviewees expressed this view clearly), a degree of negativity on this issue could be inferred from the despondent and negative tone of many contributions, particularly with respect to the anger many felt at developments in benefits policy. Participants may have been hesitant to make an argument that conditions in general had taken a clear and decisive turn for the worse, when this suggests an almost epochal shift and requires a certain degree of confidence in one’s ability to discern trends at a national level. Participants may also have been hesitant to make this kind of assertion at the time of interview because the effects of these measures were being anticipated or just beginning to be felt. Tellingly, no participants felt that conditions had improved of late and few were able to point to valuable policies initiated by the current government, although one (‘David’) did feel that developments under the coalition had brought about a combination of opportunities as well as challenges.

In summary, this section has been based around the current challenge of isolation and potential loss of social participation for many disabled people. We have seen how participants expressed concerns about the possibility of isolation and alienation in their lives and those of other disabled people. Cuts to personal budgets, funding of services and the abolition or reform of redistributive benefits were seen as restricting the range of activities that disabled people could engage in. As budgets are limited so even adequate basic and personal care can be threatened, engagement in social and community life beyond one’s own home was viewed as increasingly difficult for many. These challenges were also seen as creating a climate of fear, and for some people this was perceived to be having a negative indirect effect beyond those directly affected.

It is possible these changes might appear to some as the withdrawal of discretionary and precarious benefits, but for many participants they were experienced as coercion as some disabled people are effectively forced to live more isolated lives. The outrage and fear expressed by many participants about the current situation was often related to shifts in policy away from the rights-based independent living approach many of them had campaigned for. The perceived discrepancy between the principles of the DPM and those underpinning the government's policies will be explored further in the third section of this chapter.

In the next section, I will explore participants' views about the challenges facing DPOs. This is important, not least because these organisations could mitigate and challenge the isolation faced by disabled people described above.

## **The Challenge To Organisations: Conditions Facing Disabled People's Organisations**

I now turn to the second challenge identified from participant contributions concerning challenges to DPOs. Before detailing the challenges they face, it is important to note how most participants emphasised the crucial role they could play. For example, 'Kate' described the integral role that was foreseen for DPOs in the formulation of the ideas of independent living:

“[Q]uite clearly in the independent living movement's mind, direct payments always went with a support system so that you weren't left on your own trying to manage the full workload by yourself, that you had an organisation, a CIL, that would help you at whatever level was needed, whether it was a bit of moral support or actually sitting with you while you interviewed people, or doing payroll or whatever, you know it would be support at the level you required it. That idea got lost along the way because it was just seen as being too expensive.”

Describing the flexible role DPOs could play, Kate argues that they can provide the necessary peer-support and advice through which more may be yielded from direct payments and markets in support. In addition, DPOs may also serve a political role in which poor treatment from professionals can be challenged and restricted budgets can be highlighted. Most participants felt that DPOs played an indispensable role, and

without them, many felt that the risk of isolation in the lives of individual disabled people is increased, as many disabled people face the challenges of reduced budgets, reduced benefits and defunding of services without the organised support of peers.

Adding further to data regarding the perceived value of DPOs, it is important to note that they were seen by participants as a vital supplement to the individual empowerment possible through extending individualised funding to more disabled people. Support for individualised funding was often expressed with the caveat that, for the most to be gained from personal budgets, DPOs were necessary to provide advice and peer support. Responding to my provocations regarding critical literature on the subject of personal budgets, 'Rachel' felt these criticisms were excessive and betrayed an ignorance of the value that DPOs can have in mitigating the downsides of personalisation, warning of the limitations of personal budgets without User-Led Organisations (ULOs) or CILs:

“The problem with some of those critiques [of personal budgets] is that they've missed the role of ULOs and CILs in it. So yes if you sat somebody with a learning disability in front of a computer, and they didn't have the skills to use the A4e<sup>31</sup> site and then they were given a pre-payment card because someone didn't trust them and thought they'd spend the whole thing on Jack Daniels, then yes that's not choice and control. Do I think it can be done well if there is a ULO and peer support at the heart of it and it's a community approach? Definitely.”

Within this answer, Rachel firmly dismisses arguments against personal budgets in general, but in arguing for the unique value of ULOs and CILs, she also gives an example of the manner in which personal budgets could develop *without* their input. The example of a person with a learning difficulty navigating an A4e site could certainly be imagined as part of the problem of isolation developed in the first section of this chapter. Overcoming this type of problem was not seen as likely to come about purely

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<sup>31</sup> According to their own website A4e is a 'leading public service provider, serving tens of thousands of people across Europe, Australasia and Asia.' They run a 'range of 'frontline' public services including employment and welfare, training, education, and financial advice, a great deal of which we provide in partnership with a variety of public sector, not for profit and private sector organisations' (see <http://mya4e.com/about-us/who-we-are-what-we-do/>). A4e has been the subject of a series of controversies and criminal investigations.

through the extension of personal budgets to more people. Most interviewees felt that 'user-involvement' should go beyond the isolated demands of individual personal budget recipients to include the collective input of DPOs. To illustrate this, 'Beverley' explained her experiences of the absence of responsiveness and real user-control in markets lacking the input of DPOs:

"Disabled people want service user involvement, that's part of the disabled people's movement: wanting service user involvement. You know the agencies have no service user involvement. So they may or may not provide the service, if you don't like the service, you may or may not have another agency you can go to, and if there isn't one, you're stuck and there isn't much you can do about it."

In making this point Beverley contrasts the level of choice available in uncompetitive markets of care agencies with services characterised by active user-involvement. The collective input of disabled people is something Beverley perceives to be entirely absent from care agencies who have "no service user involvement". Individual disabled people can be forced to make do with what can be a poor service when markets do not function to their benefit because of a lack of local competition between agencies and the low level of budgets awarded to individuals who cannot pay for more flexible services. These conditions were used by participants to add to the case for the value of DPOs. Rachel re-iterates this point, identifying the importance of DPOs in the context of personalised funding and the growing risks of isolation and denial of autonomy:

"The first thing is that people live where they want to live; that they have the choice over support and that they have the chance to have contact with other disabled people and non-disabled people, and I think that's why Roulstone and Harris<sup>32</sup> put such an emphasis on CILs and ULOs in their disability policy book because without advocacy and peer support it can be individualised [... ] So it's that collective voice and that peer support that needs to be there, otherwise it's just individualised and that's where people are at risk."

Pointing to the essential value of "advocacy", "peer support" and "collective voice", Rachel is again suggesting that markets of personal budget recipients and agencies

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<sup>32</sup> Harris, J. and Roulstone, A. (2011) *Disability, Policy and Professional Practice*. Sage, London.

without DPOs will fail to deliver on the potential of personal budgets. It is of note that she points to the danger of services becoming “individualised”. The individual responsiveness of personal budgets, or the way they are “individualised”, is often seen as their great strength, but here this term is used to denote a potential weakness of personal budgets. The point is that, without the collective input of CILs and ULOs, the increasing availability of personal budgets may develop into a situation in which isolated individuals are left without adequate power, understanding or resources to navigate ‘care’ markets. The emergence of CILs underpinned and supported the campaign for direct payments, and it has long been seen as a necessity that DPOs are present within a locality to support individuals to access the best support possible (Barnes and Mercer, 2006). As is made clear by Vera below, the absence of DPOs from many areas is a departure from the version of independent living campaigned for by the DPM:

“[W]ell the original idea behind independent living was that there will always be disabled people’s organisations to support disabled people in independent living, and um those organisations don’t exist in every area and a lot of them ...have actually have folded due to funding pressures”

In this quote Vera helps to take our discussion on from the value of DPOs to the challenges they face. Vera, like many other participants with direct experience of working in DPOs, stressed the significant challenges that DPOs are currently encountering. The first of these challenges is the increasingly competitive procurement environment they face. This procurement environment was seen to be inimical to the flourishing of DPOs as they compete with larger organisations that have greater resources and expertise to deploy in securing tenders. It was felt by several participants that competitors to DPOs generally offered a poorer service because of a lack of the values, expertise or democratic control by disabled people that characterise DPOs. The qualities that distinguish DPOs from other providers were not perceived to be valued within procurement.

As in the case of care and support budgets for disabled people, reductions in funding to local government as a whole has driven a requirement for reductions in



spending on DPOs. For DPOs, funding has to be applied for through a competitive tendering framework that has been increasingly common within local government, since the so-called 'purchaser-provider split' (National Health Service and Community Care Act 1990). For 'Robert' it was unsurprising that DPOs would fail to win contracts when they are made to compete on primarily cost-based criteria:

"You've got some local authorities who've taken the approach of doing competitive tendering and very often it's the big companies with the huge economies of scale, who can undercut the price of some of the user-led organisations, who are getting the contracts, and so the user-led organisations are going under."

As DPOs compete with more commercially orientated organisations who may have no history of working in the disability field, there is no longer the chance of a council 'block' awarding a grant to a DPO that could provide some stability of funding for the organisation. There are few restrictions on who is able to compete with DPOs for services (such as brokerage), and, according to Andrew, they have suffered through competing with organisations with inbuilt commercial advantages:

"throughout the last, I don't know, ten years it's become increasingly difficult for small organisations, with the move from funding local organisations, and particularly local disabled people's organisations by grant, to expecting them to tender, as part of the commissioning process, it's very difficult to compete, particularly with large organisations who can deliver economies of scale and can employ full time tendering teams"

Andrew here is emphasising the need to compete with organisations that benefit from in-built advantages of "economies of scale" and "full-time tendering teams". The procurement framework allows these organisations to benefit from their strengths, but the values and practices of solidarity and peer insight that characterise DPOs are not similarly recognised. Arguably this portrays an ignorance of the reasons that DPOs came into existence in the first place, including the capacity to give disabled people an organised voice in the provision of support. Even within an economic cost-benefit procurement framework, it could still be argued that DPOs strengths are not accounted for, in that the support of DPOs could be a cost-effective means of limiting

the damage done through the isolation and loss of participation resulting from the government's austerity program. In this context, 'Liz' noted the value of DPOs for individual disabled people, making the connection between the collective input of DPOs and the realisation of the goals of individuals:

There needs to be a lot more attention given to the outcomes for the individual because if you look at the evidence where there's a strong CIL, there's a very vibrant community of disabled people living independently and accessing employment.

The evidence referred to by Liz does not appear to have convinced all of government of the value of investing in DPOs or creating a procurement environment in which they can flourish. Under the last government the value of ULOs was officially recognized in a set of design criteria by which progress could be measured toward the goal of developing a user-led organisation, based on existing CILs, in every locality by 2010 (Cabinet Office - Prime Minister's Strategy Unit, 2005). However, several participants voiced fears that DPOs were not currently receiving adequate support. In particular, these participants were concerned that DPOs faced challenges from so-called 'User led organisations' (ULOs) who, some participants claimed, lack the clear cut control of disabled people in many cases, but can trade on an association with the values of DPOs. These organisations have grown while competitive procurement for provision of a range of services for disabled people has created opportunities for profitable enterprise. In this light, Andrew stated that both disability charities and private sector companies have displaced DPOs from the provision of services they would hope to deliver:

"[T]here are a number of organisations which are bidding for work, which in our historical context have always been seen as best done by a disabled people's organisation, like direct payment support, some of those will be ULOs which in my humble opinion might not be ULOs, but some of them will be big charities, some of them will even be commercial organisations who can see that they can make a little bit of money doing this"

In this excerpt when Andrew refers to ULOs 'which in my humble opinion might not be ULOs' he suggests a large degree of ambiguity is involved in the use of the term. Taken

together with other contributions on this matter, it was clear that the definition of 'ULO' is not straightforward or the subject of consensus. Tellingly, Andrew brings up this issue in relation to the challenge of private sector and charity organisations, who, he suggests, may benefit from the ambiguity.

The ambiguity of the term 'user-led' and the way in which these sorts of organisations have encroached on the territory of DPOs was referred to by nearly every participant directly involved with DPOs. The challenges to DPOs from increasingly competitive and ill-funded markets is added to when ambiguously named, inauthentic ULOs can displace them. The identification of what is an authentic and inauthentic DPO is not always black and white, and the uncertainty surrounding this issue forms the subject of an important debate. Rachel referred to an on-going intra-movement debate:

"There's a distinction between ULO and DPO which is very contested and some people don't think there should be a distinction between a user led organisation and a disabled people's organisation, and others think you can be a disabled people's organisation, be activists, and not be running services. So you can be a group that goes out on protests and campaigns around certain issues and definitely be a disabled people's organisation, but if you're not running that advice and advocacy and information kind of function, that are in the ULO design criteria, then you aren't necessarily a ULO, but there's disagreement about that."

Other participants were more forthright than Rachel in sharply differentiating DPOs and ULOs, raising this issue as one of the challenges to DPOs and questioning the value of ULOs. For instance Roger observed that:

"Disabled people's organisations have bid to set up these CILs, and they've been outbid by not what we would call user-led organisations. To be a user-led organisation, that's not the same as being a disabled people's organisation, all a user-led organisation needs to be is reflective and accountable to the people that use the services, so that could be parents, carers, disabled people themselves. So it could be a mixture that makes up a user-led organisation, whereas for a disabled people's organisation, it's quite clear that the control would be with disabled people."

In the first sentence here Roger refers to ‘not what we would call user-led organisations’ suggesting an independent definition through which he and other activists gauge the extent to which organisations are controlled by disabled people. He goes on to contrast the degree of control of disabled people over DPOs with that in ULOs. Andrew makes a similar point, again insisting on the distinctiveness of DPO’s over ULO’s:

“I try, in a constructive way, to differentiate between what I would call disabled people’s organisations and what other people might call user-led organisations. There is no doubt that some user-led organisations are really not user led organisations at all, so I differentiate between those two groups. I mean there are a number of organisations that have been set up which are kind of pretending to be something they’re not, and I say that in a very honest way, probably don’t employ very many disabled people, if any, and may have a slight majority of disabled people on the management committee. But I think my experience is that certainly doesn’t mean anything.”

By stating some ULO’s are “pretending to be something they’re not” Andrew is clearly identifying inauthentic/false ULOs as a challenge to authentic voices of disabled people. What is at stake in the debate over terms is not merely a definitional confusion but competing views on the degree to which disabled people should determine their own support and exert an organised local voice. By using the term ULO without criteria in place that would meet with the agreement of disabled people, the danger is that the term is used to endow practices and organisations with a credibility they do not deserve, allowing valuable sites of solidarity and peer support to be supplanted and isolation to grow. Many participants felt strongly about this issue and included it within their discussion of the most prominent challenges facing disabled people. This is made clear in the following passage in which ‘Victor’ links the emergence of ULOs to other setbacks and positions the matter at the forefront of problems of the movement:

“[W]e’ve got this generalised idea of user led organisations which can mean anything, you just have to set up a bid for something, and with that bid find three disabled people who are prepared to act as gophers as your chair, treasurer, secretary and hey you’ve got a user-led organisation. Now how we’ve ended up in that situation from

twenty years ago with CILs being a core part of our demands, I just don't know, it's been more spectacular than the loss of disability rights.”

Some participants noted that there was promising recognition of the importance of DPOs within the current Government from the Office for Disability Issues (ODI)<sup>33</sup>. However, within participant accounts of the challenges to disabled people, little mention was made of the capacity of the ODI to limit the malign influence of actors within government departments with far greater power such as the Treasury or other parts of the Department of Work and Pensions. In this respect, it would be a welcome development if those like the ODI who endorse distinguishing DPOs from ULOs could gain enough influence to legislate on the principles they support. For instance, Andrew would value an official distinction of this sort, both as a measure of the level of control and staffing by disabled people, and also the more subjective question of the values they embody:

“What's been done recently, which probably is constructive, is we have, and the office of disability issues has started to, understand the term DPULO: disabled people's user-led organisation as a way of trying to make a differentiation between those organisations that are run and controlled by disabled people and those which are something else [...] I think we should be clear about whether they really are run and controlled and staffed by disabled people or not, and if they are working to, if you like, a social model philosophy or not.”

Arguably, to adequately support 'DPULOs' a transfer of funds would be necessary to overcome the funding pressures resulting from cuts to local government spending. In the current situation, funding pressures and the policy of government to support ULOs has led to local authorities accepting groups that differ from those that the DPM had envisaged. Referring to a national survey of ULOs, Vera expresses her unease at the

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<sup>33</sup> The ODI is part of the Department for Work and Pensions. It has a broad brief to 'support the development of policies to remove inequality between disabled and non-disabled people' (<https://www.gov.uk/government/organisations/office-for-disability-issues/about>). The specific responsibilities of the ODI include 'developing and monitoring Fulfilling Potential, the cross-government disability strategy' and 'encouraging the use of the social model of disability' (ibid).

national growth of organisations unconnected to the values and needs of disabled people:

“A lot of organisations claiming to be disabled people’s organisations actually weren’t. So they didn’t have a majority of disabled people on the board or even employ any disabled people, you know that kind of thing. So yeah it was quite disheartening in a way [...] these organisations were being run by other people in the main and those that delivered independent living services, I mean this isn’t universally true, there are some very good, exemplary organisations that still run their services and still are run by disabled people and are run in disabled people’s interests, but there are quite a number where supporting people with independent living has become more of a business really.”

This situation may have come about in part because of the possibly benignly intended support from central government for ULOs. In Andrew’s view, the consequence of this, combined with budgetary cuts, is that local authorities are insufficiently discriminating about the credentials of would-be ULOs:

“[L]ocal authorities have duties and targets round ULOs and are therefore prepared to accept definitions that don’t have very much at all to do with what the department of health has characterised as being part of what they call design criteria.”

Bringing this section to a close, it was notable that the challenge of ULOs was positioned by some participants within a wider account of frustration and disappointment with the procurement environment in which they compete. This may be because the break-down of monolithic state-controlled services was felt to have had created an opening in which DPOs could assert their unique suitability for the task of guiding disabled people in the landscape of direct payments and personal budgets. However, participants suggested that any dream they had of an open field, liberated from oppressive institutions in which DPOs could flourish, seemed increasingly unlikely. Instead it had given way to a landscape in which price seemed to be the primary barometer of merit, incentivising the presence of other organisations who are increasingly able to dominate the provision of support. These organisations may be led by business principles rather than the politically motivated values of the DPM,

meaning their commitment to disabled people's wellbeing may be more readily compromised because of their need to generate profit.

As we saw at the beginning of this section and in chapter one, DPOs were seen as a key element of the independent living approach. Overall, their strengths and characteristics were not thought to be accounted for within procurement frameworks that narrowly focused on short-term cost considerations. Participants suggested that such frameworks, combined with cuts to council budgets, and ambiguous use of the term ULO, were allowing charitable and private sector institutions to regain power over disabled people while gaining reputational advantage from association with the values of DPOs. This is a cause for concern because, through advocacy, advice and other services, DPOs can promote the principles of the DPM, allowing more to be gained from the innovation of personal budgets and direct payments (Harris and Roulstone, 2011; Dodd, 2013). Furthermore, they can challenge poorly functioning markets and inadequate providers, helping to mitigate the isolation highlighted in section one of this chapter.

Linking to the next section concerning ideological challenges, the power of the language of 'user-led' was thought by Andrew to fit into a pattern of the colonisation of the language of the DPM:

"Large organisations, traditional disability organisations, like Leonard Cheshire, Scope etc, started to use the language of disabled people's organisations to say they were including disabled people, they were letting them take control, basically they were saying they were doing the same as disabled people's organisations but that they could do it better and they could do it cheaper and that's very difficult."

The importance of language, and the need to carefully distinguish subtly differing approaches that ostensibly promote empowerment, leads to the concern of the next section with ideology and competing meanings attached to the narratives of choice and personalisation.

## The Ideological Challenge: The Ideology of Choice Informing Government Policy

In this section, I will highlight the ways in which participants identified current ideology as a challenge to the DPM. As we have seen in the previous two sections, when developments have departed from those called for by activists, participants often related these developments to differences in underlying principles and ideas. Participants' insights into the principles of 'independent living' or 'choice and control' reveal what they perceived as the differences between these ideas and the underlying ideology of choice underpinning current policy.

To understand the differences between these two approaches, it is necessary to first define what participants understood as the DPM's ideal of independent living or 'choice and control'. These principles were seen as synonymous and both choice *and* control were seen as necessary means to bring about independent living. Consistent with the account given in chapter one, I define independent living as the demand that disabled people are extended the means to exercise the independence any other citizen would take for granted. In this approach, impairment is severed from any notion of dependency. Independent living is based on the assumption that disabled people should be seen as equal and active citizens, and that their impairments do not constitute a valid reason for them to have less independence. It insists that independence, autonomy, and self-determination are a right and should not be contingent upon fluctuations in resources. Service users must be able to control the services they use, make their own choice among service providers and be at the core of needs assessment. In order to achieve these objectives, direct payments and personal budgets are seen as preferable to traditional 'provided' services.

in the UK the history of the independent living approach has a great deal of overlap with the social model of disability (Barnes, and Mercer, 2006), and there is arguably a greater recognition that disablism suffuses society, and that independent living therefore requires a political campaign for the removal of physical, institutional and attitudinal barriers to achieve its goals (ibid). In the following interview excerpts 'choice and control' and 'independent living' tended to be used interchangeably, and



therefore in essence, independent living meant choice and control and can be read as equivalent to it.

Using data from interviews, I will now draw out participants' understandings of the ideological underpinnings of the independent living approach, to differentiate it from their understanding (and critique) of government's policies which focus primarily on choice. To provide some perspective on the origins of independent living, Kate explained how, to reverse the "control" historically held over disabled people by the state and charities, funding need to be directly transferred to disabled people, removing this degree of control from charities and the state. Thus the vehicle of direct payments was conceived in the British approach to independent living as a response to the power held over disabled people:

"There were good reasons for those things [direct payments] when we brought them in, and I think they were to do with where we were at the time and how much disabled people's lives were controlled by other people at the time, and we were trying to get to a situation where people would have absolute control and autonomy over their own lives."

This particular mechanism of independent living has now been endorsed (and even embraced) by successive governments. However, direct payments for some disabled people are a necessary but not sufficient condition to bring about what Kate describes as "absolute control and autonomy". Vera made this clear as she showed how "choice and control" had a political meaning, challenging society to provide adequate adjustments and resources for disabled people to be able to exercise independence. As Vera noted, this differed from some other approaches and was a distinctive aspect of the British definition of independent living:

"I suppose, in the US and in other European countries, the emphasis for independent living is on employing personal assistants, whether that's through mostly cooperatives in Europe, or directly employed in the US, and that's what people would think of as independent living. But in the UK, we've developed a rather different narrative to that, particularly in recent years, so it's a narrative about where independent living is about choice and control and, you know, being

able to participate fully in society on the basis of equality, and we see that as applicable to all disabled people.”

Describing a “narrative” of choice and control, Vera is suggesting the importance of the way practices are embedded within ideological frameworks (or “narratives”). If one accepts this, then ideologies may be an important dimension to be considered in the challenges facing disabled people. In the passage above, Vera distinguishes the British emphasis on choice and control through mention of “being able to participate in society on the basis of equality”. Considering the barriers that disabled people face and the challenges DPOs endure when competing against more commercially orientated organisations, coexistence on the basis of equality requires redistribution of power and resources to counterbalance these disadvantages. ‘Andrew’ made this point in relation to DPOs in striking and clear language:

“If we want to create organisations that empower people, and I think DPOs are one of the best ways of doing that, we have to accept that a level playing field is automatically unfair because you’re dealing with groups of disempowered people, and forcing them to work in exactly the same way as people who aren’t disempowered.”

This summarises the key aspect of independent living that “a level playing field is automatically unfair”. Another way of making this point would be to say that the ‘playing field’ is automatically uneven if left unadjusted through redistribution. Later, Andrew elaborated on this point:

“I think the central point is that you don’t treat everyone fairly by treating them the same, procurement forces everything to be treated the same, and inevitably it always comes down to prices and stuff like that, which is an issue if you want to provide quality and a good outcome as well, rather than just making a bit of money.”

Arguing that fairness is not the same as treating people and organisations uniformly, Andrew is further explicating ‘choice and control’ to demonstrate that it does not assume a flat or uniform distribution of power, resources and capabilities.

In addition to the necessity of prior redistribution, participants were keen to stress the necessity of collective user-involvement to add ‘control’ to individual

'choice'. Rachel clarified this point, noting how personal budgets can work well with the active involvement of DPOs. In saying this, she shows how choice and control is as much collective as individual, not only involving individualised funding, but also control brought about through collective input:

“Do I think it [personalisation] can be done well if there is a ULO and peer support at the heart of it and it's a community approach? Definitely, so what's been critiqued in the past is poor commissioning with commissioners who designed services and contracts without referring to disabled people. So when we talk about choice and control, for me, it's about disabled people having a voice in how that service is designed, instead of some widget office manager going 'oh today its office pens, tomorrow its personalisation' and putting together a tender that bears no relationship to the values that we need to live.”

By linking ULOs and peer support to the “values we need to live” she suggests that ULOs (or DPOs) can have the role of introducing the collective values of the DPM into markets for care and support and driving better outcomes for individual disabled people. Arguing that ULOs should be “at the heart” of the process she shows their centrality to achieving choice and control, and suggests markets characterised by personal budgets may not bring it about *without* their involvement.

We saw in the previous section how redistribution and collective involvement through DPOs was seen as having practical value for disabled people. Within this section so far I have established their role within activist's definition of independent living, showing how redistribution is seen as necessary to redress unequal power relations, and how collective user involvement is seen as a necessary supplement to the value and responsiveness of personal budgets. Noting how the government's own ideology of choice can be seen to underpin policy development, participants perceived government policy to be departing from their principles of choice and control. Principles underpinning policy can be more implicit than those advocated by activists, lacking explicit definition and even appearing contradictory. Nevertheless, participants discerned the ideology of choice underpinning government policy as a challenge to the ideal of independent living. I identify this as an ideological challenge to the DPM, which I demonstrate below.

Participants saw particular welfare reforms as emblematic of a divergence from their notions of independent living. Certain policies were seen to express the essence of independent living by distributing resources to disabled people in such a way that would better enable them to live on the basis of equality with others. When payments such as the ILF or DLA are abolished or reformed, activists who base their work on the principles of independent living perceive them to be under threat. To illustrate this point, Vera pointed to the reform of DLA as an example of the unwillingness of government to accept the axiom that disabled people require extra resources to coexist upon a 'level playing field':

“[D]isability living allowance really goes alongside all the thinking about independent living, because the disability living allowance recognised that there needs to be a level playing field and that if you’re a disabled person and you have an extra cost, and therefore it seemed sensible to have a benefit that contributed towards meeting those extra costs, which meant that then you could just get on with your life just like anyone else. But with the replacement of personal independence payment you know a lot of people are going to live now without those extra costs being met, and if you’re not going to have those costs met, then that undermines one of the fundamentals about independent living which is about participating in society on the basis of equality.”

As we can see from this excerpt, many participants evaluated policy based on its lack of adherence to certain fundamental independent living values such as the ability to “participate on the basis of equality” and a “level playing field” through redistribution. As policy becomes increasingly decoupled from this ideal, the capacity of individual disabled people to exercise choice is diminished. In the following excerpt ‘David’ argues that the decreased level of available resources reduces the possibility of choice and control:

“[B]ecause of budgetary constraints, local authorities are no longer funding services which were deemed part of somebody’s care package previously, for example funding provided for shopping or cleaning just aren’t provided for. So budgetary constraints and service providers and care companies charging from ten to twenty pounds per hour could limit the amount of freedom an individual may have. Obviously if you have less money but the care provider is

still charging fifteen pound per hour, there's going to be limits to what you can do with your budget."

Without specifying the ideas underpinning policy, he is evaluating policy in light of the need for it to bring about the goal of "freedom". This suggests a particular ideological construction of freedom which he detects to be missing from policy. He is linking the government's failure to preserve existing levels of redistribution to the decline in the conditions required for disabled people's freedom. In this way, like Vera, he is using the ideals of choice and control to gain a view of the implicit ideology of policy and establish its limitations.

As with the principle of redistribution, the other key principle of collective user control was also found to be lacking in recent government policy. As Liz pointed out:

"[B]rownie points don't go to user-controlled, because at the end of the day, able-bodied people are still sceptical that we can have groups, and many areas can't, but it's up to us to support them to get them to feel confident enough to take control of their lives, and if there are disabled people's organisations we can support them to take as much control as they possibly can."

Liz uses the 'scepticism' from policy makers regarding the general viability of DPOs to indicate another gap between the Independent living ideology and government policy. For Liz (and others), choice and control is impossible without the realisation of user control through the integral role of DPOs. To add data on this matter, Beverley also felt that the ideology informing policy failed to grasp the need for user-control:

"Their [pioneers of disability activism] idea of a centre for independent living, was again to support disabled people in the process of living independently, so again it was about having somewhere where disabled people, well an agency if you like, where disabled people could get help and advice and support in using their direct payments and getting personal attendance, and I think that's something which is not there today in the government's interpretation of personal budgets, there's not this kind of collective support which was there in the early days."

Arguing that collective user-control is not something which is apparent in the government's "interpretation" of personal budgets, she is noting how practical

differences between government policy and the DPM can be seen through the way in which they are embedded in ideology. This suggests the importance of ideology as a distinct, but related, challenge to the others we have examined. This could mean that the struggles of DPOs to survive in markets in which their unique qualities are not recognised can be partly attributed to different background assumptions regarding the manner in which provision of care and support can best function.

Nearly all participants shared the view that government had failed to grasp the necessity of collective user control and redistribution. In some participants' accounts this lead on to a related concern with the challenge of the ambiguity and obscurity that inheres in government notions of choice. For some, this represented a complex challenge to unpick the differences in the idea of choice involved, while for others government rhetoric of choice simply cloaked or obscured the true intentions of policy. Notwithstanding these differences in interpretation, the elusiveness and ambiguity of the dominant government notion of choice formed another ideological challenge.

As an example of this, 'Malcom' maintained that the use of language by governments could be deceptive and misrepresent their intentions:

Q: "are they [the current government] using choice to mean something quite different to what you would then?"

A: "yeah definitely, I mean that's true down the current benefits agenda as well, welfare rights agenda, because it's interesting that, in terms of the personal independence payment, rather than disability living allowance, they say it's about bringing the best out of people and enabling them to reach their potential, really what they really mean is getting them off benefits. It's not really about seeing the potential in people. But when you read the words and it's 'not about a person's disabilities, but how they can fit in to society' it all sounds wonderful, but they've definitely used the language of the independent living movement to do it their way."

Malcom is dismayed at the use of the term choice in conjunction with the removal of benefits that redistributed funds to disabled people. For Malcolm, this has been facilitated by the use of the language of independent living to confer credibility onto

policy. Rachel also feels that a conscious “cloaking” of undesirable policy in the language of rights and equality has taken place:

“The move to individual budgets for the conservative party, the direction of travel has to be smaller and less support for fewer people, you know we’re not going to have under this government...I just think it’s that stealing of what’s been said in terms of rights and equality and cloaking a consumer and market economy in that language. And the reduction of levels of welfare for people and the reduction of welfare is what we’ve seen in the FACs criteria going to critical here, the use of private companies to assess people.”

Unlike Rachel and Malcolm, others argued that rather than language ‘cloaking’ the true intentions of policy, government policy represented an uneven realisation of the principles of independent living. The government’s emphasis on personalisation was often seen to express the complications of this ideological challenge, arguably embodying a partial realisation of the DPM’s ideals in its focus on empowerment through personal budgets. The presence of these tensions can be read in the following contribution from Rachel where she explains that receiving a direct payment or being allocated a personal budget will not necessarily lead to choice and control, and should not therefore be seen as equivalent to personalisation:

“I think what I’d like to see is a distinction between the choice and control and the personal budget, that personalisation doesn’t just mean a direct payment or personal budget, for us it means choice and control over how and what and at what time, and there is a direct payment element to it. For most people, politically and in the literature, personalisation has meant a direct payment, and that’s the wrong angle ...the choice and menu of what people do with their lives, and the contact they have and the value they have in society, that’s the valuable bit about how that’s personalised, with a personal budget for me really, and the provision of advocacy for that, whether that’s mental capacity advocacy or peer support, advocacy is the key thing, not the direct payment.”

Rachel does not want to completely discount personalisation but seeks to disassociate it from direct payments alone, instead stressing advocacy. By staking her own distinctive claim to the meaning of the term, it is suggested that she discerns some level of value remaining within the idea and does not consider it lost to negative

connotations. However, the version of “choice” underpinning policy was perceived as excessively individualistic without the application of corresponding collective values that would support user-control through the presence of DPOs.

The danger of the implementation of personal budgets without corresponding application of the values of independent living is that empowerment is seen too one-dimensionally as emerging automatically from the allocation of individualised funding. Trying to account for this ambiguity and the uneven realisation of choice and control within government ideology, David felt it could partly be accounted for by the government’s endorsement of a ‘free-market’ version of personalisation:

“I believe the current form of personalisation that is trumpeted by government is a form of personalisation where the individual is responsible for every step of their lives. I think the form of personalisation that the government trumpets is a form of free market personalisation where the individual is an economic actor and, you know, everybody wants to be responsible for the administration of care packages, and you know, the current form of personalisation advocated by the government is free market and individuals are seen as isolated individuals and not within communities.”

Like Rachel, David is arguing that the government’s version of personalisation involves an individualistic ideology. The way that David refers to a “form” of personalisation suggests that other forms may be possible, including a less individualistic form informed by the values of independent living. The feeling that ‘choice’ and personalisation were tainted by consumerism was not uncommon and David contributed more on this matter:

“I kind of cringe at the word customers and this idea that if you give somebody a care package their service providers will offer a good service and an affordable service; it’s ridiculous because service provision is very often based on need. It’s not like buying a widescreen TV where you can do without, service provision, for myself say, I need to get out of bed in the morning, it’s not a choice it’s a need.”

Here the common reference to the need for redistribution, in addition to the availability of individualised funding, is based on an important distinction between



human need and other commodities. Treating support and the requirement for relationships just like any other commodity means that the values of independent living embodied by DPOs can be 'crowded out' because they are not valued in a finance led procurement environment based on the logic of market exchange of commodities. This could be seen as ironic when government and its supporters often justifies austerity and savings made through strict procurement rules on the grounds that an over-wieldy state can 'crowd out' private sector initiative and innovation through excessive spending (Blyth, 2013).

Referring back to the beginning of this section it will be recalled that independent living was conceived as a political challenge to society to provide adequate resources for disabled people's independence and coexistence on the basis of equality. For Andrew, markets that can facilitate choice need to develop from an understanding of this challenge:

"We're still, despite the rhetoric, living in a world where disabled people are second or even third class citizens, who cannot expect the same opportunity that everyone else just takes for granted. And so we need a social debate which says "what do disabled people realistically need, support that other people might not need, what do we want those people to enjoy in life?" and until we've had that debate, we can't really line up whatever funding might be necessary to make that happen."

Participants understood that demands for choice are made against a background of unequal power relations and the principles of independent living were consciously constructed to overcome such inequalities. Whilst participants tended to support the mechanism of individual choice, the version of choice and control supported by most of the participants was based less on consumerism and more on human rights and social participation. Markets were seen as a means to these ends and not an end in themselves. The ideological construction of choice through markets, in isolation from the principles of independent living, seemed to obscure what is required to bring about choice and control.

Summarising this section, we started off by seeing how the DPM's ideal of independent living was often articulated through the twin notions of 'choice and

control'. This was seen as constituting a broader political challenge to society to provide adequate adjustments and resources for disabled people to coexist on the basis of equality. This was based on an account of power which understood the need to offset the inequalities that disabled people endure. In addition to redistribution, collective user-control was also seen as necessary. Demands for collective user involvement were based on a belief that accommodations to the preferences of personal budget holders alone would not bring about adequate choice and control.

Having defined these aspects of choice and control, we saw how participants' understood government policy to be departing from these principles. Examples such as the threat of abolition of the ILF and the reform of DLA were seen to demonstrate an unwillingness to accept the axiom that disabled people require extra resources to coexist upon a "level playing field". The principle of collective user control was also found to be lacking in recent government policy, as was shown in section two concerning challenges to DPOs. Unlike independent living, the government's version of choice was seen as viewing power as uniformly distributed, or flat. Where choice and control emphasised collective user-control, the current government's version of choice was thought to assume that empowerment could come about automatically through the choices of personal budget holders.

A further challenge concerned the ambiguity of the policy narratives of personalisation and choice. Generally, participants did not wish to entirely dispense with these terms, but were at pains to distinguish their definition of them from government policy. While these narratives embody the valuable principle of individual choice and the personalisation of services, they were currently seen as inadequate owing to the absence of redistribution or collective user-involvement within (or alongside) them. This complicates matters because an endorsement of these narratives could be mistaken for narrower and more individualistic notions of empowerment than is characteristic of the philosophy of independent living. Participants often framed both collective and individual empowerment as necessary as the route to independence, whereas the government's choice and personalisation was seen as more one-dimensionally individualistic.

Much of the discourse informing policy formation construes choice in market terms based on a theory in which more exercise of choice is seen to punish poorer providers, meaning it is always favourable and leads to a better market in general. By contrast, the DPM's ideal of independent living recognises that individual choice and personal budgets are necessary but not sufficient for empowerment. The rejection of a one-dimensional focus on individual empowerment should not therefore be mistaken for a rejection of the importance of individual choice. Without prior redistribution and support of DPOs, the exercise of individual choice intersects with power relations that disrupt the demand that all disabled people exercise choice and control. Thus it appears that for most activists, the relationship between individual and collective empowerment is not either/or, but that to have one you need both.

## Summary

Within this chapter I have identified three key challenges facing disabled people. In the case of social isolation, themes emerged from interviews about the impacts on individual disabled people because of reductions in public funding on social support. The concern was that these reductions would limit the extent to which disabled people could participate as active citizens in their communities or share in life outside their own homes. The fear expressed by participants was that many disabled people would be constrained in the range of activities they could engage in, while their dignity was undermined by the absence of even basic supports. Regarding the second threat of deteriorating conditions facing DPOs, participants felt that the vital role DPOs play within markets of care and support could be undermined. It was believed by many that cuts and downward pressure on costs, combined with a competitive tendering framework, were disadvantaging DPOs. The conditions facing DPOs threaten their existence, in the process endangering an integral element of choice and control concerned with collective user-control. The third and final threat identified by participants' concerned these very ideals of choice and control and how these were seen as diverging from the ambiguous ideological constructions of choice and personalisation that informs policy.

The overall extent to which the standard of living and level of support of disabled people has deteriorated under this government is an important aspect of analysing the challenges facing disabled people. Experienced participants were aware of past challenges under previous governments and seemed keen not to be perceived as naively romanticising the past, or downplaying the structural or ideological underpinnings of disablism that have persisted through different governments. In individual, organisational and ideological terms, disentangling whether participants were referring to immediate problems of the current government or to longer run structural problems was difficult, and interview data will need to be supplemented by analysis of further evidence to better understand this issue.

Considering the challenges discussed in this chapter as a whole, there is a similarity to those faced by individual disabled and DPOs in that both may require additional resources to coexist on the basis of equality with non-disabled people and commercial organisations. We saw in the first section of this chapter how withdrawal of resources from individual disabled people is not experienced as equity but as a form of coerced isolation and a contradiction of the independent living approach. Equally, in the case of DPOs, treating them identically to other providers fails to recognise their unique strengths and the competitive disadvantages they face against larger more commercially orientated organisations. In the case of both DPOs and individual disabled people, a prior redistribution of resources is required to achieve coexistence based on a degree of equality.

In this light it is important to note that the government's ideological construction of choice assumes a flat distribution of power and resources and lacks a notion of redistribution. When disabled people are denied more than enough to 'survive' (see section one above), the degree of resource redistribution is far removed from the demands for 'choice and control' based on a level of redistribution that would bring about participation 'on the basis of equality' and the opportunity to act as citizens with an active role in social and community life. Individual choice alone is not enough and must be augmented with a transfer of power and resources and the democratic control of disabled people.

While this continues to be the case, it appears that the overall situation of both many individual disabled people and DPOs may worsen, meaning fewer empowered disabled people can contribute to DPOs and help sustain them in this difficult climate. Meanwhile, the worry is that DPOs will be less able to reach out to, and contribute to better outcomes for local disabled people, or highlight the challenges many individual disabled people are facing, including when their budgets are reduced or “picked off” one by one. As these challenges to individuals and DPOs grow, it may become harder to challenge the limitations of a one-dimensional view of choice and empowerment that underpins government policy. This ideology is reinforced because the individualism of government notions of choice mean collective user involvement is not valorised and DPOs are not seen as intrinsically valuable. This construction of choice also ignores the preconditions which were seen as necessary by activists to enable the equitable exercise of choice through redistribution, offsetting disablism.

These challenges are mutually reinforcing and intersect in complex ways. Taken together, they comprise novel forms of disablism that coexist with older and more familiar forms of disablism associated with paternalism and oppression within institutions. In the next chapter (six) I seek to reflect on these challenges in greater depth, before turning to participants responses to them in the following chapter (seven).

## Chapter 6: The Challenges of Enforced Individualism and their Relation to Personalisation

In this chapter I will further develop the data presented in the previous chapter, broadening my analysis by drawing on relevant literature to deepen the examination of participant contributions. I will do this by linking the challenges facing many disabled people to Roulstone and Morgan's (2009) notion of 'enforced individualism'. The idea of enforced individualism is useful in articulating the shifting challenges facing disabled people in the UK and the shortcomings of current disability policy. To strengthen the conceptual framework provided by the idea of enforced individualism I will explore the policy narrative of personalisation, analysing its relationship to enforced individualism.

The goal in this chapter is to explore the logic of enforced individualism and how it relates to the personalisation narrative (Needham, 2011). This will develop the interpretation given of the challenges facing disabled people, before the resulting positions taken by participants in reaction to these challenges are analysed in subsequent chapters. The analysis presented in this chapter is predominantly concerned with the ideas at work in enforced individualism and personalisation. As we saw in the previous chapter, current challenges to disabled people have an ideological component but also have material dimensions concerning individual isolation and challenges to DPOs. Enforced individualism can relate to all three challenges outlined in the previous chapter and thus may be a good way of conceptualising them. In the case of personalisation, while I will focus on its narrative qualities, these qualities cannot be completely separated from material developments such as the promotion and increased availability of personal budgets. Although both enforced individualism and personalisation have definite material dimensions, the goal in this chapter will be to distinguish their ideological dimensions from the ideas of the DPM's, in the process developing an understanding of how personalisation and enforced individualism relate to each other. In later chapters I balance this focus on ideas with a focus on the

political and economic conditions which have driven much of enforced individualism and formed the context in which personalisation has been promoted.

## **Enforced Individualism**

Through my analysis of interview data and awareness of other relevant evidence, I have chosen to theorise the growing influence of a form of disablism that coexists with more familiar forms of disablism associated with paternalism and oppression within institutional settings. I argue that the challenges presented in the previous chapter collectively reconfigures the nature of the oppression many disabled people face. Borrowing from Roulstone and Morgan (2009), I refer to this reconfiguration as a movement toward the challenges of ‘enforced individualism’ away from one which had been chiefly characterised by ‘enforced collectivism’. To be more precise, I argue that these two types of challenges now coexist, with enforced individualism likely to continue to grow in influence in future.

These terms originate in Roulstone and Morgan’s (2009) study of the impact of self-directed support on care provision in one local authority, in which they present data from interviews carried out in 2006 with users of day centres undergoing a process of modernisation. The authors found that the quality of life experienced by former users of day centres had often not improved. Their findings about lives outside of institutions anticipate many of those reached in the previous chapter. For example, the challenge of increased isolation for individual disabled people was anticipated, as the authors argue that those leaving institutions could be ‘prey to the rhetoric of self-directed support without receiving the quantity of financial support required to engage with other disabled people and wider society in a safe and genuinely freely chosen way’ (ibid: 342). This concern was actualised in the previous chapter when participants warned of a situation in which support merely “kept people alive” rather than “giving them a life” characterised by citizenship, participation and recreation. Independent living requires disabled people have the choice required for active citizenship and that they not be isolated in their own homes or, as a participant in this study put it, “institutionalised in their own homes”. Roulstone and Morgan appeared to anticipate the risk of such problems, noting that as participants had begun to spend more time

away from day centres, 'a great deal of former centre-based time was beginning to be spent at home' (ibid: 342). This issue typified the concerns of many participants in this thesis with the growing risk of isolation and social disconnection in the lives of many disabled people.

As well as the dangers of greater isolation and alienation in the lives of individual disabled people, Roulstone and Morgan also anticipated the compounding problem of the undermining of DPO's capacity to mitigate isolation and support disabled people through the process of accessing and using individualised funding. The authors point to the value of collective contexts that are not enforced or paternalistic, and highlight the significance of CILs and DPOs as a means to decrease the likelihood of 'individual support solutions fostering enforced individualism and isolation' (ibid: 343). They warn that 'in the absence of adequate funding and exposure to organisations of disabled people, day service recipients risk moving from a position of enforced collectivism to an enforced individualism characteristic of neo-liberal constructions of economic life' (ibid: 333). The reference here to enforced individualism clarifies the concept I draw upon to theorise my findings. In the same quote the reference to 'neo-liberal constructions of economic life' is also of relevance, corresponding to the third challenge I identified in the previous chapter concerning obstructive ideas which undermine the conditions required for individual disabled people and DPOs to exist on the basis of equality with others. Taken as a whole, Roulstone and Morgan identify the isolation of individuals, challenges to DPOs, and the importance of ideological constructions as key aspects of enforced individualism, in each case foreshadowing my analysis of the challenges facing disabled people.

This goes some way to explaining why enforced individualism is an appropriate vehicle for analysing my findings. In the rest of this chapter I will elaborate its importance through its relationship to personalisation, further conceptualising my analysis of the challenges to disabled people identified in the previous chapter. Before I can go further in this task it is first necessary to more carefully define enforced collectivism because of its inextricable relationship with enforced individualism. Roulstone and Morgan use the concept of enforced collectivism as they explore the individual and collective influences upon disabled people's lives, noting that many



disabled people who have little experience of political forms of collective mobilisation will have experienced 'enforced collectivities' (ibid: 338) typified by 'now reduced segregated long-stay, residential and day centre contexts' (ibid). These collectivities characterise the concept of enforced collectivism which denotes the damaging influence of institutions upon the lives of many disabled people.

Enforced collectivism, and the institutions which characterise it, arguably represents the most negative facet of an ambivalent inheritance of collectivist values from a time when the benevolent and caring function of institutions was more often assumed to outweigh their harmful practices. In such 'one-size-fits-all' institutions, disabled people were crudely grouped together with those with whom they may have shared little in common. This destructive process was a central part of the objections of the earlier DPM (Hunt, 1966). It is hard to overstate the role that segregation, underpinned by ideas of normality and sub-normality, has had in the experience of oppression of disabled people (Barnes, 1990). Experience of this segregation continues to colour analyses of disablism, particularly while it persists, albeit to a lesser degree. Attendees or residents of these institutions may be denied full autonomy through regimented institutional practices or even through coercion. Even in the best examples of day centres, the nature of the institution means that individuals will lose a degree of independence, choice and autonomy through the necessity that they compromise their priorities to fit with large numbers of fellow attendees and staff.

In the climate in which these institutions grew, the individual empowerment that many disabled people demanded was suppressed by a climate of opinion which valued collective approaches to risk and solidarity over the unequal realisation of individual goals. These institutions decreased in influence in parallel with a process in which the fundamental values that underpinned their existence were questioned. This is to say that shifts in how services for disabled people are commissioned and delivered mirror a broader transition from a time of greater collectivism to the more individualist values of the present day. In the complex transition from 'embedded

liberalism<sup>34</sup> (Harvey, 2005) to neoliberalism<sup>35</sup>, the inviolability of individual freedom from coercion arguably became better recognised. This provided a justification for the closure of many institutions as the goal of individual independence for all became more established. It is arguable that the greater acceptance of individual empowerment is in evidence today as more disabled people are able to gain a form of empowerment through an employer-employee relationship, increasing their power to realise their goals and desires through personal budgets or direct payments. Although the means to exercise greater choice are intended to be made widely available, the degree to which these choices can be realised continue to be uneven and influenced by cognitive and economic resources (Stevens *et al*, 2011).

In the previous era, characterised by greater collectivism and paternalism, and the current environment, appreciative of autonomy but prey to atomism, differing forms of injustice are produced. Enforced collectivism was likely to breed institutional oppression, and enforced individualism the forms of isolation and alienation referred to in the previous chapter. This is not to say that deinstitutionalisation had to lead to isolation or alienation in a direct causal manner, but that when deinstitutionalisation is combined with drastic cuts in government expenditure the result is isolation for many disabled people, including those receiving personal budgets or direct payments. The shift to deinstitutionalisation and individualised funding mechanisms has of course been broadly welcomed by disabled people, but when combined with drastic steps to control government spending, it leads to different challenges from a situation in which this reduction in spending is combined with institutionalisation. While deinstitutionalisation is in no way a cause of austerity, it may be that aspects of the ideological forces which facilitated the process of deinstitutionalisation are also

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<sup>34</sup> Harvey (2005: 11) uses the term 'embedded liberalism' to describe how in the post war period 'market processes and entrepreneurial and corporate activities were surrounded by a web of social and political constraints and a regulatory environment that sometimes restrained but in other instances led the way in economic and industrial strategy'.

<sup>35</sup> Harvey's (2005: 2) definition of neoliberalism is elaborate but it's beginning states that neoliberalism is 'in the first instance a theory of political economic practices that proposes that human wellbeing can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterised by strong private property rights, free markets and free trade. The role of the state is to create and preserve an institutional framework appropriate to such practices.'

supportive of falls in state expenditure on support for disabled people as pursued through austerity.

The historical movement between enforced collectivism and enforced individualism, and the environment which gives rise to their development, begins to show why I arrived at enforced individualism/collectivism as an appropriate conceptualisation for my analysis. In interviews for this thesis some participants criticised the continuing paternalism of day centres and segregated institutions, but when asked to assess significant or emerging threats, their responses were typically more characteristic of enforced individualism. In this sense a perception of the movement from enforced collectivism toward enforced individualism appeared to be manifest in interview data. This movement also provokes a consideration of the forces which shape the opportunities for disempowerment/empowerment that are available, and helps in understanding how resistance can orientate itself to these opportunities. By itself, enforced individualism can illuminate the challenges I have identified, but it is also the dynamic relationship with enforced collectivism that is useful. In this sense enforced individualism-enforced collectivism is a relational framework which requires both concepts to be meaningful.

The correspondence between the findings of the previous chapter and those of Roulstone and Morgan means that the dualism of enforced individualism and enforced collectivism is appropriate as an animating theme for this stage of my analysis. Given that the data presented by Roulstone and Morgan is from 2006, it reminds one that these trends are not entirely new or purely the outcome of the election of the coalition government and the introduction of their program of austerity. Arguably the challenges I have presented can be understood as an intensification of a previously existing trend. Overall my analysis of interviews adds fuel to the concern that 'self-direction can take on 'distinctly neo-liberal characteristics' (Roulstone, Morgan, 2009: 343). In my view, enforced individualism is growing as personal budgets become widespread but are detached from their potential as the level of each budget is restricted by rationing, and many are denied any funding at all through heightened eligibility criteria. Meanwhile, the strength of DPOs has been undermined as they are made to compete with charitable and private sector providers, who mimic their

strengths in the race for competitively awarded local authority tenders. In this situation the personalisation of social care has often been spoken of as a way of increasing the empowerment of disabled people. I now go on to relate it to enforced individualism.

## **The Personalisation Narrative and Enforced Individualism**

In this section I will scrutinise the policy narrative of personalisation in order to justify and explain in greater depth my argument that a shift has occurred toward more enforced individualism. In the previous chapter I explained the challenges of what I now theorise as enforced individualism, including the ideological challenge of obstructive and limiting ideas. It will be recalled that these limiting ideas included a failure to accept that disabled people require the resources necessary to coexist upon a “level playing field”. Another problem was the absence of the idea of collective user control in recent government policy. Unlike independent living, the government’s version of choice was seen as viewing power as uniformly distributed, or flat. Where choice and control emphasised collective user-control, the version of choice that is characteristic of enforced individualism assumes that empowerment could come about automatically through the choices of personal budget holders. To some extent each of these limiting ideas are present in the policy narrative of personalisation, mirroring its flat account of power, construal of empowerment in market terms and fetishisation of individual choice (see Dodd, 2013; Houston, 2010; Ferguson, 2007). This may be because both enforced individualism and personalisation are ultimately bound by the constraints of neoliberal policy orthodoxy. In concluding chapters I will return to this broader context, but for now will focus upon what the policy narrative personalisation can tell us about enforced individualism.

The focus here on an intangible policy ‘narrative’ might seem questionable when ‘hard’ questions of funding are driving down the level of support and benefits experienced by many. As an abstract term, the potential of personalisation will mainly be driven by the forces which make use of it and the level of resources made available to actualise it. However, the narrative qualities of personalisation as a ‘policy story’ (Needham, 2011) are a key reason why many have been persuaded of the merits of

personal budgets and direct payments. Indeed the potency of personalisation as a policy story is such that it has spread throughout many areas of public service reform (ibid), suggesting that the narrative is potent whether it denotes personal budgets and direct payments or reforms in other public services. Part of the success of personalisation as a narrative is its mutability (ibid); however, its meaning is not completely mutable and is constrained by the web of associated terms that are connected to it. The uses and meanings of terms can shift, but at any one time, what they refer to is constrained by their web-like relation to one another<sup>36</sup>. Personalisation has a relatively stable meaning that refers to empowerment in anti-structural, individual terms. It is reasonable therefore to attend to the inner logic of the narrative and to its relation to enforced individualism. Because the two are closely related and overlap to some degree, it is important to unpick their relationship.

The narrative of personalisation shares with enforced individualism some important characteristics, but is clearly not identical to it. I define personalisation as a policy narrative, associated with personal budgets and individualised funding. Enforced individualism, as I note above, refers to the totality of the three challenges identified in the previous chapter, as well as the movement away from enforced collectivism. Neither personalisation nor enforced individualism simply causes the other, rather they are causally interrelated. As a policy narrative, personalisation is a way of framing or talking about empowerment. It refers to empowerment in terms of personalising support to facilitate individual choice making. In common with the ideological challenges analysed in the previous chapter, it is inattentive to structural dimensions of disempowerment or disablism, viewing individual empowerment through personal budgets as sufficient for individuals to thrive. This means it does not refer to the full range of factors which can counteract individual empowerment and play a role in upholding conditions of isolation. Unlike the DPM's notions of choice and control or independent living, it lacks a notion of collective user involvement, meaning it does not

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<sup>36</sup> Sayer, drawing on Giddens (1979; 1987), comments that 'Once objects have been "arbitrarily" given names, the conventions governing how terms are combined to make meaningful discourse which can inform successful action are far from arbitrary' (1993: 328).

give a prominent role to DPOs. As we shall see in greater depth below, in these respects, personalisation seems to act to reinforce aspects of enforced individualism.

Enforced individualism can also affect the personalisation narrative. As the isolation that characterises enforced individualism grows, the prospect of greater empowerment through personalisation recedes. Personalisation, sold through powerful stories of empowerment (Needham, 2011) could then be seen to be failing by the standards it has set for itself. If isolation grows, and personalisation is seen to fail to deliver on its resonant stories, it may mutate into a story primarily about ‘freedom from’ paternalistic institutions. Another way in which enforced individualism could affect personalisation is that challenges to DPOs could mean they are less able to remind personalisation proponents of the multifaceted nature of disablement and the collective effort needed to challenge it. This could reinforce within personalisation an increasingly one-dimensional view of power that assumes empowerment will arise from personal budgets alone.

### **Personalisation, its Relation to Power, and its Divergence from the Principles of the DPM**

Interview participants appeared to be suspicious of the one-dimensional notion of empowerment at work in personalisation that assumes the award of a personal budget will, by itself, lead to empowerment. Some explained this simplistic view of empowerment and the associated challenges of isolation and social alienation through reference to the disparity between the model of direct payments pioneered by the DPM and the version of personalisation being promoted by the government<sup>37</sup>.

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<sup>37</sup> This distinction might be questioned given that, without personalisation, direct payments could be cut in conditions of austerity and themselves then be seen as a vehicle for regressive cuts. It may be that the investment of activists in developing direct payments meant they were disposed to viewing them more positively. On the other hand, participants may have been right to be critical of differences in process that are embedded within personalisation such as resource allocation systems and indicative budgets. Recent evidence suggests a worrying degree of opacity in this aspect of personal budgets and personalisation. Slasberg *et al* (2013) find that the average real allocation to recipients of personal budgets falls far below what they are initially awarded through the resource allocation system (RAS). An upfront and reliable indication of the level of budget through the RAS was conceived as a cornerstone of personalisation. The differences between upfront and real allocations are so great that Slasberg *et al* conclude ‘the actual budget was being decided without regard to the upfront allocation. This would mean that personal budgets, defined as they are by the upfront allocation with which to plan support, do not even exist’ (2013: 94).

Whether participants were correct to sharply distinguish personal budgets from direct payments or not, the idea that control had been lost over the direct payments agenda to another set of values, seemed quite a common way of explaining the challenges facing individual disabled people and DPOs. In this way, participants were linking personalisation to the challenges I have described as enforced individualism. As an example of the feeling that disabled people's control of the direct payments agenda had been lost under personalisation, Robert argued that there was a tenuous link from the direct payments he and movement colleagues had campaigned for and what is now promoted as personalisation:

"I've always been sceptical; you know we've always been fighting for direct payments and I was involved very closely with the campaign to legalise direct payments years ago, but we've never been campaigning for resource allocation systems or SEQs; not really in that form...I guess it made us feel, to be honest, a little bit like the direct payment thing 'oh it wasn't working' and that was because 'it was a bad idea'. It wasn't because it was a bad idea, it wasn't working because it wasn't implemented properly, and actually if it had been implemented in the way that we'd been suggesting with a degree of flexibility and choice and control, and the right levels of investment in support structures and systems, it would have been accessible to a lot more people."

Similarly to Robert, Liz felt that personal budgets, embedded within the narrative of personalisation, had proven to be more susceptible to being used for reducing support, fuelling isolation:

"I'm very suspicious of personalisation and personal budgets, because as far as I can see so far, everyone who's been assessed as needing a personal budget, who was once on a direct payment, has had their support reduced, and I just think, maybe I'm being sceptical, but the way it's been administered and delivered is far more to do with local authorities ability to be imaginative, creative and cost-effective than it is about taking direct payments to another level."

The divergence of personalisation from the principles of independent living disappointed some participants who argued that personal budgets, embedded within personalisation, rather than extending the empowerment of direct payments to more

people, are in danger of becoming a distortion or perversion of the original intentions of direct payments. For example, Liz explained that:

“When disabled people began to control the cash that was supposed to be there for our benefit, that kick-started what was going to be a long process of emancipating disabled people through direct payments, and I think personalisation has taken our idea of the right to control and has manipulated it in a way that the control is steadily going back to central provision and to support for the professionals, cos they’re now going to determine what personalisation is and how much money we need to achieve.”

Liz refers here to the way in which “they’re now going to determine what personalisation is and how much money we need to achieve”, suggesting a decline in the extent to which disabled people are in control of policies ostensibly designed to deliver empowerment. This drives a “suspicion” at the malign values at work in place of disabled people’s in personalisation today. If this suspicion is correct and personalisation is not based on the principle of redistribution and coexistence on the basis of equality, personalisation is compatible with the challenge of isolation to disabled people. This may be an example of how the ideas identified as a challenge in the previous chapter can obstruct the demands of disabled people. The DPM argued that the level of resources required for a “level playing field” were necessary. As personalisation takes hold it is arguable that the processes associated with it provide a means to subvert this logic, putting the level of resources deemed available above the need of the individual to achieve independence (Slasberg *et al*, 2013).

This shortcoming in the logic of personalisation can be illuminated by contrast with the inversion of individual models of disability represented by the social model of disability. The social model sensitises one to the individualisation seen in personalisation as an over-arching framework for empowerment. Presented as a self-evident good, the wide appeal of the personalisation narrative can obscure persistent inequalities and differences in disempowerment, promoting an ideal of independent market actor who realises meaning through market decisions (Houston, 2010). Barnes’ reasons for doubting the potential for personalisation as a framework for



empowerment are of interest here, as she notes the limits of such a one-dimensional approach to addressing disempowerment:

Any strategy that claims 'empowerment' as an objective requires an understanding of the processes and circumstances that give rise to disempowerment. People's experiences of the way in which public services are delivered is one factor in this, but it is not the only one. Claiming transformational effects from a strategy that focuses solely on this aspect of people's lives simply will not do (2008: 156).

Without the imposition of cuts, a focus on personalising public services could lead on to more participation in society. However, whilst personalisation may be seen as heightening positive freedom<sup>38</sup> in this way, these gains will not necessarily be realised equitably as they interact with pre-existing inequalities that permit greater or less degrees of participation. Reinforcing this point, Stevens et al (2011), drawing on Clarke et al (2006; 2008), found that users of personal budgets required significant determination and high levels of cognitive and social resources to realise, as well as to make, choices. Overcoming the effect of these inequalities could begin with allocations of personal budgets that provide 'enough money' to enable independent living and full citizenship (Slasberg *et al*, 2013). This could also help to remove some of the bureaucracy and opacity from a process which according to Slasberg *et al* frequently does not provide the user with anything close to what is initially agreed for a 'indicative budget' through the resource allocation system (*ibid*). A model of fairness as 'enough money' has never been part of personalisation, with the model of fairness at work closer to one of 'a fair share' of whatever budget the political process had made available (*ibid*: 95). With what is deemed affordable built into the logic of personalisation as a fundamental principle, it would seem the allocation of 'enough money' to achieve independent living and overcome inequality and disempowerment would always be very difficult to achieve. Personalisation is 'power-blind' by suggesting that 'transformational' empowerment can occur through a shift in social care practice.

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<sup>38</sup> Positive freedom must be understood in relation to negative freedom. To briefly explain these terms, negative freedom is the 'freedom from' external restraints on individual freedom, while positive freedom is the 'freedom to' realise one's potential (Berlin, 1969).

To achieve transformational levels of empowerment and overcome the challenges of enforced individualism, disablism and the basic relations of society must be changed, requiring that concentrations of power are challenged and made to cede power. The DPM has generally understood that 'choice and control' must be fought for against a background of concentrated power and wealth (Finkelstein, 1980; Oliver, 1990). Power relations are not referred to within the logics of personalisation, mirroring my analysis of the ideological aspect of enforced individualism and its essentially flat account of power. The context determining enforced individualism is informed by existing power structures including disablism in the form of inadequate budgets, extremely demanding assessments for benefits and over-powerful private sector 'care' agencies.

As an example of the need to challenge disablism, Andrew argued that the need to address power dynamics means that one must go beyond market discourse to explore other metrics and perspectives on quality and effectiveness in 'care'. This point is used to inform an argument that distinguishes cost and effectiveness:

"So disabled people, if they are one of the most disempowered groups, and I think they probably are, then they're going to fare worst and lo and behold we obviously hear loads about benefit cuts and entitlement cuts and all sorts of things like that, and clearly without money, without resources, it's pretty difficult to make much headway if you're looking to live independently and to do something different. For some there needs to be an acceptance that cost and effectiveness are two different things. Something that is cheap may be cheap but it inevitably will not be as effective as something that might cost just a tiny bit more but will deliver three times as much benefit."

For Andrew, to place effectiveness above cost would entail a radical restructuring of procurement and a measurement of effectiveness by other means. One barrier to this occurring is that personalisation neglects any notion of structural disablism beyond individual acts of discrimination. To value DPOs on criteria other than cost would require greater recognition of disablism and the use of DPOs as a defence against it. This could help with the conditions facing DPOs that were recognised in the previous chapter, but the personalisation narrative has seldom focused upon this need.

## The relation of personalisation to DPOs

It is significant that policy associated with personalisation has had little to say on the issue of disempowerment or the vehicle of DPOs as a means to address it. In this light Barnes (2008) warns that the influential early proponent of personalisation, Leadbeater (2004), is dismissive of collective activity such as the challenge put forward by the social model of disability to the understanding of disability as an individual phenomenon. She warns that 'without collective action neither the political analysis nor the interpersonal support necessary for such transformations would have been achieved' (Barnes, 2008: 154). In this sense Barnes observes a difference between personalisation proponents and those activists who 'understand very well that it is not just about 'making it personal' (ibid: 155). In tandem with changes to how services are delivered is a need for collective action that could 'realise human rights in conditions of inequality and vulnerability' (ibid: 155). This is a key point in that personalisation is blind to economic, health or social inequalities (Stevens *et al*, 2011; Ferguson, 2007), and contains little in the way of a vision of positive freedoms or support for organisations that would seek to bring it about and overcome enforced individualism (Dodd, 2013).

There is a tight relationship between the negative conditions facing DPOs identified in the previous chapter and a lack in the personalisation narrative of an analysis of disempowerment and the need for practices of anti-disablement. DPOs have a crucial role to play as sites for opposition to disablism led by disabled people and embodying their right to self-determination. Given the challenges of isolation of individual disabled people and of a crudely individualistic discourse, DPOs have a vital role to play as 'collective bridges' between disabled people, ensuring that they can collectively articulate a vision of a changed society necessary for the achievement of positive freedoms, and collectively challenge disabling social relations (Dodd, 2013). Roulstone and Morgan (2009) share an appreciation of the value of DPOs in a climate of enforced individualism, noting the important issue of how such organisations, rooted in ideas of collective organisation, can fit into the landscape created by personalisation. An aspect of the potential of DPOs is that they could potentially link individual control with collective identity 'advancing new ways of viewing disability,

and one could argue new sites of solidarity' (ibid: 338). Boxall *et al* (2009) also argue for collective user-involvement, identifying the role that CILs can have in increasing the accountability of providers and improving the protection of users of individualised funding mechanisms. They suggest that funding and service brokerage should be removed from local councils and placed with local organisations, including 'existing centres of independent living and disabled people's organisations instrumental in the original development of DP schemes' (ibid: 511).

As we have seen in chapters 2 and 5, DPOs, as agents of social change, are seen as receiving too little support in a competitive procurement environment. For Andrew, the advantages of DPOs and the lack of recognition of their contribution meant that the procurement framework should be adapted to take account of disabled people's disempowerment within society:

"[Y]ou don't treat everyone fairly by treating them the same, procurement forces everything to be treated the same, and inevitably it always comes down to prices and stuff like that, which is an issue which wants to provide quality and a good outcome as well, rather than just making a bit of money. But there's no doubt, and I think this is accepted outside of our movement as well, that the procurement environment we have favours big organisations and effectively discriminates against smaller organisations, simply because bigger organisations have got a commercial advantage in being able to bid, and having the human resources to put together nice sounding tenders, and we don't have that resource... if we're talking about agents of social change, which I think we are, then we should be creating environments where good ideas, innovative ideas come from small groups of people who want to change the world."

Failure to support the role of DPOs as "agents of social change" reflects an inability to account for differentials in power, or in other words to "treat them the same". Unable to account of structural disempowerment and inequality or the need to articulate a positive vision of an alternative social configuration, personalisation is arguably consistent with what Andrew complains of. Without an understanding of disempowerment, or of the value of DPOs to fight against it, the individualism of personalisation means it endorses a narrow measure of quality based on cost and cannot adequately endorse the role of DPOs as agents of anti-disablement. Without

the articulation of a position against structural disablement and accepting the necessity of cost constraints on individual's autonomy, the focus of personalisation may drift toward the surer ground of anti-paternalist negative freedoms from institutions and the threat of enforced collectivism. This could further threaten DPOs as their role in challenging structural disablement and projecting a positive vision of freedom is further undermined.

Implemented in a neoliberal context that is likely to amplify rather than ameliorate its excesses, the danger is of personalisation supporting a situation characterised for many by isolation and loss of participation. Participants often seemed to invoke collectivism as a quality missing in current policy. An identification of an absence of collectivism implies a perception of excessive individualism. An excess of individualism is connected to the challenge of isolation in that isolation can be seen as representing the worst aspects of individualism, and the absence of the means to realise the positive aspects of individualism such as self-actualisation. An excess of individualism is also arguably connected to the challenge facing DPOs, in that an absence of collectivism means the function of DPOs as 'collective bridges' is not valued.

DPOs could be a force that corrects the enforced individualism within which personalisation is implicated. DPOs would be crucial to a counter-narrative that would take account of social oppression and the poverty of solely individual views of empowerment. Collective spaces such as DPOs enable individual grievances to be transformed by the knowledge that individual experiences are part of a broader experience of disablement. Such spaces allow the diverse tendencies within disability politics to converge and debate (Barnes and Mercer, 2006).

### **Summary of arguments regarding personalisation**

We have seen how the personalisation narrative lacks a notion of structural disablement, and the need for DPOs as vehicles of anti-disablement. It has also been suggested that personalisation is excessively individualistic, lacking sufficient reference to the collective forces that can cause isolation or the need for DPOs to act as

collectivising bridges to connect holders of individual funding for support. To put these shortcomings of personalisation and its relation to enforced individualism into a wider context, it is interesting that before the introduction of the term 'personalisation', Priestley argued that 'the disabled people's movement has been partially successfully in securing negative rights, it has as yet, made rather less progress in obtaining the positive rights necessary to exercise active and inclusive citizenship' (1999: 213). There has been some progress on positive rights since Priestley wrote as personalisation is, in abstract terms, concerned with the creation of conditions which would allow individuals to personalise their care in order to achieve what they require. Progress has also continued to be made on the matter of negative freedom because personalisation and increased take-up of personal budgets is seen as a further blow to institutions which frequently compromised individual autonomy.

Delving deeper into the issue of positive freedom, beyond a purely abstract view of personalisation, it is evident that the cuts currently affecting personal budgets derail the realisation of positive freedom because the range of choices available to the individual are so limited. At a higher degree of abstraction another problem is that wider positive freedoms entail a vision for a way in which society could be changed for the better to enable individuals or groups to better realise their potential. Personalisation contains little in terms of a positive vision of an alternative society that could address, at a structural level, the inequalities that disrupt realisation of choices. Although personalisation is often depicted as a utopian, positive vision of users freed and empowered, expressed in emotionally resonant, utopian language (Boxall *et al*, 2009; Needham 2011), it actually lacks a vision of a collective political project to bring about a shift that would allow positive freedoms to be realised. In this sense, personalisation stands for nothing other than removing unnecessary restraints on individual freedom and allowing individuals to better exercise their choices.

It will be recalled that interview participants focused upon challenges such as isolation related to cuts to personal budgets, cuts to benefits, and cuts to services they depend upon. These cuts are likely to decrease personalisation by restricting choice. To a limited extent this means that the narrative of personalisation could provide a position from which to critique the cuts. On the other hand, personalisation is not a

framework for empowerment which can allow one to understand and mobilise against aspects of enforced individualism such as the conditions facing DPOs, the structural nature of disablement, or the obstructive ideas which prevent understanding of disempowerment and the requirements for coexistence on the basis of equality. For these reasons and because of the absence of a vision for a changed society, it can be argued that personalisation is unlikely to adequately address positive freedoms, despite its rhetorical commitment to doing so. As a result, negative freedoms from institutional power may perhaps serve as a fall-back justification for the changes promoted as personalisation. In such a case the movement from enforced collectivism to enforced individualism would neatly conceptualise the drift of personalisation from its original goals, as it becomes a narrative that is primarily against 'enforced collectivism' but tacitly justifies enforced individualism. It can therefore serve as a self-limiting agenda for change that limits the imagining of any collective vision beyond the good of increased individual autonomy and choice.

In summary, personalisation is implicated in enforced individualism because by concentrating solely on personalising services to individual needs, it holds the danger of taking the focus away from the social process of disablement and the policies required to overcome it. There are continuities here with earlier developments in disability policy, such as the community care reforms of the 1990s. Priestley observed of these reforms that the formulation of policy almost exclusively around individual needs functions ideologically by 'masking the collective oppression of disabled people' in such a way that 'prevents us from discussing the removal of disabling barriers in the wider social world' (1999: 49). Priestley's point applies well to the present day. Again empowerment is claimed through the telling of stories of empowerment through individually tailored solutions, while many experience drastically worsening levels of isolation and participation. To overturn enforced individualism, it seems that action informed by structural and social analyses of disablism is required.

We saw in the previous chapter how cuts to, and reforms of, support and care along with threats to DPOs formed the dominant and overriding theme in many interviews. The challenge of enforced individualism is multiple but is driven in great part by the removal of funding for support and redistributive benefits. I will turn to this

aspect of the overall conjuncture in concluding chapters. In this chapter and the previous chapter I hope to have laid bare the inadequacy of the ideas driving disability policy and documented some of their effects. In this chapter I have found the ideological limitations of enforced individualism at work in the policy narrative of personalisation. A one-dimensional and impoverished view of empowerment is arguably apparent in the government's focus on the personalisation of social services. By focusing attention on personalising services to individual needs, a divide can be created between improvements in the dynamics of individual support relationships and other forms of empowerment, redistribution and social justice. Disabling barriers are far from exhausted by those tractable through personalisation, and yet this is the language through which government almost exclusively chooses to express the possibilities of empowerment for disabled people. West (2013) offers some empirical evidence in support of this interpretation of personalisation. Her analysis of the practice of social workers within a local authority highlights the ideological potency of personalisation as social workers continue to deploy the narrative to endow their practice with meaning, while they are forced to implement cuts to services and restrict service user's quality of life. In my view this adds weight to my argument that personalisation is implicated in challenges of enforced individualism, and is ill equipped to foster opposition to growing isolation or challenges to DPOs.

## **The Scope of Enforced Individualism**

A possible criticism of the arguments made against personalisation above is that no narrative of reform could by itself exhaust the multifaceted challenges of disempowerment and empowerment. There is truth to this and personalisation has the virtue, as one of many imperfect narratives, of stressing individual empowerment. However, I believe I have shown its congruity with the challenges of enforced individualism. In the politics of disablement, individual support and politics are interpenetrated and an ostensibly empowering narrative such as personalisation has to be considered for how fit it is for the task of overturning enforced individualism.

Before moving on in subsequent chapters to analysis of the positions taken by participants in relation to the challenges of enforced individualism, I will first introduce



some caveats in acknowledgment of the limits of the arguments presented above. In the first instance, it should be noted that, when offering a coherent interpretation of trends on a large scale over a long period, it is of necessity that only the most general tendencies can be drawn out, meaning details that don't correspond to the interpretation can be obscured. Analytically separating enforced individualism from enforced collectivism illuminates shifts in the challenges facing many disabled people, but continuities in sources of oppression can be underplayed in a story that emphasises discontinuity and rupture from one form of oppression to another. Indeed, the risks posed by the desire to control costs and to increase bureaucratic control are older than neoliberalism, let alone enforced individualism.

A related danger is of believing that, if the threat of enforced individualism grows, the threat of enforced collectivism will necessarily become more distant. However, institutionalisation in large scale residential 'care' 'homes, typical of enforced collectivism, remains a reality or a threatened reality for many, and if cost constraints become even greater, re-institutionalisation may be considered as the only 'realistic' option within tight spending limits. Therefore, even negative freedoms from 'enforced collectivism' can be threatened when cost considerations and austerity are allowed to trump all other arguments. The danger of enforced collectivism should not be forgotten even when contemplating the emergence of new challenges. I have tried to avoid any downplaying of this form of oppression by arguing that the threat of enforced collectivism persists and coexists with enforced individualism rather than being replaced by it. Indeed, I have aimed to ground my criticisms in the value base of my participants and their commitment to measures which increase the autonomy and independence of disabled people and erode enforced collectivism. It is important to avoid undermining the very real benefits that can be derived from personal budgets or direct payments. Yet it is questionable if personalisation is the way forward through this difficult territory, because framing empowerment without due attention to structural and collective concerns can undermine the understanding of disablism which is necessary as a complement to the focus on individual needs.

In closing, it can be seen that a shift has occurred from a situation in which enforced collectivism was the dominant form of disablism, in which individual rights

were overlooked, to one of hegemonic neoliberalism in which enforced collectivism coexists with increasingly influential enforced individualism, meaning a limited range of individual rights are the only terms in which the empowerment of disabled people is understood. In the following chapters we will explore the capacity of differing positions taken by activists to orientate themselves to this shifting terrain of disablement.

## Chapter 7: Participants' Strategic Positioning

In the previous chapter I explicated the combination of challenges currently facing disabled people, theorising them as enforced individualism and relating them to personalisation. I now turn to data concerning how participants strategically positioned themselves. In my analysis of participants' contributions regarding political strategy, I analysed the interviews in relation to their views about three key themes. Firstly, almost all participants made reference to the influential social model of disability. Here participants interpreted events in light of the model or offered varying appraisals of the model's use, in the process offering hints at a range of other positions as the model served as a point of differentiation within disability activism. Secondly, participants' contributions tended to fall within more radical or gradualist tendencies. These tendencies were related, but not equivalent to, the third theme concerning the degree to which participants endorsed protest or professional service provision as the appropriate vehicle for opposing disablism. I now turn to the first theme of the social model of disability.

### The Social Model of Disability

Since its formulation in the work of UPIAS (Union of Physical Impaired Against Segregation) (1976) and following its subsequent elaboration and extension in the work of Oliver (1990), the social model of disability has exerted great influence within the British DPM, forming its 'big idea' (Hasler, 1993). Even in the view of one of the most well-known and vocal critics of the model, Tom Shakespeare, it has the virtues that it is 'simple and direct and effective' and 'understandable, memorable and relevant' (2004: 11). Given the prominence of the model within interviews and the movement as a whole, it seemed important to gauge the extent to which participants endorsed it, not least when the challenges of disablism are significant and resources of strategy and critique must be appraised for how well adapted they are for the task at hand. The significance of the model in this sense is double, functioning as a tool through which activists can analyse the barriers to the inclusion of disabled people and

identify disabling social relations, and as a guide to the evaluation of priorities in light of this.

In this section I examine the strategic significance of the social model in participants' accounts. I explore how participants positioned its value as a tool of radicalisation; its use to invert individual models of disability; its role as a point of entry to the movement; the extent of its influence; and the risk of dogmatism in the way in which it can be used. Most activists will not have the time or inclination to read academic texts concerning the social model and will primarily be aware of it as the means by which a powerful inversion in perspective occurs. This was evident as participants described experiences of the shift from viewing intrinsic personal factors as the cause of their problems to viewing social forces as their primary cause and how, in turn, this helped to challenge their understanding of disablement.

Using Roger's account as an example because he exemplifies this view, we can see the politicisation and shift in political consciousness that occurred through exposure to the model:

"I suppose it was the introduction to the social model of disability, turning the whole traditional notion of disability about the individual being broken and how they can be fixed, into a notion that society was set up in a way that didn't include disabled people. So what we needed to do was change society, not change ourselves. I suppose that was a huge thing to get my head around, that it wasn't me as an individual that was wrong, it was society that was wrong, and disabled people coming together; we wanted to change society."

Roger neatly encapsulated the core of the model's power when he said "what we needed to do was change society, not change ourselves". In this phrase he shows how the model can be politicising as individuals turn their attention outward from inner 'deficiencies' toward confrontation of the social forces that exclude them. This implies a commonality of interests with others facing the same forces, meaning it can be politically potent, both as a force for individual politicisation and as a source of collective mobilisation. Of further interest is Roger's comment that "it was a huge thing to get my head around". It can be seen in this remark that, even as a disabled person who would later become a prominent activist, Roger did not easily take to the

inversion in perspective involved in taking on a social approach to disability. This suggests that individual understandings of disability benefit from a deep and ingrained hegemonic domination in which they are viewed as the 'common-sense' approach to disability. As a disabled person, Roger is likely to have been at the intersection of a series of individualised discourses of disability that would have been repeatedly reinforced as the means by which to understand his situation. The "huge thing" to get his "head around" expresses the radical break with, and inversion of, these discourses.

In many cases this perceptual shift had led to participants undergoing an experience of politicisation or consciousness raising. As an example, Rachel described the shift in her views that occurred upon exposure to the model at university:

"One of these guys said to me "stop bleating on, stop worrying about things, there's this thing called the social model" and there's where I learnt that actually it was the barriers that were the problem and that there was a whole new identity and culture I guess."

In the first sentence of this excerpt reference is made to the need to "stop worrying" and the psychological impact of the model is hinted at, as a process by which one turns away from inward looking worries to challenging the macro scale social forces of disablism that may underpin these worries. Of further note is the second sentence in which the model is linked to nothing less than "a whole new identity and culture". Linked in this way to "identity and culture", we see how the model is an entry point to the movement. In analysis of the interview data below I show how the significance of the model endures beyond introduction to the model and the initial politicisation that follows as seasoned campaigners use it as the departure point for differentiation around a number of other key issues.

To further explore the social model in relation to strategic positions taken, we can look at the uses to which the model is put by activists, both as a practical tool and as a theoretical construct for understanding the nature of disablism. As noted in relation to Roger above, the social model is of use as a tool to expose hegemonic and damaging individual understandings of disability that locate the cause of disablism within individuals, with regressive consequences for efforts at tackling disablism at a

structural level. In this context, it may be that the social model continues to have value in exposing the tendency of government policy and rhetoric to frame disability policy in individual models of disability. Arguably this tendency is detectable in the trend, highlighted by Beverley, for highly personal intrusions during assessments for benefit eligibility. In making this criticism, Beverley looked back to the earlier days of the movement, showing how unnecessarily intrusive assessments can be critiqued from a social model perspective:

“One of the things that Vic [Finkelstein] said was that with the social model of disability, by focusing on society, they wanted to move away from this highly intrusive investigation of your own life and your own impairment, and today we’re seeing a lot of that, even with a computer choosing about someone[...] so to switch the focus and to say rather than “lets assess you in small detail to see how much you can work” its “let’s look in all the workplaces and see if they have all the provision for people with whatever impairment”. So the social model is saying let’s look at the businesses and seeing if anyone with an impairment can work there, we’re not looking at each individual and the minute details of their lives. So Vic Finkelstein in this discussion really struck me with this point, because all of this now, there is so much of this hugely intrusive questioning.”

Here Beverley is suggesting the social model and its earliest proponents continue to have relevance for understanding and challenging present day forms of disablism. Using the example of adapting workplaces to make them accessible, she deploys the social model to highlight the possibilities for change at a more general level than the “minute detail” of individual people’s lives. By making this comparison with individual models, Beverley’s use of the social model shows the impoverishment of addressing the exclusion of disabled people through intrusive evaluations of their capabilities. This use of the social model may be important in light of the narrow individualism and even potentially victim-blaming tendencies that characterise the ideological component of enforced individualism, and arguably underpin the isolation and denial of autonomy facing many disabled people.

A complementary point to Beverley’s was made by David who also uses the social model to critique current policy:

“I think over the last twenty years a lot the rhetoric is pretty good around personalisation, but the political classes have re-individualised the problem of disability; it’s kind of our fault for being disabled, ...no social model principles underpinning that.... And one other concern is the recent step by Lord Freud to advocate the bio-psycho-social model when it comes to assessing disabled people and their eligibility for benefits.”

Although David did not specify the means by which disability had been ‘re-individualised’, this contribution is nevertheless revealing in showing the scope of the social model as a frame to interpret the development of policy over the last twenty years. It continues to assert an immediate significance in this account as the support of an alternative model such as the ‘bio-psycho-social’ model is seen as a concern, presumably because it would represent a departure from social approaches to disability and a return to an individual approach. Of further note in the excerpt is the contrast he draws between the praiseworthy rhetoric of personalisation and a negative process of re-individualisation. One might think personalisation is itself a process of individualisation, but in David’s account they are opposed to one another.

Another example of the uses to which the social model was put by participants came from Mary, who, as a disabled activist and retired social worker, felt that the social model was still largely alien to social workers who exercise power over disabled people and are tasked with delivering some of the changes I describe as enforced individualism:

“I was never as convinced that the others [social workers] were as committed to the principles of the social model. I don’t think this is being unfair, but realistically for most social workers, in those working in this field, it’s a job, whereas for myself and the other colleague I mentioned had a bit more of a personal, fundamental motivation here. Those who didn’t work in this field, other social workers, had no idea. And I think even now, some will have heard of, and some will understand, to some extent, the principles of the social model, but I’m not convinced that they’re committed to it. I think it’s quite difficult, unless you’re living it when it becomes an instinctive way of viewing the world, as a social worker, most social workers will say they have clients who need services, and however empowering they want to be, they know that they can’t provide the services their client needs and will therefore retreat into a traditional way of service provision.”

Firstly, we see again an indication of the depth of the shift involved in viewing disability from a social model perspective as Mary comments that it is difficult to fully grasp the inversion involved without the experience of “living it” as a disabled person. Again the social model can be viewed here as an entry point to the movement, ironically forming a barrier to entry to those non-disabled people who, it is said, would struggle to grasp it. This point also arguably reinforces the case that ingrained individual understanding of disability are hard to displace, and confers expertise onto the ‘ordinary’ views of disabled people who are able to view events through the prism of the social model. This position raises serious questions about the role of (non-disabled) social workers in the fight against disablism. If it is accepted that the social model continues to have value in opposition to enforced individualism and disablism in general, and that social workers tend not to fully grasp or practice the model, the task becomes either to work with them to inculcate knowledge of the model, or to consider acting without social workers in any opposition to enforced individualism (Sapey and Pearson, 2004).

From the above examples one gets a sense of the scope and breadth of issues to which activists apply the social model. For instance, Rachel argues that it was the gateway to a “whole new identity and culture”, while David criticises the last twenty years of disability policy as insufficiently informed by “social model principles”. Given this extensive application and the extent of continuing disablism, participants wished to evaluate the use of the model and its apparent dominance. One possible drawback to its dominance is the potential occlusion of other approaches that could be complementary. On this topic, David was atypical in suggesting that there is diversity of approaches that could be considered in the category of ‘the social model’:

“It’s maybe important to talk of social *models*, because, while we all agree that society is a social construct, you can have lots of different perspectives around that. For example, the work of Ayesha Vernon<sup>39</sup>, and her work around identity – different cultural and religious experiences. Or the different ways we view the social

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<sup>39</sup> Vernon, A. (1998) Multiple oppression and the disabled people’s movement. In Shakespeare, T. (ed.) *The Disability Reader: Social Science Perspectives*. London: Cassell.

Vernon, A. (1999) The dialectics of multiple identities and the disabled people’s movement, *Disability & Society*, 14(3): 385-398.



model, for example the Swedish social model which argues from principles and the British social model which is based on a kind of Marxist materialist social struggle approach to viewing society. I think it's important to talk of social models and understand that it's not a fixed entity and different organisations and activists have different views on that".

In this excerpt David groups a number of eclectic approaches under the category of "social models". This could be valuable in that use of the social model in the UK has been criticised for exclusion of experiences of disabled people from minority ethnic backgrounds or of women (Vernon, 1998). The assumption of a singular meaning of the model could exclude the voices of these groups, many of whom are more likely to experience aspects of the threats I have summarised as enforced individualism. Furthermore, a more heterogeneous and pluralist social model could have the advantage of being less likely to be adopted as a dogma, owing to its multiple meanings. On the other hand, much of the potency of the inversion in perspective and challenge to individual models described above could be attributable to the intuitive and singular meaning usually understood as the 'social model'. This tension between unity and diversity in the movement and in the theorisation of disability is a theme I return to in concluding chapters.

More typical than David's eclectic view of "social models" is the unitary and singular meaning of the term. For example, in Roger's account, the scope of the model is almost seen as complete or exhaustive:

"We say that all of our work is influenced by and reflective of the social model of disability which says that the problem is society is not with the individual."

Speaking of a DPO, he says that "all" of their work is influenced by the social model. Given the complexity and variety of work involved in such an organisation, this says a great deal about the variety of ways in which such an apparently simple idea can be applied.

However, if it is applied pervasively and consistently there could be a risk that the social model is used inflexibly or even dogmatically. It may be applied beyond its

reach as it assumed to be applicable to every aspect of the experience of disability, leading to the exclusion of other potentially revealing ideas (this may, of course, be a risk with the application of any idea). Indeed, where participants expressed critical views regarding the social model, it was never to disagree with its central insight, but often to find fault in the ways in which the model was sometimes over-used or applied too dogmatically. It was unclear at times if this was thought to be because the model lent itself too easily to misguided applications, or was merely the fault of rare and over-zealous individuals. When 'Kate' noted the dangers of dogmatic applications of the social model, she linked it to the psychological process that disabled people experience when becoming aware of the model:

“[T]hese days I worry there are people who have adopted the social model as a religion, rather than a tool for understanding stuff, that slightly bothers me...so because when you first come across it and you relate your impairment to it, including myself, there is that thing about a light bulb going off and you re-evaluate your past experience and your experience of discrimination and so on and disadvantage, and it's really liberating and I can see why people think 'god this is really important stuff, I've got to share it with people.”

This suggests that the potency and radical break in perspective described above can itself develop into a flaw if it is translated into the 'zeal of the converted'. It is revealing that Kate herself is clearly aware of the political utility of the model, explaining her own introduction to the model as a "light bulb going off", but also balances this with a worry that it can be adopted as a "religion". This phrase suggested that awareness and adherence to the social model can be used as criteria for inclusion in the movement, while ignorance or disavowal of the model could lead to exclusion. If the social model is "adopted as a religion" in this way it could drive political unity, but at the expense of the inclusion of a wider constituency.

Following this, Kate invokes Oliver's (2004) point that the social model is a tool and not an all-encompassing theory:

“[I]t was only ever designed to be a model, I don't know if you've read Mike Oliver's work, but Mike was very clear this was a way of describing things in a way that social work students could

understand, that's was all it was, and it's a way of putting across an insight that was developed by the Union of the Physically Impaired against Segregation, that what is most keeping people from participating in society is social structures that don't take account of your impairment. Because there was a whole industry built up around disability equality training and explaining the model to people, because some people were very slow to cotton on to it, people got a bit kind of religious about it and there are still people in the movement who say that if you don't say that you uphold the social model and you agree with the social model, somehow you can't be in our team or our gang."

As well as making her point that the model is a tool and that it should not lead to sectarianism within the movement, she also linked this to the institutionalisation of the movement in "disability equality training". To illustrate her view that zealous attachment to the social model could be counter-productive, Kate gave the example of "purists" who insisted upon social model terminology at the expense of political alliance:

"I'm talking about the people who were social model purists. In [X] they had a really good CIL, but the local People First group withdrew from the local CIL because People First talks about 'people with disabilities', that's what they say because they're People First. The Social Model purist would say you talk about disabled people because it's a political category, and the chair of this CIL told off the People First<sup>40</sup> representative for talking about people with disabilities, and you think 'how stupid can you be?', here's someone who's self-defining, who's got a learning disability, who doesn't understand your very nice distinction between the two things you're talking about anyway, and you're telling them off for speaking up in your meeting, you know, how crass can you get, but not surprisingly, the local People First withdrew from the CIL"

Taken in combination with accounts of the radicalising impact of the model, the danger of purism implies a tension between the political utility of the model, and the possibility that some will become overly attached to the model, resulting in division, when alliance is likely needed to effectively oppose disablism. This may particularly be

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<sup>40</sup> People First is 'is an organisation run by and for people with learning difficulties to raise awareness of and campaign for the rights of people with learning difficulties and to support self-advocacy groups across the country' (see <http://peoplefirstltd.com/>).

the case with groups who do not as readily identify with a social model analysis such as people with mental health needs (Anderson *et al*, 2012).

Notwithstanding this criticism, I found that whilst there was generally strong support for the value of the social model, there was little sign of dogmatism. However, in one case a degree of the inflexibility that Kate complains of may have been evident. 'Peter' seemed to assume that he had 'correctly' interpreted the social model, meaning that he could advise on the 'right way' to represent oneself or point out that some long-standing activists do not grasp the implications of the social model fully:

"Every time I raise the social model, people that aren't aware of it can find things offensive, there are organisations we've worked with through the coalition, and if you point out that despite their ethos, they're probably using the wrong terms, or representing themselves the wrong way and not getting the most out of their community, people tend to think you have a personal agenda against them. I'm a bit pedantic when it comes to language anyway, so I do have to be a bit careful. But then again as someone once said to me, if you're not offending those individuals and they don't know the difference then what's the point, because what amazes me is some of these people, disabled people themselves, who have been in the industry longer than I have, they have less of an understanding of what the social model is or what it tends to advocate."

Peter realises that he may cause offence by correcting people's use of terminology, but had clearly weighed this up against the value of spreading what he considers to be valuable principles of the social model. This type of approach could conflict with Kate's concerns regarding "sterile debates about meanings of meanings" that can alienate potential allies.

Of those to raise doubts about the social model, Kate was unusual in endorsing a 'Fabian' belief in the value of incremental, gradual social progress. It was intriguing that the other main voices to criticise the social model came from those participants affiliated to DPAC, who differed from a Fabian approach in supporting a form of disability rights activism that overlapped with anti-capitalist or socialist politics. In the case of an affiliate of DPAC, 'Victor', his revolutionary politics is clear and gives him

reason to question why the social model has not been more closely linked to ‘social transformation’:

“[O]ne of the problems for me with what seems to have happened with the social approach or social model is that, although it feels like it’s always been placed in a Marxist context, and understanding of capitalism and its role in creating disability oppression and discrimination, what’s never been a part of the social model is an explicit linkage to a rejection of a gradualist, reformist change of society, to being absolutely associated with a socialist transformation of society and a revolutionary perspective.”

For Victor, the drawbacks of the model are almost the opposite of Kate’s view. Where Kate worried it could become dogmatic, Victor was concerned that it had become untethered to its historical-materialist roots, proving too flexible and adaptable to a variety of political ends. Later in the interview, however, Victor sought to moderate his opinion, noting that the social model had to be acceptable to a wide enough variety of people to take hold in their consciousness, albeit again ultimately linking it to the need for a revolutionary transformation of society.

“[Y]ou have to be careful about how you put ideas forward because you want them to become generalised and supported by as broad a layer as possible, but it becomes a problem when the social model becomes accepted by government departments like the DOH, when its accepted Life Chances<sup>41</sup>, when at the same time that department it’s part of is involved in deconstructing disability rights, and I think that that is fundamentally a problem and a weakness of that approach in the sense of how it can be used in that way, and I think the problem is that because it has evolved in that way as essentially a reformist idea and not linked to socialist transformation, in effect an idea that could be a revolutionary idea, that points to a truth of discrimination, oppression and social barriers, what it hasn’t pointed to and in some ways has become a barrier to, is that you can only remove those barriers by changing society along socialist lines.”

Although he argues that it needs to become as “generalised” as possible, its mutability had proven to be a weakness as it had evolved into a “reformist” idea that could not

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<sup>41</sup> Cabinet Office - Prime Minister’s Strategy Unit (2005) Improving the life chances of disabled people. London: Prime Minister’s Strategy Unit.

ultimately overcome the most stubborn disabling barriers. It seems at times that he goes further than other participants in criticism of the idea of the social model itself, rather than those who distort it, when he comments that it is “fundamentally a problem and a weakness of that approach” that it can be co-opted by other agendas. On the other hand, he describes it as what “could be a revolutionary idea, that points to a truth of discrimination” suggesting that he may think the blame lies with the reformist political forces for misusing or distorting the model, rather than the nature of the model itself.

Members of DPAC such as Victor are prominent within current protests against the damaging impacts of austerity on disabled people, and in the face of new threats to disabled people, there was some sense among these participants that the social model had been found wanting, perhaps accounting for Victor’s criticisms. In the case of ‘James’ this was clearer as he balanced his experience of the social model’s importance with his view of its limitations:

“It’s been the cornerstone of everything I believe in, and the social model I don’t believe actually goes far enough; it should be a starting point not an end point; it was a model that was created forty years ago now and the disabled movement and the disabled community has moved forward and I don’t believe that we’re still using a model now that is adequate. It could become as inadequate as the medical model is, we need to develop that and move forward as a group and a society [...] There aren’t inadequacies but I just think that it needs to be developed a bit more around the community that we’re living in now, and it’s okay to just say ‘remove the barriers’ but we do need some more work on how to do that as a community really.”

Going as far as to say it had been the “cornerstone” of his beliefs, James found reason to doubt that the model continued to be adequate to the task of undoing disablism. The extent to which the model continues to be adequate to the task of identifying and facilitating mobilisation against disablism is a key question and one I return to in later chapters. Saying that the social model should be a “starting point” and that it needed to be developed suggests he felt it had become static and in need of updating. He was less clear about how this might happen, but stressed that “removing the barriers” was necessary, only questioning how this could occur.

Summarising participant views regarding the social model, we can see that they concerned its value as a tool of radicalisation; its use to invert individual models of disability; its role as a point of entry to the movement; and the extent of its influence and the risk of dogmatism in the way in which it can be used. In the following section of analysis, I develop this analysis further by exploring broader radical and gradualist tendencies within participants' accounts. Concluding this section and referring to discussion in later chapters, it is important to see that the merits of the social model should be weighed against available alternative perspectives. When activists dispense with the social model or supplement it with additional analytical resources, it cannot be assumed that the alternative perspectives used will be more useful or cogent. It was noteworthy that participants did not mention other models or theories or revisions to the social model in gaining insight into disability. Although disability studies has developed a variety of other theoretical approaches to disability in the last twenty years, participants did not draw on them in their accounts. This will be important to recall in concluding chapters when a closer look will be taken at the merits and drawbacks of the social model and those of available alternatives from disability studies.

## **Radical and Gradual Tendencies in the Movement**

In this section I describe and explain the positions taken by participants in relation to activism. In doing so I will explore participant views concerning the relationship of disability to capitalism, the value of single issue political engagement, the need for compromise, and the value of alliances. During my analysis it initially seemed that participants could be grouped into two broad positions, reflecting a bifurcation between what I have called 'radical' and 'gradual' tendencies. These approximated to the classic 'reform or revolution?' division within political movements (Luxemburg, 1999). By this I mean, in the case of the 'radical' tendency, to advocate revolutionary or socialist politics, understanding disability as a consequence of shortcomings of capitalism, and a belief in the need to work with broader groups in society to create change. By 'gradual' I mean the tendency to advocate incremental progress through compromise, accommodating a degree of undesirable change, and prizing what is

perceived to be possible over what is seen as ideal or naïve. I will further discuss the adequacy of descriptions of 'radical' and 'gradual' positions in chapter eight.

The positions of participants might be seen as existing along a continuum of radicalism-gradualism, rather than requiring that one belong exclusively to one camp or the other. At one end of the spectrum, factors particular to disability could be subordinated to a wider critique of the economic model which guides current government policy in general. At the other end of the spectrum, participants expressed critiques of disablism in terms of absolute rights or morality, and economics was attributed little casual power or, alternatively, discussed as if it were a natural or pre-given force, divorced from the wider field of social relations. To substantiate these positions I give some indicative examples of each.

Radical perspectives were typified by affiliates of DPAC. For example, in the following excerpt, Victor makes an economically informed critique of austerity and argues that the DPM has failed to adequately understand and reject the austerity agenda:

“The thing about austerity though is that there’s criticism of the European approach to austerity from people like Krugman<sup>42</sup> who agree with the reduction in the welfare state but they don’t agree with the contraction of the economies, and they argue for more stimulus. Now in the disabled people’s movement we’ve not even argued for more stimulus or put forward the argument that if you meet people’s rights and give low paid people jobs, they’re going to spend all their money and encourage growth, they’re not just going to sit on it like rich people who don’t need to spend it and can put it offshore. So we haven’t even got involved in debates like that.”

Here Victor is linking the fate of disabled people under austerity to that of the economy in general, arguing that higher spending on disabled people’s needs would inject demand into the economy and boost growth. The relevance to a dichotomy of radical-gradualism is that disablism is placed within an economic framework, and as we see below, in Victor’s case a critique of capitalism itself. Interviewees such as Victor

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<sup>42</sup> Krugman, P. (2013) *End This Depression Now*. New York: W. W. Norton & Company.



linked the failure to grasp the economic issues and their relation to disablism to the limitation of parts of the movement that view the problem of disablism as single issue:

“[T]he problem then is that you have a whole generation of disabled people in Britain who....come to a radical idea through a single issue; they obviously argue for the removal of discrimination, the removal of social barriers, right to independent living, and to be part of mainstream society, but ultimately what prevents that absolute ability to take part in mainstream society is the way that society is structured. In a capitalist society that is structured along class lines, along inequality, so in effect whilst there have been improvements to disabled people’s access to public buildings and to education for the more intellectual of us, the social position of disabled people has not fundamentally altered in the last twenty five years, and you could argue has even got worse.”

Victor’s position here is that disablism cannot be overcome without reference to the bigger picture of a society structured “along class lines”. He is convinced that the “social position” of disabled people has not improved owing to a failure to address the class based nature of our society.

Without necessarily sharing a support of anti-capitalist politics, there was some support among other participants for a critique of single issue engagement. For example, Roger also regretted the tendency for more superficial engagement, although for him ‘single issue’ had an even more restricted definition as engagement with one aspect of the disability movement’s struggle at a time:

“Well I suppose the whole political scene has changed a lot in the last twenty years, not just in the disabled people’s movement.... I think people now tend not to get involved in political organisations, they tend to get involved in individual campaigns, and that’s what we find now, whereas people in the past would be involved in an organisation and go from campaign to campaign and support that organisation in their work. People tend to cherry pick now and when we recruit, or try and tell people that this is an issue that’s going to affect you. Whether its ILF being cut or whether its changes to incapacity benefit or DLA, or the medical assessment that’s being carried out by ATOS, it’s very much an individual basis now and I suppose it’s a very individualist society. I still believe sort of in that collective identity and collective voice, but that’s less recognised now I think.”

In this excerpt, Roger links engagement that is limited to issues that directly affect the individual disabled person to wider shifts in society toward a more individualistic culture in which common interests are asserted less often. For those of a similar 'radical' view to Victor, the relation of disablism to class dynamics suggest a commonality of interests with others to suffer from class division. From this perspective, the particular struggle of disabled people must be joined with the struggle of others, which is difficult if disabled people cannot coalesce into a unified movement of their own. In the case of participants involved with DPAC, a belief in alliance resulted in an endorsement of participation within broad, socialist coalitions with the objective of reversing austerity to the collective benefit of a constituency wider than disabled people alone. Following from this, 'James', also a member of DPAC described coordination with trade unions as becoming more "aware", implying this was a sign of growing maturity and potential as an organisation:

"It's something that DPAC is managing, is becoming a lot more politically aware again getting the public on our side, because it's the old adage 'united we stand, divided we fall' and the more people and organisations we can get supporting us, and us supporting them, that's why I believe the TUC thing is so important, the attitude that we as disabled people must become part of the bigger picture, rather than isolating ourselves and our individual problems"

For James, the need for broad-based coalitions and working with the labour movement followed from the need to gain mass support for the cause of disabled people and against a range of other forms of oppression. He argues that failing to take such an approach can lead to parochial and limiting politics or, in his terms, "isolating ourselves and our individual problems". This latter phrase could be seen as mirroring the isolation that I identified as an aspect of enforced individualism.

Another aspect of radical tendencies was evident in James' account of the importance of cooperation with trade unions:

"[I]t's very important, not just for the disabled movement but more so for the trade union movement to identify the issues around disability and I think that a lot of unions are realising that disabled groups are not segregated, they no longer see us as us and them, I

mean you can become disabled at any time, after all the highest percentage of disabled people are the elderly and if you're lucky we're all going to become old, so we're all going to become less physically able to do things or have less mental capacity to understand that. So we are all basically, it's no longer us and them, its society as a whole that has to take up the issues around the disabled community."

Arguing for the importance of trade unions understanding disability issues, he is arguing for a unity or even identity of purpose with trade unions. For James, this follows from the ubiquity of potential impairment and the need for "society as a whole" to come to grips with the threat of disablism.

At the gradualist end of the spectrum, it was not that cooperation was rejected; more that disability issues were not seen as inextricably linked to class politics or wider constituencies and thus different forms of cooperation were seen as legitimate. In contrast to more radically inclined participants, those involved in professional work within DPOs, tended to be concerned with the immediate problems of those the organisation represented and worked with, rather than political struggles shared with other groups. Therefore, those working in DPOs tended more often to be disposed towards the gradualist tendency. The radical and gradual tendencies are related, but not equivalent to, the degree to which campaigning and protest are valued over the value of service provision. This is hard to demonstrate explicitly through excerpts of interview data, but it was discernible through the omission of topics of protest or campaigning by those invested in service providing organisations. As an illustrative example, when 'Andrew' was asked to comment upon his priorities, he responded in terms of the further development of DPOs and empowerment of individual disabled people:

"[O]ur priorities at the moment apart from keeping going is to work and put in everything we can into creating more DPULOS [Disabled People's User-Led Organisations] and helping more disabled people to become empowered so much that they can see the point of forming user-led organisations or other vehicles that can enable them to live an independent lifestyle of their choice, be that a social enterprise, be that a non-profit making CIC, whatever it might be, so we're putting this much energy into creating more that are like us basically and we think that will be good for the marketplace."

This shows a difference with the 'radical' tendency which considers the highest priority to be involvement in coalitions and in protest. A key difference is the extent to which the roots or origins of disablism are seen to be addressed or if greater stress is put onto immediate gains that can be made for DPOs and disabled people within the terms of the current "marketplace" of care and support. The notion of the "marketplace" or 'market' is itself of significance in that it can signify political allegiance through the extent to which one endorses, rejects or acquiesces to a capitalist market as the framework in which provision of support occurs. This is a crucial point of differentiation between radical and gradualist tendencies.

This is again arguably evident in the case of Liz, who, rather than focusing on addressing the inequities or assumptions built into the economy, accepts it to a degree, commenting:

"You know, whether we like it or not, disability support has to be paid for, and it's a pot of money that can be cut."

On one level this statement is completely uncontroversial, but underlying it appears to be an assumption that expenditure on disabled people is an unrecoverable cost rather than an investment. Within this framework, the task becomes one of appealing on the grounds of a cost-benefit analysis, rather than working through protest to change the terms of the debate.

A similar attitude was expressed by Mary, who again assumed relatively narrow parameters within which the struggle against disablism must unfold:

"We're talking about a country in billions of pounds of deficit and a fairly strong Tory government which says 'we're going to cut welfare'".

Framing the terms of the struggle within the terms of deficit, she seems to accept the importance of this metric, implicitly accepting the necessity of deficit reduction above other objectives. This perspective still allows for a variety of means of achieving deficit reduction such as increasing taxation rather than reducing expenditure on disabled

people, but a 'radical' perspective might differ on the importance of even addressing the deficit in the short to medium term.

Even if radical perspectives might differ from these in their way of viewing these situations, it is notable that even these gradualist views relate the struggles of disabled people to economic fluctuations. In this respect the differences between gradual and radical positions could be quite nuanced, referring to the response to a commonly understood problem. Those from either perspective could not fail to see how the fate of disabled people was linked to the economy. Roger who worked full-time in a DPO and was primarily concerned with how best to run his organisation, explained this point using the example of scapegoating that he sees as accompanying economic downturns:

“Various campaign groups are aware of the scapegoating tendencies that any time we enter an economic crisis or a downturn in the economy, that politicians and the media are looking for someone to blame. You know, yesterday it might have been single parents, today it might be immigrants, and tomorrow it'll be disabled people, and the politicians and the press are sometimes working in tandem and together on this”

Although Roger and others shared with the radical tendency an analysis of the economic origins of current problems, they tended to part ways on the implications of this. For instance, when radicalism might demand no compromises during an attack on disabled people's autonomy and wellbeing, gradualism might insist on the need to compromise on goals of the movement in order to succeed in having others accepted. Where the radical tendency would be less compromising and more oppositional, contributions such as Kate's assumes the necessity of compromise:

“[I]n order to get a broad enough coalition to get your ideas through, you have to compromise on a number of things ... Now every time you do that, you do lose something, so you have to think pragmatically, if you're a Fabian like me, about whether you're losing stuff you'd die in a ditch for or not, and on the whole, it was worth getting what we got, and I think that's partly the influence of a lobbyist is that you have to see which way the wind is shifting and see how far you can push people. You should always try and get a bit

further, but sometimes you have to accept that if you push too far you get people turning off.”

As a self-identified activist, Kate is not pleased to compromise on anything the movement campaigns for, but she considers it important to gauge what is ‘realistic’ and ‘pragmatic’ and what can be compromised upon. This suggests a particular mind-set that takes account of “which way the wind blows”, which can be opposed to a less accommodating and more oppositional approach that could be positioned by those like Kate as naïve and unrealistic. Tactically, for Kate, it was important not to be overly oppositional and to remain palatable to vested interests that had the power to block progress toward greater rights for disabled people. This is apparent in an account she gave of a previous campaign:

“[T]here were some parts of the charitable sector that were just really unhelpful to us, and we had to sort of head them off at the pass as well and also overcome the resistance in local government to what they thought was an outrageous idea, you know ‘how can people with learning difficulties possibly take, how can older people with dementia possibly take charge’ and so we had a lot of work to do on lobbying. I also of course had to keep our own core support happy, because as you’re negotiating through a legislative process, inevitably there are compromises, and there were some people within the movement, who had a very clear idea of what they wanted and that any deviation from that was a betrayal and that we’d go backwards and never get what we wanted, like sort of purism. So there was a lot of stuff about how do you keep your core support on board.”

Here it is suggested that those in the movement with power or influence need to balance the idealism of more radical elements with the ‘art of the possible’ in political lobbying. This endows those to make these judgments with a certain degree of power and leadership, and assumes expertise to judge what constitutes ‘realism’, ‘purism’, ‘pragmatism’ and ‘idealism’. As with the notion of a market of service provision, these terms can serve as important signifiers around which radical and gradualist tendencies attribute differing rendering and value judgments. Use of these terms by participants suggests a conscious awareness of these tendencies and the need to locate themselves

in relation to them, perhaps hoping to distance themselves from accusations of ‘selling out’ or of political naivety.

Having provided some examples of tendencies for radical or gradual approaches, a note of caution should be raised. By drawing out a contrast between radical and gradualist positions, it is important to consider the risk of positing polarised positions that are unreflective of the way in which activists really position their activity. In practice, participants seemed to recognise that different positions may be valuable in different situations. By using the term ‘tendency’ to describe radical and gradualist contributions within interviews, I try to avoid them being seen as fixed, absolute or mutually exclusive positions. They are positions people adopt rather than categories of people, although certain participants were more or less likely to adopt one or another. To view the tendencies as fixed in this way would be misleading as participants would move back and forth between more radical and gradual arguments. To use an example, Rachel described how she could combine what might be termed a gradualist approach with the more radical work of protestors to maximise each other’s impact:

“[W]hat we did at that time was help with a policy voice, so we tried to take what the issues were for DAN [Direct Action Network], not in any formal way, but we used our spare time to when we weren’t doing formal work to try to improve things. So, for example, DAN would say the [.....] building is not accessible; they’d do a protest, and then we’d go in and try to do the development work and develop an access plan with them to try to make the building more accessible[...] It wasn’t anything formalised, and then in our spare time we’d go protest and stuff, but it was difficult when you’d have a vigil outside the council building for someone who had died of neglect and then you were in the council building a couple of days negotiating a contract, it was not an easy path to tread.”

Through this example she warns against a simplistic opposition of these positions and suggests a rich strategic alliance that involves complementary use of skills and tactics. Applying these labels to individuals can be misleading because individuals can make surprising arguments, such as individuals in more ‘gradualist’ professional roles calling for greater protest. On the other hand, in her reference to the difficulty of protesting against and cooperating with her local council, Rachel says it was “not an easy path to tread”, suggesting some tensions between these roles and offering some validation of

the analytic distinction I have created. Arguably offering further validation of the distinction is the fact that Rachel was alone in offering an account like this of combining radicalism and gradualism within a short space of time. The movement between the tendencies and the tensions between them may reflect a deeper structural issue. This issue is one of the need to carry out incremental work required to facilitate independence and dismantle disablism, while balancing this with the risk of working within and endorsing structures of disablism. This leads into the next section concerning the degree to which protest or service provision are seen as the appropriate vehicle for opposing disablism.

## **The Role of Protest and Service Provision within the Movement**

It is possible to see some of the tensions between radicalism and gradualism played out in participants' views about the role of protest and provision of services for disabled people by DPOs. In making their points on this subject, participants referred to an apparent decline in campaigning, and the impact on the activities of the movement of entering into competitive procurement environments and relationships of dependency with local authorities.

Among participants there was a degree of unanimity that there had been a decline in the influence of the campaigning vigour of the movement over recent years and since the high profile work of the Direct Action Network (DAN) in the nineteen nineties. Referring to this period, participants' with a long history in the movement spoke of simultaneous work within campaigning and in CILs as parts of a larger whole of movement activity. In that time there appeared to be a greater unity of purpose between these twin functions within the movement, as greater reference was made to simultaneous work within both. Vera gave an example of her organisation:

“[I]n our day we were one of the biggest disabled people's organisations in the country because we, I mean, it was basically set up because we wanted to campaign, that was for sure, but also, services for disabled people were very very poor in [...], so rather than wait around for other people to set up services, we thought well we'll establish them ourselves.”



This shows a clear unity of campaigning *and* service provision. For reasons I explore below there is a lesser degree of unity now, and this is thought to have resulted in a decline in campaigning. The significance attributed to this did not necessarily correspond to the background and/or role of the participant. For example, those in full time positions within DPOs and not involved with current campaigning were quite likely to complain of the decline in campaigning activity. For example, 'Robert', who worked in a large DPO, said that he had no involvement in protesting on the streets in decades, but recalled that:

"I've heard people say it's [protest] lost its way a little bit, and in a sense I think what really gets things moving is when people are angry about something and it starts to motivate them to direct action. I gave a talk last week and showed a few slides from the nineties of different things that we were involved in that were getting us angry at the time... until the recent lot of welfare reforms came along, there's almost been a bit of apathy around it, but I understand that's really motivating people."

In this contribution, Robert offers a more positive note on the recent upturn in protest related to government policy. In contrast, Beverley was less convinced that an adequate challenge would be offered to the poor conditions faced by many disabled people:

"To me there is an absence. You know who is saying that adults are having to go to bed at seven o'clock<sup>43</sup>, who is saying that? And yet that will be all the disabled people in our estate who are using the agency. I don't think there is enough exposure because there aren't the organisations that were exposing these kind of things."

This view more closely typified those of other participants than the more hopeful view of Robert. For Beverley protest and campaigning is having little impact in her locality as those in her estate cope with a poor service from a private sector care agency. She links this to an absence of organisations that can raise the profile of such issues and finds this an unfortunate comparison to her more radical past in the movement.

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<sup>43</sup> Beverley explained elsewhere that no care agencies serving her area would provide support any later than seven o'clock.

Beverley's views on the level of campaigning seemed to characterise most interviewees who tended to feel that the response to shifting conditions of disablism had been inadequate. Referring directly to current threats, Victor argued that the implications of the decline in campaigning vigour of the movement were prominent and high profile elements of the movement had been found wanting in their response to current threats:

“The shame with the UKDPC is that on the eleventh of May 2011, there's about five thousand disabled people in its supporters... in about '88 in London, that demonstration because it was radical and rights based and it put forward a perspective that a lot of disabled people hadn't heard before it won a lot of hearts and minds. Now in 2011, the UKDPC had an opportunity to win hearts and minds again but in much bigger numbers, and it had an opportunity to call for organisations to join it and affiliate to it, but it didn't do any of that, it had a rally at the beginning but not at the end. So there was an opportunity there for the movement to reinvigorate itself, to refresh itself, but it failed and in effect it largely went through the motions on the day; I think it knew along with the charities that it had to do something because there was a lot of anger with the austerity policies.”

Victor's views here correspond to many in regretting the level of opposition to austerity, but he goes further than other participants in specifically finding fault with the organisational capabilities of the United Kingdom Disabled People's Council (UKDPC). He indicates an untapped potential in this national organisation, noting that it had five thousand supporters in 2011 and contrasts its lack of subsequent success with the 'radical' and 'rights based approach' of the movement in the nineteen eighties, suggesting these qualities are now lacking in the influential UKDPC. This he links to the need for the organisation to be refreshed and reinvigorated, implying that it is an ossified organisation that is incapable of responding to the “anger” of disabled people with “austerity policies”.

This contribution falls towards the 'radical' end of the spectrum of contributions, seeming to profess the need for a rejection of the most prominent parts of the movement because they were perceived to have become too accommodating to

attacks on disabled people's standard of living. However, as noted above, the decline in protest was noted widely in interviews and not just by those of radical views.

A common account of the decline in protest centred on the entry of DPOs into a procurement environment in which they had to compete with other organisations, and even each other, for tenders awarded by councils who can leverage influence over them. In a general sense there was a feeling among some participants that adapting to this environment meant that values of solidarity and collective action could be compromised as organisations orientated themselves to the need to gain contracts to survive. For Mary this had been discernible in her own time working with DPOs since the nineteen eighties:

“Again it's competing. Certainly in the early nineteen nineties there was a feeling of collaboration, but it's now all about competing and it sets organisations against each other.”

This absence of collaboration could damage the possibility of concerted political action arising from the traditional sources of CILs or DPOs. Mary herself made this link, citing how collaboration had given rise to perceived successes of the movement such as direct payments and anti-discrimination legislation in the past:

“Those sorts of organisations, they helped create a coming together of people with a variety of impairments, and the whole lobbying and achieving of anti-discrimination legislation and then direct payments, I think that in the working towards those achievements, there was more cooperation and participation together.”

In these cases we see how the individual empowerment of disabled people had come out of *collective* mobilisation and collaboration. Elsewhere, James related a similar insight into the division that could grow from an exclusive focus on service provision:

“My experience of disabled people and their organisations is they have become very protective of their patches and of what they're doing.”

For James this can be destructive to the pursuit of the goals of the movement, or in his terms:

“Basically getting lots of organisations working together and not to be worrying about the minutiae of detail rather than the overview of the situation.”

The phrase “overview of the situation” implies an overview can be discerned that reveals the common strategic interests of disabled people in general. Taken as a whole, the contributions of Mary and James might suggest that “competing” and an absence of “collaboration” and defensiveness over one’s “patch” could prevent disabled activists involved in these organisations from addressing the broader situation. They were not attacking these people but suggesting that institutionally and structurally a bias had been built-in towards competition and against collaboration in political protest.

A related issue that could serve to divide political protest from service provision is the possibility that local authorities can leverage influence over DPOs when they have financial power over them. As a former employee of such an organisation, James expressed this in the language of “control” being lost over the organisation:

“[W]hen it stays political it’s much easier for disabled people to keep control of it, but once it becomes service led, because we’re then talking about service level agreements, we’re talking about where they’ll get their funding from, and I know that the one I worked with, disabled people lost control of the situation because the people who were giving the finance were setting down far too many stipulations around what they wanted, rather than disabled people, so therefore disabled people and the disabled community lost control of it, and once that happens it becomes a puppet of the local authority and able-bodied people....the local authority saw it as something they could control for their benefit rather than the benefit of the community, and the local social services wanted to have far too much control over it and its policies and they felt because they held the purse strings they could dictate the policies of the organisation, and once that happened I decided I could no longer be involved and had to leave the organisation.”

Initially James describes organisations that stay ‘political’ as easier for disabled people to retain control over. This circumscribes a fairly narrow definition of ‘political’ as other than service provision, presumably referring to direct action, campaigning and protest. Other disabled people might argue that service provision by and for disabled

people and securing disabled people's rights in practice is a form of political practice, although it involves difficult relationships that have to be negotiated with local authorities. Contrasting being "political" with being "service-led" James clearly felt the price paid for gaining financial support were too great. Whether other activists accept this or not, there is clearly a difficult balancing act to be drawn between preserving autonomy and protest and having a presence in the provision of services to disabled people.

This influence of local authorities over DPOs was referred to in other interviews. Rachel gave some insight into the power dynamics at work. In her contributions it seemed as if the relationship between DPOs and local authorities could lead to a strategic position of 'forced gradualism' as the functions of DPOs can be shaped by their relations with their funders:

"I would say most of the ULOs and CILs throughout the country, more than fifty per cent of their income comes from one local authority or one health authority, and that's a huge risk because the levels of pressure that the local authority can bear on you; to tell you not to campaign; to deliver a bit of a service that you really don't want to deliver, because they need that met; or to not have a part of a service that you think is really important because they fund you, is really difficult."

Using her knowledge of the national scene, Rachel shows that this is a common issue, and is likely to be a consideration in the strategic positions taken by those in many DPOs. It seems likely that whilst local authorities may not directly interfere, the perceived preferences of the local authorities indirectly influence the behaviour of DPOs<sup>44</sup>. Again this is a matter of institutional constraints and not a criticism of DPOs, who, as Rachel points out, may "need" the safety net of funding from a local authority to survive.

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<sup>44</sup> For a more extensive discussion of the constraints on political activity of DPOs, and a discussion of the extent to which they engage in direct action and protest, see Barnes and Mercer (2006). In their research it was found that most DPOs 'regarded political campaigning as central to their aims and objectives although this was interpreted in different ways' (2006: 156), as some supported proactive campaigning and others a 'behind the scenes' approach.

This dynamic interacts with the effects of austerity as the requirements for funding become more tightly constrained and only the core functions of DPOs, if anything, are likely to be supported by local authorities. This was apparent in Mary's contribution of when she explained how the scope of local lobbying by the CIL had been limited:

"A: You have to be very careful when you're lobbying, so for example the CIL locally will lobby but only on direct issues such as service provision issues. So there was an issue two or three years ago when the local council just messed up service provision in a huge way and the CIL were quite active in lobbying against that, and helped to achieve a positive outcome,

Q: So that would now be prohibited?

A: Yeah by terms and conditions, for example if funding is given to support an organisation like a CIL, which is tied usually to providing services, if any political activity is to happen then there needs to be a source of funding which is separate from local authority or government funding."

Being 'careful' in this account might be read uncharitably as being quietist or being silenced. She explains how recent changes mean that effective lobbying is less tolerated by governmental funders. Such functions could be viewed as entirely legitimate given that disabled people are disempowered in many ways. Mary would seem to support such a reading as she notes that a "positive outcome" of prior lobbying would no longer be possible, as protest is limited by the "terms and conditions" stipulated by funders.

Among contributions at the gradualist end of the spectrum, shifts away from protest and toward a greater inclination to professional involvement in service provision and consultation was, in a small number of cases, framed in more positive terms. This approach assumed that if one ignored the need for efficient and effective service provision, the source of DPOs vitality could evaporate. Rachel put it thus:

"[W]e'd had UK Disabled People's Council, BCODP as it was then, but you'd never really got a chance to sit and look at business and look at what worked and what didn't in terms of service delivery [...] I saw

quite a lot of ULOs and CILs. At the time there were the DIALS, the disability information advice lines which have since folded, the CILS and the ULOS, and out of all of those the ULOs were the most flexible and the most locally based and fastest in responding to new things [...] they were generally smaller and more nimble on their feet and a bit more efficient.”

In this contribution, Rachel is seen to prize ‘efficiency’, ‘flexibility’ and ‘responsiveness’. These terms are synonymous with success in a competitive market. In the previous chapter, we encountered the controversial nature of ULOs, and in this passage they are seen as a progression from DIALS and CILs due to their capability to act flexibly and efficiently. Thus the more overtly political CILs are seen as more backward, inflexible and inefficient by implication. This did not seem to be consistent with everything that Rachel argued, and this variation in her account might hint at how individuals adopt differing positions in order for their organisation to survive, and in their capacity as activists, that they retain integrity and political conviction.

In a contribution from David a similar point is made to Rachel’s in which changes from older organisations and a decline in overt protest might be seen as a growth in maturity and influence as DPOs gain a greater voice in policy formation:

“Now, I’d say the difference between Derbyshire Centre for Independent Living<sup>45</sup> and the current centres of independent living is that in the seventies and eighties disabled people didn’t have a seat at their own policy making table. Now you could argue that the effectiveness of government’s engagement with disabled people over the last twenty or thirty years is that slowly but surely the disabled people’s movement has advocated taking notice of disabled people when creating policies that focus on disabled people. And I would argue a watershed moment was the previous government’s life chances report, the prime minister’s strategy unit Life Chances

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<sup>45</sup> Derbyshire Centre for Integrated Living (DCIL) pioneered a distinctive version of ‘integrated living’ in which a ‘personal support scheme’ employed personal support workers on behalf of the end user, while the end user retained control over who supported them. DCIL worked on the basis that Independence required the fulfilment of seven needs and could be best achieved through a close level of cooperation with local government. Priestley (1999) provides a thorough analysis of the work of DCIL.

report<sup>46</sup> on disabled people. It sought to have a Centre for Independent Living in each local authority, I think by 2015.”

Other participants might find reason to object to the suggestion that the influence of disabled people in policy formulation had grown, as the role of DPOs in policy formation appears more recently to have gone into decline. David may have been more aware of this than it first appears as he notes that a report published in 2005 (the Life Chances report) may have been a “watershed” moment, perhaps suggesting a decline had set in more recently. If the price of apparent inclusion in policy formation was the decline of organisations with the political values of Derbyshire CIL, the question might be raised by others whether the influence of disabled people had really grown, or if co-option had occurred coupled with a loss of campaigning vigour.

Elsewhere, David appeared more ambivalent on these issues, recognising that campaigning and protest would still be necessary in some circumstances, but arguing this needed to be married to ‘pragmatism’:

“The reason that I got involved with [.....] is because it was idealistic in terms of advocating the social model but it has a pragmatic edge to it, so it campaigns for disabled people at a theoretical level and seeks to influence government policy.... the great thing about [.....] is that its idealistic; it does campaign for change and breaking down barriers and stuff. Buts it’s politically pragmatic as well, which I like about it, it’s not just a campaigning organisation, it has the wherewithal to do things like write policy documents to encourage government thinking. So it doesn’t just campaign, its constructive in its criticism.”

Here David assumes that campaigning is “idealistic” or unconstructive and distances it from “influencing government policy”, but in contrast to his previous contribution appears to offer greater recognition of the need for protest as well. His argument is that the role of protest and provision cannot be resolved through an either/or solution. This more closely typified most participant thoughts regarding the role of protest and provision, in that answers would often be characterised by a call for a

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<sup>46</sup> Cabinet Office - Prime Minister’s Strategy Unit (2005) Improving the life chances of disabled people. London: Prime Minister’s Strategy Unit.



balance between the two forms of activity. Another example of such an approach came from Vera who pointed out that it is precisely the threats I've described as enforced individualism that make the type of civic engagement involved in protest more difficult:

"If you only protest on the streets and make so much bother, you know, I can see an argument for that, [inaudible] where you make government's life really difficult and they're forced to have a re-think. Or there's the other kind of view where you need to do the two things, you know, cos I think, this is my view, that it's quite hard for disabled people to protest on the streets anyway in large numbers, simply because of the stuff that we need to protest about, so people are living in poverty and not getting their support needs met, you're certainly not going to be able to get out there and protest on the streets, and that's why I think we need to do the two things. Anyway, it's the same as used to go on you know, cos when we were campaigning of the right to direct payments in the eighties and nineties, the Disability Action Network, DAN, always thought that the British Council of Disabled People was always too accommodating and cosying up to often to government, so they were the militants, but you get that with any movement, any change movement."

Here Vera recognises some of the trade-offs between protest and professional work and hints at the dilemma regarding the trade-offs between them. An example of such a dilemma came about in Roger's account when he expressed his ambivalence regarding the need to take on work in order to secure the future of his organisation when it might not always correspond to the campaigning ideals that motivate him and his organisation:

"I'm not sure what added value a disabled people's organisation brings to running a payroll service for example, so in some ways that's a distraction and that's not why I got involved with the disabled people's movement. So I think there's more pressure on us ... to bid for contracts, and as our funding pots are shrinking, sometimes you find yourself applying for funding and you think to yourself 'well does this meet the aims of our organisation just because it enables us to survive another year? Is it fulfilling our aims to enable disabled people to access mainstream services or does it change society to make it more inclusive to disabled people, does it meet our central goals?' So sometimes you think to yourself 'are we simply doing things to maintain ourselves in jobs', and that's not

what we're here to do...It's a difficult situation; do we say 'no this is not what we're about, we're about campaigning for choice and control and change', or do we say 'if we don't do it then the disability charities will'? It's a difficult one and I'm not sure I've got the answer."

As part of a movement as a whole that has gained influence within service provision, this type of dilemma is likely to be common. It might be expressed as the need to balance securing sufficient funding to survive with not losing sight of overriding goals and political conviction in the process.

We saw above that there was a degree of unanimity in the view that protest had declined. Even among those with little involvement in protest, it was notable that they generally felt this development was undesirable and that a balance or division of labour needed to be maintained between these functions. For instance, Robert, working full time job in a DPO, felt that more protest would be welcome, even considering a return to protest for himself:

"Yeah I mean there have been some successes; there's been more achieved through the kind of sit down and get involved and work and in partnership rather than manning the barricades stuff, but I think sometimes you need both. I'm getting to an age now where I'm more likely to be sitting down and working in partnership than manning the barricades, but you never know."

To again make use of a contribution from Andrew, who had previously offered a service-based and gradualist contribution, it was notable that he sensed that a radical paradigm shift was required in the way that disabled people were viewed.

"The whole reason that CILs came into being in the first place is to challenge the place of disabled people in society, and that debate is still largely unaddressed. We're still, despite the rhetoric, living in a world where disabled people are second or even third class citizens, who cannot expect the same opportunity that everyone else just takes for granted. And so we need a social debate which says 'what do disabled people realistically need, support that other people might not need, what do we want those people to enjoy in life?'

It is hard to see how such a radical shift in how disabled people are viewed would come about purely through patient dialogue and cooperation with the government. Pointing out that CILs came into being to “challenge the place of disabled people in society” he recalls the politicised origins of the movement and warns against becoming too gradualist or technocratic. Tellingly, he joins this to the fortunes of DPOs, stating that a fundamental debate is required to ensure adequate funding is provided to DPOs to address disabling barriers. Overall there was a level of consensus that protest was welcome even though not surprisingly, radical contributions tended to attribute relatively greater weight to it.

## Summary

Within this chapter I have analysed participants’ strategic positioning in relation to three themes: the social model of disability; radical and gradual tendencies; and the priority given to work in service provision or protest. We saw how participants emphasised the potency of the social model, noting how it could serve as an entry point to the movement and could be deployed effectively to reverse individual understanding of disability. This potency may be part of why it was felt by some that the model could be employed dogmatically and applied to too wide a range of issues. In the case of the second theme, examples were given to show how participants moved in and out of radical and gradual positions. It was noted that it would be an error to over-stress the dichotomous nature of this split, and that impediments could serve to prevent those in professional positions from engaging in protest. These impediments were linked to the final theme of the tension between professional and protest. Here a dilemma presented itself concerning the degree to which participating within services could endorse structures of disablism. On the other hand, a position of pure protest could surrender important areas of disabled people’s lives to other actors.

Participant contributions that I have grouped as pertaining to the social model of disability, gradual/radical tendencies and provision/protest priorities, exhibited careful differentiation of positions and the balancing of competing objectives. An important punctuation point in many varied accounts was a sense that things could

not and should not continue on present trends. In the case of the social model, some long-term advocates felt that it was beginning to be found wanting. In the case of radical tendencies there was a feeling among some that disabled people could not ignore social class and the bigger picture, as economics seemed to drive increasing disablism. Even in the more gradual tendency there was recognition that economic factors were tightly restricting disabled people's life chances. In the case of service provision there was widespread agreement that greater protest would be welcome to stem the tide of unwelcome policy changes. In the previous chapter we saw how threats to disabled people and their organisation could be viewed in the context of unhelpful ideological preconceptions and the orthodoxy of neoliberalism. In concluding chapters I will explore in greater depth the relationship between the particular struggle of disabled people and the background political factors that I argue constrain the possibilities for change for the DPM. In the next chapter I further analyse the positions examined in this chapter by using Nancy Fraser's theoretical framework.

## **Chapter 8: The Merit of Nancy Fraser's Analysis to Theorising Anti-Disablism**

This chapter develops the analysis carried out in the previous chapter by building up a greater understanding of the positions taken in response to the challenges I have theorised as enforced individualism. I begin this process by restating the challenges of enforced individualism. I then go on to present Nancy Fraser's (1995; Fraser and Honneth, 2003) analysis of injustice and resistance in order to apply it to my analysis of participant positions. First, I apply Fraser's analysis to the categories of 'radicalism' and 'gradualism' that I used in chapter seven to analyse the political positions adopted by participants. In the second application of Fraser's analysis, I argue that her notion of 'bivalent' political struggle is a fitting theorisation of participants struggle against economic and cultural disablism. Despite the relevance of Fraser's analysis, I examine the limitations of applying her preferred political strategy to anti-disablism. Drawing on the work of Vehmas and Watson (2014), I highlight ways in which the requirements of anti-disablism defy Fraser's preferred political strategy. This leads to an analysis that positions the independent living approach as an appropriate response to the bivalent nature of the cultural and economic struggle against disablism.

### **Summary of the Challenges of Enforced Individualism**

Before I begin to further theorise the positions taken by participants, it is helpful to restate the conclusions from chapter six concerning the current challenges of disablism. It was argued that the current challenges to disabled people could be theorised through the notion of enforced individualism. This encapsulated the tripartite nature of challenges including: the isolation of individual disabled people; problematic conditions for DPOs; and obstructive ideology. The framework provided by the dynamic between enforced collectivism and enforced individualism was found to be of further use in data analysis. This is because the historical movement between enforced collectivism and enforced individualism provides a fruitful means of thinking about the prevalence of differing forms of disempowerment and the forces which

shape their emergence. This analysis informs the theorisation of resistance and activism that follows in this chapter.

Within the theorisation of enforced individualism in chapter six I analysed the limiting ideology that underpinned the challenges of disablism. I claimed that the arguments of disabled people for the social model of disability and the independent living approach had been incompletely realised, in part because of the way they had been filtered through the prism of predominant ideology. This meant some principles of the movement had been formally accepted, such as arguments for autonomy, self-determination and negative rights from coercion by the state. However, this had been easier than gaining the redistribution of power and resources required for positive freedoms. This uneven progress was illustrated through an analysis of the personalisation narrative. It was argued that personalisation, emblematic of dominant policy notions of empowerment, lacked an analysis of structural disablism and the impact of power and inequality on autonomy and participation. I went on to argue that focusing attention solely on personalising services to individual needs can divorce individual support relationships from other vitally important forms of empowerment, such as redistribution and social justice.

The next section further theorises the positions taken by participants in relation to the challenges of disablism. By applying Fraser's analytical framework, the challenges of disablism, and the range of responses to it, are further clarified. Before I apply Fraser's analysis to the positions I referred to as radicalism and gradualism, or apply her notion of 'bivalency' to anti-disablism, I must first present the pertinent aspects of her analysis.

### **Fraser's Analysis of Injustice and Resistance**

Fraser's (1995; Fraser and Honneth, 2003) analysis essentially involves two fundamental and irreducible forms of injustice and two modes of resistance. Of the two forms of injustice, one concerns cultural injustice or misrecognition, and the other economic injustice, or maldistribution. Of the two fundamental forms of resistance discussed by Fraser, one involves 'affirmative' strategies that tacitly endorse structures

and seek adjustments within them, and the other, 'transformative' strategies that seek to fundamentally alter underlying structures.

Central to Fraser's theory of justice and resistance is the principle of parity of participation. Parity of participation refers to 'social arrangements that permit all (adult) members of society to interact with one another as peers' (Fraser and Honneth, 2003: 36). There are two principle preconditions required for parity of participation and failure to meet either of them creates injustice. One is the 'intersubjective condition' of participatory parity (ibid). Violations of this condition are 'status injustices', the paradigmatic example of which is misrecognition. Drawing on Honneth (1995; Fraser and Honneth, 2003), Fraser argues that recognition denotes 'intersubjective regard' through which one's status is increased or decreased in cultural value. Injustices of misrecognition are rooted in 'social patterns of representation, interpretation and communication' (Fraser and Honneth, 2003: 13) operating through mass culture and inter-personal communication. Recognition 'corresponds to the status order of society' (ibid: 50) in which some individuals are deemed worthy of greater esteem and respect than others. Institutionalised patterns of misrecognition deny individuals the cultural value that they should enjoy by perpetuating norms that depreciate some categories of people and undermine their treatment as full and equal participants in society.

The other primary precondition for parity of participation is the 'objective condition', meaning the 'distribution of material resources [...] to ensure participants independence and voice' (ibid: 36). Maldistributive injustice is driven by economic structures that systematically advantage some groups over others. As with injustices of cultural misrecognition, processes of maldistribution block parity of participation among society's members. Socio-economic structures of disadvantage are rooted in the class basis of society. Examples of maldistribution include exploitation, meaning the extraction of surplus value as a worker's labour is used for the profit of others. Another example is economic marginalisation, referring to the prevention of participation in certain forms of labour, or participation in any form of labour. Fraser also refers to the example of deprivation, meaning the denial of the basic means of subsistence required for a reasonable standard of living.

Fraser offers a way of distinguishing cultural and economic forms of injustice by noting the differing collective subjects who face each form of injustice. In the case of redistribution, the subject of injustice is 'defined economically by a distinctive relation to the market or means of production' (ibid: 14). Fraser is careful to explain that this form of injustice would not only involve the classic case of the working class, but also other groups that can be economically defined as a pool of labour for menial work or, or an underclass who are excluded from work entirely. This latter description could accurately describe the position of disabled people, who are typically excluded from employment (Wolff and De-Shalit, 2007). By contrast to the economic classes who are the collective subjects of maldistribution, the collective subjects of misrecognition are conceived by Fraser as 'status groups', who face injustice as the result of 'relations of recognition'. They are 'distinguished by the lesser respect, esteem and prestige they enjoy relative to other groups in society' (Fraser and Honneth, 2003: 14). This could also accurately describe the situation of many disabled people (Tyler, 2013).

When these subjects of injustice seek remedies for either maldistribution or misrecognition, Fraser identifies two principle routes available for social change: 'transformation' and 'affirmation'. Affirmative remedies for injustice 'aim at correcting inequitable outcomes of social arrangements without disturbing the underlying framework that generates them' (1995: 82). Transformative remedies 'aim at correcting inequitable outcomes by restructuring the underlying generative framework' (ibid: 82). The distinction between affirmative and transformative remedies to injustice is combined with Fraser's initial dichotomy between injustices of misrecognition and maldistribution. In the case of misrecognition, affirmative remedies to injustice would be typified by 'mainstream multiculturalism' in which unjustly devalued group identities are revalued and diversity of identity is celebrated. By contrast, transformational remedies to misrecognition would redress injustice not by revaluing existing identities but by changing the 'underlying cultural-valuational structure' (ibid: 83). By changing the underlying structure, transformative remedies of this sort have the effect of destabilising identities and differentiations and raising the status of disrespected groups. This would have broader affects, altering the sense of



affiliation and self of all members of society. Fraser calls this transformative politics of recognition 'deconstruction' (ibid).

Affirmative remedies for economic injustice would leave the underlying political-economic order intact but seek to shift the allocation of resources to a more equal level. In Fraser's terms, such approaches 'raise the consumption share of economically disadvantaged groups without restructuring the system of production' (1995: 84). In contrast, transformative remedies to economic injustice involve fundamentally shifting the relations of production, the social division of labour, or the structures of ownership of economic resources. Characterised by Fraser as 'socialism', this would not only shift the allocations of resources to particular individuals or groups, but also alter the economic conditions of existence for all of society.

Fraser does not merely describe these differing permutations of injustice and strategies of resistance, but assesses their mutual compatibility and coherence. She concludes that the optimal strategy of resistance for groups subjected to economic and cultural injustice is one that combines a transformative politics of both recognition and redistribution. In Fraser's terms, this amounts to an endorsement of deconstruction and socialism.

Fraser's endorsement of a transformative politics of deconstruction and socialism are a result of her view that affirmative remedies for injustice can be counter-productive, and that combining forms of resistance can be self-defeating. To illustrate this, Fraser uses the example of affirmative remedies for economic injustice typified by wealth transfers such as 'social-insurance programmes' for the employed, or means tested 'public assistance programmes' for the unemployed. Rather than diminishing or abolishing class differentiation, Fraser argues these affirmative remedies 'shape and support' class differentiation because 'their general effect is to shift the attention from the class division between workers and capitalists to the divisions between employed and non-employed' (1995: 85). This is problematic as deeper structures are left untouched necessitating surface transfers of wealth again and again, marking the 'most disadvantaged class as inherently deficient and insatiable, as always needing more and more' (ibid). Such a process has an unintended

effect as the groups in receipt of redistributive efforts are increasingly differentiated from the rest of the population, appearing, through repeated wealth transfers, as if they are 'the recipient of special treatment and largesse' (ibid). In this way, Fraser argues that an affirmative strategy of redistribution can also generate injustices of misrecognition through the differentiating effect they have upon those in receipt of benefits. Although the intentions of such an approach are underpinned by a universalist recognition of the equal worth of all, it can generate a stigmatising process which contradicts universalism in the sphere of recognition (ibid).

Fraser argues that transformative remedies for maldistribution are preferable because they tend to reduce class differentiation and stigmatisation. As examples of transformative, socialist remedies for maldistribution, Fraser cites 'universalist social-welfare programmes, steeply progressive taxation, macroeconomic policies aimed at creating full employment, a large non—market public sector, significant public and/or collective ownership , and democratic decision making about basic socioeconomic priorities' (Fraser, 1995: 85). Such measures tend to sever the link between employment and the share of consumption one benefits from, and therefore do not stigmatise the subjects of injustice in the same way as affirmative remedies.

Fraser also applies this insight to the sphere of recognition arguing that transformative strategies tend to diminish or abolish the boundaries between groups by transforming the structures that create divisions. To illustrate her case Fraser draws on the example of the struggle against homophobia and heterosexism. She identifies 'gay-identity politics' as an affirmative politics of recognition that seeks to revalue gay and lesbian identity. As an example of a transformative politics of recognition she identifies 'queer theory', which has as its goal 'not to solidify gay identity, but to deconstruct the homo-hetero dichotomy so as to destabilize all fixed sexual identities' (Fraser and Honneth, 2003: 83). Fraser argues that affirmative remedies to misrecognition have two main disadvantages. Firstly, they reify collective identities, in the process 'drastically simplifying people's self-understanding – denying the complexity of their lives, the multiplicity of their identifications, and the cross-pulls of their various affiliations' (ibid: 76). This can even extend to conformity in the service of group loyalty, reducing experimentation and dissidence from group norms. This has

the important effect of leading to separatism through an excessive sense of loyalty to the group. The other disadvantage of an affirmative politics of misrecognition is that, for groups facing both cultural and economic subordination, the differentiating dynamic of affirmative remedies for maldistribution and misrecognition reinforce one another, both serving to separate the group from the rest of society and maintain the deep structures that create subordination and injustice.

For Fraser, the tendency to stress differentiation in affirmative remedies of either sort means that they combine poorly with transformative remedies that tend to undermine group differentiation. Due to this contradictory relationship, Fraser argues that groups facing economic and cultural injustice should disregard strategies that combine affirmative *and* transformative remedies for injustice. To be clear, because transformative remedies diminish group differentiation, and affirmative remedies feed group differentiation, Fraser argues it would be inconsistent and self-defeating to attempt to combine affirmative and transformative forms of resistance because they work against each other. An example of such an unpromising combination of remedies might be an anti-racist politics which sought to deconstruct the binary of black/white 'racial' identity while calling for resources to repair economic injustice in predominantly black communities. It could be found in such a case that the effort to deconstruct the constitution of black identity undermined the effort to secure resources for black communities because it brought into question the very notion of blackness.

In order to be consistent and not counterproductive, this effectively means that strategies should either combine affirmative *or* transformative strategies, in the sphere of both recognition and redistribution. Fraser finds the affirmative combination unpromising because affirmative redistribution tends to undermine reciprocity and create antagonistic group differentiations, while an affirmative politics of recognition exacerbates this problem by calling attention to the cultural specificity that may have been stigmatised, deflecting attention from the structural origins of either form of injustice. Fraser finds more promise in the combination of a transformative politics of recognition and redistribution. Here, the modes of resistance would work in harmony as both serve to undermine structures through which individuals are differentiated. As

we saw above, Fraser argues that for the various collective subjects of injustice who face both economic and cultural injustice, a transformative politics of redistribution reduces economic injustice without creating class differentiation and stigmatisation. This is consistent with a transformative politics of recognition which deconstructs hierarchical dichotomies, blurring reified identities and promoting recognition of multiple identifications.

To illustrate her endorsement of this strategic combination of remedies, Fraser uses the example of the cultural and economic injustice that are the subject of feminist politics. In this case she endorses the value of socialist feminist transformative redistribution combined with deconstructive feminism. Transformative socialist feminism would attend to the deep economic structures that generate economic gender disadvantage, avoiding the tendency of affirmative remedies to 'mark women as deficient and insatiable, as always needing more and more' (1995: 89). This is complemented for Fraser by a deconstructive feminism which 'opposes the sort of sedimentation or congealing of gender difference that occurs in an unjustly gendered political economy' (1995: 90). For deconstruction of this sort to be possible, the equality that can be achieved through transformative economic politics is required to allow the space for new constructions and deconstructions of identity and difference to be continually reinvented.

To illustrate Fraser's four-fold categorisation of injustice and resistance I reproduce the tabular representation of these categories from Fraser's article of 1995:

	<b>Affirmation</b>	<b>Transformation</b>
<b>Redistribution</b>	<i>The liberal welfare state</i>  surface reallocations of existing goods to existing groups; supports group differentiation; can generate misrecognition	<i>Socialism</i>  deep restructuring of relations of production; blurs group differentiation; can also help remedy some forms of misrecognition
<b>Recognition</b>	<i>Mainstream multiculturalism</i>  surface reallocations of respect to existing identities of existing groups; supports group differentiation	<i>Deconstruction</i>  deep restructuring of relations of recognition; blurs group differentiation

**Table 3. Fraser’s categorisation of forms of injustice and resistance (Fraser, 1995: 87).**

Having established Fraser’s framework for analysing injustice and resistance, and the reasons for her endorsement of transformative political strategies, I will add one final aspect of Fraser’s analysis which I will apply to my analysis. These are Fraser’s notions of ‘bivalency’ and ‘perspectival dualism’. Perspectival dualism means that struggles for recognition and redistribution demand the use of ‘an integrated approach that can encompass, and harmonize, both dimensions of social justice’ (Fraser and Honneth, 2003: 26). Refusing to reduce either one of recognition and redistribution to the other, but never treating them entirely separately is, in Fraser’s terms, an approach characterised by perspectival dualism. Such an approach can ‘accommodate both the differentiation of class from [cultural] status in contemporary society and also their causal interaction’ (ibid: 93). From a perspectival dualist position, Fraser asserts that some injustices are primarily cultural in origin (such as heteronormativity) and rooted in the status order of society. In such cases, Fraser argues that economic injustice can result, even if it is ultimately the result of the ‘status order’. At the other extreme, Fraser identifies class struggles as originating in the economic structure of society, but again urges that they should not be seen as solely concerned with the redistribution of

wealth. Between struggles which are more clearly economic or cultural in origin, most struggles are closer to the middle of the conceptual spectrum, and face 'two-dimensional' subordination, in which neither economic or cultural subordination can be identified as the ultimate origin of injustice.

This is what Fraser refers to as 'bivalent' struggles in which neither a primary politics of redistribution or recognition alone can suffice. In 'bivalent' struggles, such as gender politics, the 'subordinated group suffer both maldistribution and misrecognition in forms where neither of these injustices is an indirect effect of the other but where both are primary and co-original' (Fraser and Honneth, 2003: 19). Similarly, I will argue that the subjects of such injustice include many disabled people who face oppression that is irreducibly rooted in both the status order and economic structure of society. Attending to such injustice requires action at the level of both redistribution and recognition.

## **Applying Fraser's Analysis to Anti-Disablism:**

### **1. The Relevance of 'Bivalency' to Anti-Disablist Struggle**

I argue that disablism is a bivalent struggle in which injustice is both status and class determined, being irreducibly both cultural and economic in origin. Remedies to the injustices that disabled people face must, therefore, reflect the two-sided origins of disablism, but also pay attention to the particularities of prevailing contemporary forms of disablism such as those I have identified as enforced individualism. By applying the notion of bivalency to my analysis I can avoid underplaying the role of either redistribution or recognition in contemporary injustices of disablism.

Fraser's analysis of economic subordination, particularly in the form of economic deprivation and marginalisation, helps to make sense of my theorisation of enforced individualism. For example, in the analysis of enforced individualism I argued that both DPOs and individual disabled people had suffered from being denied the means to parity of participation. In discussing the barriers to achieving parity of participation both economic marginalisation and deprivation were referred to by

participants and informed my analysis of enforced individualism. Participants tended to focus upon the lack of material resources available for disabled people to leave home or for DPOs to compete on level terms with other providers of services. This included examples in which participants referred to the lack of material support that disabled people were experiencing, meaning they were marginalised from participation in social life in general, including the labour process. Participants also referred to disabled people facing deprivation such as in Andrew's reference to the "existence and support that keeps people alive rather than support that gives people a life". In another example, Roger discussed the marginalisation caused by "care cuts" lowering support to only cover "the very most basic things in life; getting yourself out of bed and getting fed, and that's not independent living that's about surviving". Clearly a remedy to these challenges would require redistribution.

Enforced individualism can also be seen as having cultural elements. It was noted above that the 'status groups', who face injustice as the result of 'relations of recognition' are 'distinguished by the lesser respect, esteem and prestige they enjoy relative to other groups in society' (Fraser and Honneth, 2003: 14). This could be said of disabled people who, as a group, face cultural disablism through the media (Briant *et al*, 2013). This adds to the prima facie case for the relevance of the notion of bivalency to theorising disablism. In respect of my theorisation of enforced individualism, whilst the cultural aspect of disablism at work was a less remarked upon aspect of current challenges, there were important instances where participants noted how negative cultural representations combined with, and compounded, economic challenges. For example, participants noted how disabled people's empowerment was culturally constructed in narrow terms in which the structural barriers to their parity of participation were underappreciated. The cultural under appreciation of structural disablism was also apparent in my analysis of the conditions facing DPOs as their unique role in combating structural disablism was ignored, as they were made to compete on price grounds with private and charitable providers of services. These cultural aspects of enforced individualism reinforce the argument that disablism is a bivalent form of injustice, involving maldistribution and misrecognition.

The more obvious aspects of enforced individualism might be economic but it would be wrong to let this obscure its cultural dimensions. For example, cultural representations of disabled people can affect the esteem in which disabled people are held as a group. This can play a role in the extent to which the public at large will accept cuts to benefits, support and public services for disabled people, and the extent to which disabled people experience discrimination and abuse (Briant *et al*, 2013). In addition, a feedback relationship can form between cultural subordination and economic disadvantage, as the absence of disabled people from community life can mean their presence is less able to combat negative cultural representation in the mass media. If negative cultural representations are less challenged by the prominence of disabled people, the esteem in which disabled people are held may fall, meaning they are put at a disadvantage in the pursuit of work, or considered unworthy of redistributive benefits or independent living payments.

A perspectival dualist approach is useful in this context because wider cultural attitudes can reinforce the economic rationale for austerity, and serve to justify much of what I have described as the challenges of enforced individualism. The lower frequency with which cultural aspects of enforced individualism were invoked in interviews does not mean that cultural factors are unimportant, and could reflect a failure on my part to illicit answers of this kind. Indeed it could even be argued that enforced individualism is primarily cultural in that prevailing cultural norms determine the perceived importance of disabled people's standard of living. However, on balance, it would be mistaken to view enforced individualism as *primarily* culturally driven because the cuts which are driving so much of enforced individualism, both within individual's lives and DPOs, are most obviously caused by the commitment of the government to lowering state expenditure in general. Disentangling the relative role of cultural and economic factors is a difficult task. In this light, applying the notion of bivalency and perspectival dualism to enforced individualism will be an important tool in deciding how best to theorise and challenge disablism.



## 2. Applying Fraser's Analysis to 'Radicalism' and 'Gradualism'

By further applying Fraser's analysis, we can now gain a different view on the categories I previously referred to as 'radicalism' and 'gradualism'. In chapter six I was careful to state that these tendencies shouldn't be seen as absolute positions but positions that exist along a continuum, along which participants would assume different positions at different times. In other words, they were positions people adopt rather than categories of people, although certain participants were more or less likely to adopt one or another.

Referring back to Fraser's distinction between the collective subjects of misrecognition and maldistribution, it is notable the position I referred to as 'radical' tended to advocate participation within broader social movements, emphasising a common subjectivity among diverse groups in opposition to the government's economic program of austerity (Gleeson, 1999; Finkelstein, 1980). I argued that expressions of the radical position tended to advocate revolutionary or socialist politics, understanding disablism as a consequence of shortcomings of capitalism. In this sense, radicalism strongly tied disablism to economic subordination. From this followed a belief that disabled activists needed to cooperate with other groups in society who shared an interest in challenging austerity, or even capitalism itself. This was observable in James' account when he praised the growing "awareness" apparent when disabled people worked in political coalition with others, and argued that the best response to austerity was one informed by the adage "united we stand, divided we fall". In such cases, participants can be seen as closely aligned to Fraser's collective subject of economic injustice defined 'by relation to the market or means of production' (Fraser and Honneth, 2003: 14). This suggests the position I identified as 'radical' involves understanding disablism as primarily driven by economic injustices of maldistribution. For example, Victor firmly located the struggles of disabled people within an economic framework, linking growing disablism to austerity and a failure of the DPM and others to offer convincing counter arguments to austerity. For Victor, this implied a shortcoming within the DPM because of its failure to engage in economic debates and its tendency to view the problem of disablism as a "single issue". The

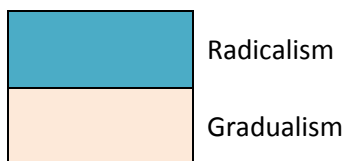
remedies for injustice that followed from this varied but were more likely to involve a transformation of economic/class structures than the gradual position.

By contrast to 'radicalism' I argued that the gradualist position tended to phrase critique of disablism and endorsement of forms of protest within the terms of rights or morality. In this sense economics was attributed relatively little casual power in comparison to radicalism. In present circumstances, the gradual position could not fail to include recognition that economics had an impact on prevalent forms of disablism. However, in contrast to the radical position, economics was discussed as if it were a natural force, divorced from wider social relations. It was important but only as an external force disrupting the realisation of disability rights. Rather than seeking to change economic structures through a broad-based political movement, gradualism placed greater stress upon the immediate gains that can be made for DPOs and disabled people within the terms of the current 'marketplace' of care and support. Such a view presupposed that incremental progress could be made through compromise, requiring that one be accommodating to a degree of undesirable change and aware of what is possible and what is idealistic or naïve.

Overall, the gradual position supported remedies which were more affirmative, assuming that broader political-economic conditions were held constant, and demanding that existing structures recognised disabled people's rights. As an analysis of disablism, gradualism can be seen as construing injustice as primarily cultural, as a violation of disabled people rights and a failure of the status order to accord disabled people status. It is also, to a limited degree, economic in that it assumes the marketplace is the arena in which disabled rights will be won. It is therefore affirmative of economic structures. Gradualism was also economic in the limited extent to which those adopting this position were driven to accept the salience of economic factors by the apparent impact of cuts on disability rights. As we saw above, the radical position construes disablism as far more strongly tied to economic factors with little significance attributed to cultural factors. This could then lead to either transformative or affirmative remedies for economic injustice and did not have to lead to a commitment to transform cultural structures.

Below I adapt Fraser’s tabular representation of her analysis to demonstrate the composition of the radical and gradual positions I used in the previous chapter

	Affirmation	Transformation
Redistribution	Radicalism	Radicalism
Recognition	Gradualism	



**Table 4. Applying Fraser’s analysis of injustice and resistance to categories of ‘radicalism’ and ‘gradualism’**

The table illustrates the focus of radicalism upon economic factors, and how this can bifurcate into transformative/structural or affirmative economic remedies for injustice. Gradualism is affirmative in the cultural sphere in that it seeks greater recognition of disabled people’s status within the existing status order. It is also affirmative in the economic sphere and the extent of its economic analysis is more limited than radicalism. It tended to construe economic factors as external forces interrupting progress in the status order, rather than as part of the same social relations. To the extent that gradualism involved an analysis of both cultural and economic disablement, it might be argued that it more closely mirrors the bivalency of disablism. Radicalism tended to downplay the significance of the status order, doing less to reflect bivalent disablism. On the other hand, radicalism arguably better reflects

the prevalence of economic factors at work in contemporary disablism. Neither radicalism nor gradualism seemed to involve a transformative politics of recognition in which the notion of disablement itself was under question. This is interesting given that academic disability studies has often involved an endorsement of deconstruction, such as in the 'critical disability studies' approach (Shildrick, 2012; Goodley, 2013). Later in this chapter I explore some reasons why this might be the case, noting how the shortcomings of such an approach seem to repeat the problems of applying Fraser's endorsement of deconstruction to anti-disablist struggle.

The table shows that the distinction between radical and gradual would perhaps have been too simplistic if left untroubled and not returned to. At the earlier stage of analysis, radicalism and gradualism appeared as apt descriptors, but using Fraser's categories shows that more was at work than a contrast between the two terms could convey. Fraser's analysis shows that within the categories of radicalism and gradualism are dual concerns with the extent to which disablism is a matter of redistribution or recognition, and a strategic concern with the extent to which one endorses affirmative or transformative political activity. My analysis of radicalism and gradualism was not a mistake, but with the benefit of Fraser's analytical framework, more can be seen about the positions that were taken. This can be seen in the case of radicalism. Although radicalism could be revolutionary or socialist, it could also demand redistribution within economic structures. What unified 'radical' perspectives was an analysis of disablism that saw it as rooted in economic structures. Radicalism was an economic analysis but this could lead to affirmative as well as transformative prescriptions for political-economic change. Without Fraser's analysis there could have been a tendency on my part to conflate economic analyses of injustice with transformative remedies for injustice. The structure of Fraser's argument also highlights how gradualism is not only cultural but also, to a limited extent economic, in that it perceives economic factors as a disruptive influence upon the realisation of disabled people's status and conceives of the existing marketplace as the domain in which to address disablism. Without the use of Fraser's insights this may not have been as apparent. Further applying Fraser's analysis to my interview analysis will help to understand why the movement has deployed differing arguments at varying times,

and why the arguments and strategies of the movement have developed in the way they have.

### **3. Fraser's Endorsement of Deconstruction and the Value of the Independent Living Approach**

Up to now I have argued that Fraser's analysis is relevant to my theorisation of the challenges of contemporary disablism and political positions taken by participants. Her notion of bivalency illustrates the combined challenges of economic subordination, particularly in the form of deprivation and marginalisation, and cultural subordination and misrecognition. Both of these can be seen at work in enforced individualism. This led to a discussion of how cultural disablism was a less prominent theme in interviews, and in my analysis of enforced individualism, but could serve to highlight the important role that cultural constructions of disability have in underpinning and compounding the challenges of enforced individualism. Fraser's analysis of recognition and redistribution was also useful in highlighting the differing 'collective subjectivities' that were implied by varying forms of injustice. For example, her identification of a collective subjectivity of economic, class injustice was paralleled by my category of 'radicalism' which understood the struggle of disabled people as being one of a matrix of struggles commonly rooted in class injustice. Fraser's argument that subjects of cultural injustices could be understood as subordinated status groups had its parallel in 'gradual' positions which stressed the failure to recognise the equal status of disabled people and their rights.

As I combined Fraser's analysis of injustice with her analysis of affirmative and transformative remedies, we saw how what had previously been referred to as 'radical' and 'gradual' positions incorporated differing analyses of the nature of disablism and the optimal form of resistance against it. 'Radicalism' comprised an analysis of injustice as primarily economic, but this was not always followed by a call for structural economic transformation. The category of 'gradualism' comprised an analysis of injustice as primarily cultural and an endorsement of affirmative resistance. This is helpful because it serves to clarify with more precision what is at work within radical and gradual positions. Of further value was the way in which the four-fold

categorisation highlighted the absence of transformative remedies for misrecognition as participants did not appear to rely upon deconstruction.

Beyond what I have argued so far, Fraser's analysis chimes with the struggle of the DPM in a broader sense. Fraser's key principle 'parity of participation' was foreshadowed in interviews by common use of phrases like Vera's use of "coexistence on the basis of equality" or Andrew's call for the creation of a "level playing field". Both the demand for independent living, and an analysis informed by the social model of disability, share similarities with Fraser's central principle of parity of participation. Indeed, demands for independent living can be seen as an assertion of disabled people's *right* to parity of participation. Independent living is commonly associated with improvements in how support services are delivered and in overturning power relations with 'carers', but it is also a demand that cultural and economic conditions are created to deliver rights to disabled people (Shakespeare, 2000). Parity of participation is also relevant to the social model of disability (Danermark and Gellerstedt, 2004) in that a social model analysis identifies historically contingent, transformable relations which block the participation of disabled people on an equal footing with others (Thomas, 1999).

As I have argued, Fraser's analysis is useful for understanding disablement and anti-disablism. Fraser herself does not refer to the struggle against disablism in the examples she uses to illustrate her theoretical framework. With such close synergy with aspects of anti-disablism it is perhaps surprising that Fraser's analysis is not more heavily drawn upon in disability studies<sup>47</sup>. One of the reasons why this is the case may be that while her analysis is very helpful to understanding disablement, her endorsement of a transformative politics of deconstruction seems less helpful as a remedy to disablement. This is not to dispute the overall value of Fraser's framework to my analysis. Despite the limitations of her strategic endorsements, the manner in

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<sup>47</sup> There is a range of research combining a theorisation of disability and the politics of recognition. This is particularly the case with the work of Honneth (see Calder 2007, Ikaheimo, 2010) but reference to the work of Fraser in relation to disability is less well-developed. Ferguson (2005), Vehmas and Watson (2014) and Shakespeare (2014) have briefly discussed the relevance of her work to disability. Of the sources I have uncovered, the most developed applications of Fraser's work to disability are Danermark and Gellerstedt's (2004) and Gleeson's (1999).

which they fall short when applied to disablement is revealing. Fraser's analysis illustrates the bivalent nature of disablement, but in order to adequately respond to the challenges of bivalent disability, one needs to look beyond Fraser's endorsement of deconstruction and socialist transformation. The shortcomings of the strategic inferences Fraser draws from her analysis, when applied to disability, might help to explain why the conceptual tools of the movement have been developed in the distinctive way they have.

To begin to analyse why Fraser's strategic endorsements falter when applied to disability, it is first useful to recall that, in the exposition of Fraser's analysis above, we saw that her theorisation of injustice and resistance led her to a consideration of the mutual compatibility of different forms of resistance. Within this discussion we saw how she endorsed transformative recognition and redistribution (deconstruction and socialism). Fraser makes this case in relation to other bivalent struggles, such as those around issues of gender or 'race' and I have argued that disability is similarly bivalent.

To examine the shortcomings of Fraser's analysis when applied to disability, it is useful to draw upon Vehmas and Watson's (2014) criticisms of another example of deconstruction, from 'critical disability studies'. As critical disability studies is essentially an attempt to apply the concept of deconstruction to disability, Vehmas and Watson's criticisms are relevant here as it gives reason to doubt the application of Fraser's ideal of combining transformative action in the economic sphere with transformative deconstruction in the cultural sphere. Vehmas and Watson doubt the 'ethical and political applicability' (ibid: 638) of 'critical disability studies' and probe its project to 'deconstruct ideas about disability' and explore 'how they have come to dominate our approaches to the subject' (ibid: 639).

Vehmas and Watson question whether an account of the discursive construction of disability can ever lead to an adequate strategy for challenging disablement. Perhaps their most telling argument is that 'in order to create fair social responses to disadvantage, we have to have a common understanding about disadvantage, and a reasonable (non-arbitrary) way of comparing disadvantages and correcting them' (2014: 643). Deconstruction works against this by focusing on

dismantling the ways that people are categorized, rather than focusing on the relatively stable categories through which people can be identified as subjects of oppression and marginalisation. If a goal of the movement is to achieve a minimum level of well-being for disabled people, this presupposes a definition of 'disabled people' and an understanding of the ways in which disabled people are disadvantaged. Both independent living and the social model of disability presuppose a category of 'disabled people' who face disabling social relations and require that their equal status be recognised. For Vehmas and Watson, in a context of scarcity, criteria to assess disadvantage and injustice are required, in order to allocate resources more fairly (ibid). Deconstruction is ill-suited to these requirements because, as Vehmas and Watson argue, paraphrasing Lister (1998) 'if disability and impairment are simply to be deconstructed into a kaleidoscope of shifting identities and ableist discourse, there will be no disabled people left to fight for the right to be, or be a citizen' (ibid: 646).

As well as its inability to define categories of social disadvantage, applying deconstruction to disability is also problematic in its refusal to acknowledge or engage with difficult ethical debates surrounding the status of impairment. Vehmas and Watson argue that many people consider that some forms of embodiment are preferable to others because they believe that 'some impairments may in and of themselves prevent people from acting and moving as they wish, from doing valued activities or faring well in general' (2014: 641). The analysis provided by a deconstruction of disability and impairment implies that impairment is neutral and that freeing society from ableist assumptions is enough to overcome the challenges of disability (ibid). Vehmas and Watson insist that differences in impairment and social disadvantage are real and 'produce tangible difference that cannot be challenged, let alone abolished, merely by pointing out the wanton nature of difference, and deconstructing the meanings attached to disability' (ibid: 647). Contrary to Fraser's view that deconstruction is complementary to transformation of economic structures; they go on to argue that redistribution demands recognition of the reality of social disadvantages among groups of people. They summarise their position by arguing that 'it is impossible to fight the oppression of a group of people that does not exist' (ibid: 648).



It is useful here to locate Vehmas and Watson's position within the framework of Fraser's analysis. Their critique of critical disability studies and deconstruction parallels participant contributions in that participants did not endorse, or even refer to, the value of a deconstructionist politics. Arguing that '[d]isability is rooted in the economic structures of society and demands redistribution of goods and wealth' (2014: 647), Vehmas and Watson recognise the economic dimension of disablement. Although they extensively criticise deconstruction, they also praise the research critical disability studies has produced on the 'cultural reproduction of disability' (ibid: 643). It would therefore also be fair to say that they recognise the role misrecognition and cultural subordination play in disablement. As for the remedies for injustice that Vehmas and Watson appear to endorse; their focus upon the disadvantages of impairment mean they believe there are limits to the power of deconstruction in alleviating injustice. They therefore reject transformative remedies for misrecognition. Although they are less explicit on the matter, their emphasis on the need for redistribution within existing economic structures appears to mean that they would also question the extent to which a transformative politics of redistribution could overcome disablement. By stressing the scarcity of resources and the intractable disadvantages associated with some impairments, it is implied there are limits to the potential of transformative redistribution to alleviate disadvantage. This does not mean that they reject the potential for addressing disabling economic structures, but it does suggest that they would reject the idea that disability is socially 'created' (Oliver, 1990). Oliver uses this term to distance his account from social constructionism, arguing that disability is a bivalent *creation* of economic and cultural factors. Vehmas and Watson would not question the importance of either cultural or economic factors of disablement, but would reject the argument that disability is either social constructed or created. Their view is that there are limits to the reach of redistribution or recognition. Their approach could therefore be characterised as affirmative, in that they do not believe economic or cultural transformations could remove the disadvantages that many disabled people face.

Vehmas and Watson's argument about impairment may highlight a shortcoming of Fraser's analysis, at least in its application to disability politics. As

Vehmas and Watson argue, deconstruction is clearly inadequate when applied to a struggle in which impairment is a factor because 'disability is not the same as many other group identities [... ]There are no rational reasons to consider homosexuality or gender as undesirable characteristics whatever the social context, but there are many impairments that can reasonably be seen as undesirable' (ibid: 649). The nature of impairment may be a factor that limits the potential of a transformative politics of recognition (deconstruction) in disability politics. This can be seen in the principle of independent living which relies on the argument that disabled people should experience the same rights to independence as the rest of the population. What disabled people require for independence is not a matter of charity but of a right (Shakespeare, 2000). Such an argument presupposes a definable group who demand their rights are met. Deconstruction would run against this by trying to dismantle the binary relations which allow a definition of 'disabled people' to be established.

In the terms developed in this chapter, independent living could be read as an affirmative demand for redistribution of resources to satisfy the equal rights of disabled people to independence. This is because affirmative remedies leave the underlying political-economic order intact but demand a shift toward an equalisation of the allocation of resources. This affirmative remedy to injustice is present in the independent living approach, and its demands for redistribution to realise disabled people's right to independence within the current social order. Equally, it could be read as an affirmative demand for recognition, in that it requires changes in relationships and the recognition of the equal status of disabled people's self-determination. It is also concerned with recognition insofar as demands for redistribution are premised on acceptance of disabled people's equal status and right to independence. Again then, Fraser's notion of bivalency speaks to this aspect of anti-disablism, but in this case her recommendation of deconstruction (combined with socialism) is inadequate because independent living presupposes a defined category of disabled people who are demanding their rights are met.

While independent living may be read as affirmative in the sphere of redistribution, its implications in the sphere of recognition are less clear. Cultural recognition of an individual's right to 'autonomy and self-determination' (Morris,

2014b)<sup>48</sup> requires a thoroughgoing ‘transformation of power relationships’. Articulated in this way, independent living is affirmative in demanding adequate resources for independence within existing political-economic structures, but could be read as transformative in demanding fundamental shifts in disabling relationships. However, within the terms of Fraser’s framework, independent living can only be read as an affirmative politics of recognition, calling for the rights of disabled people to be better recognised and for the category of disabled person to be revalued and raised within the status order. Within Fraser’s analysis, independent living cannot be understood as transformative because it does not involve deconstruction of the category of disabled person. The nature of impairment imposes limits on the extent to which such a transformative politics of recognition can be applied to disability. Within these limits, independent living is transformative in demanding a fundamental shift in the logic which underpins the support of disabled people, and is a far-reaching remedy to misrecognition.

This critique of Fraser’s endorsement of deconstruction enables us to grasp why the independent living approach has developed in the way that it has. The issue of impairment and the right to independence must be premised on a relatively stable category of disabled people. An argument for independent living demands a fundamental shift in intersubjective relations of recognition, but it cannot go as far as a deconstructive politics which, when applied to disability, suggests ‘that impairments are ethically and politically merely neutral differences’ (Vehmas and Watson, 2014: 647). Although disabled people are typical of the bivalent collectivities theorised by Fraser as facing cultural and economic injustices, they differ in that their impairments mean that the recognition of their rights to independence must be fundamental and never secondary to goals of deconstruction. The issue of impairment places limits on the applicability of deconstruction to disability politics. No amount of transformative deconstruction could remove the non-social dimension of impairment and this means the recognition of equal status and the right to independence is always likely to remain at the forefront of the movement’s demands.

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<sup>48</sup> <http://jennymorrisnet.blogspot.co.uk/2014/04/personal-budgets-and-self-determination.html>

As we saw in the initial presentation of Fraser's analysis, one of the reasons that Fraser supports deconstruction combined with socialism is that affirmative redistributive benefits can create stigmatising group differentiation. This is relevant to disabled people in that redistributive benefits could tend to create stigmatisation for disabled people, and that structural change could achieve changes beyond regular redistributive payments. On the other hand, this argument of Fraser's could again be questioned in light of independent living and the arguments of Vehmas and Watson. The point of the right to independent living is that society as whole should come to terms with the need for redistribution to disabled people because of the physical and socially created disadvantages they face. Independent living refuses the logic of Fraser's critique of affirmative remedies to maldistribution as potentially stigmatising. Rather than seeking to avoid the stigmatisation that may follow affirmative redistribution, independent living demands that those who stigmatize disabled people should be the subject of change. By combining an affirmative call for redistribution with an affirmative demand for recognition of disabled people's rights, independent living attempts to shift the focus from the process of redistribution towards an acceptance of disabled people's right to independence.

Having developed this understanding of independent living, I can return to my initial application of Fraser's analysis to my categories of radicalism and gradualism. In the first instance, I noted how radicalism and gradualism contained within them differing analyses of disablism. Radicalism saw disablism as primarily economic, requiring affirmative or transformative resistance to maldistribution. Gradualism was affirmative in the remedies it offered and saw disablism as primarily an issue of misrecognition and a failure to recognise disabled people's rights. Independent living is affirmative in the economic sphere, demanding redistribution to fulfil rights, and is affirmative in demanding a shift in the way disabling relationships are configured. It is thus similar to what I had previously described as gradualism. It could be read as a subset of gradualism or its most clear example. The case of independent living and its link to the existence of impairment shows that an affirmative demand for recognition and redistribution, or in my terms 'gradualism', may always be necessary and cannot always be superseded by a transformative politics of redistribution.

Equally, the radical position seemed to capture an important aspect of anti-disablist resistance. Through its materialist insistence on the economic determinants of disability it points to an important feature of contemporary disablism. The challenges I identify in chapter one and chronicle closely through my theorisation of enforced individualism are, at least superficially, driven by the political-economic goal of reducing the size and scope of the welfare state in Britain. I argued that such an economistic understanding of disablism could, in the radical position, bifurcate into transformative or affirmative remedies for maldistribution. As Vehmas and Watson argue, there may be a minority of disabled for whom no amount of transformative deconstruction or redistribution could remove the disadvantage they face due to their impairment. This does not negate an argument for transformative change to disabling economic structures. There are many disabled people for whom such a change may be able to yield massive benefits. This insistence that transformative social change could change disabled people's lives is partly what is represented by the social model of disability. In this sense, Fraser's endorsement of socialism may be less problematic than her endorsement of deconstruction. There may be limits to what either could achieve, but a transformative politics of redistribution need not suggest that 'impairments are ethically and politically merely neutral differences' (Vehmas and Watson, 2014: 648) in the same way that deconstruction seems to.

## Summary

To summarise this chapter, we have seen throughout that Fraser's analysis is valuable in stressing the bivalency of cultural and economic injustice. In combination with her analysis of affirmative and a transformative politics, it was possible to see more clearly what was at work behind my depiction of radical and gradualist positions. Fraser's analysis of bivalency problematised my initial categories of radicalism and gradualism and showed that they risked conflating the two distinct issues of forms of injustice (maldistribution and misrecognition) and forms of resistance (affirmative and transformative). Although Fraser's analysis was useful on several counts, her strategic conclusions that followed from this analysis were found to be wanting. In particular, it

was argued that the independent living approach problematises Fraser's privileging of transformative politics.

In the remainder of this thesis I will further reflect on injustice and resistance. My focus will tend toward analysis of political economy rather than cultural disablism but this should not be seen to diminish the importance of cultural disablism. In part this decision is driven by a pragmatic need to restrict the range of factors covered in the remainder of the thesis. My decision to focus on political economy is partly driven by the way contemporary disablism seems to be driven in great part by factors of political economy (see chapter ten), and the lack of academic work to reflect this. Another reason I choose to focus on this aspect of disablism is that I believe the theory produced by some of those from the field of political-economy/political theory, such as Holloway (1991; 1993a; 1993b; 2005), can provide a novel means of conceptualising the relationship of disability studies and disability activism (see chapter ten). This focus on political-economy also informs the concern of the next chapter of the thesis with the extension of the social model of disability presented by Thomas (1999; 2007; 2010; 2012). I will argue that Thomas' extension of the social model is relevant to political-economy because it has been generally been developed against a background of understanding of political-economy (Oliver, 1990) and as a way of conceptualising the structures and barriers than can obstruct the rights asserted by the independent living approach. Thomas' social relational approach to disability opens the door to theorising multiple structures of disablism, including those of political economy.

## **Chapter 9: The Strengthening Of Social Model Politics in Carol Thomas' Social Relational Theory of Disability**

In this chapter I turn from the concerns of the previous chapter toward the social model of disability. In the previous chapter one of the topics touched upon was the independent living approach and the way in which it attends to the bivalency of cultural and economic disablism. I argued that the independent living approach gives an affirmative argument in favour of redistribution within existing economic structures. Counter to Fraser's argument that affirmative and transformative forms of resistance should not be combined, the independent living approach has been combined to useful effect with the social model of disability and a historical materialist analysis that offer greater insight into the potential for political-economic structures to shift and undermine progress toward independent living.

In this chapter I will first present the 'social-relational' contribution to theorising disability developed by Carol Thomas (1999; 2007; 2010; 2012). This elaboration on the 'disability as oppression' foundations of the social model provides a theoretical starting point for interrogating broader shifts in social relations, including economic and cultural disablism. It also focuses upon micro-cultural and interpersonal patterns of misrecognition. Drawing on Thomas' development of the model, and making some methodological points regarding the appropriate scope of the social model, I argue that Thomas' development of the social model need not involve the failings attributed to it by some participants and academic critics. In closing, I discuss how Thomas' relational approach complements Fraser's analysis and how it can serve as an important element in challenging enforced individualism.

### **Why Examine The Social Model?**

An examination of the social model of disability is not only of theoretical interest but is valuable because of how central it is to activist understandings of disablism and resistance. We saw in chapter seven how important the social model was to

participants' positioning in relation to the challenges of disablism. Participants explained the re-evaluation of experiences that followed their introduction to the social model and, in some cases, described the radicalising impact it had upon them. Introduction to the model had frequently been followed by a turn to activism in order to challenge the social causes of disablism. The participants who criticised the social model did not reject it out of hand but questioned if it had been adopted as a dogma and applied too widely, acquiring more significance than it should.

There is merit to these worries, but I will argue that an analysis inspired by the view of disability as oppression remains vital to understanding disability. Scholars such as Thomas (2012) develop the political commitments underpinning the social model, without claiming that the simple social model can serve as a complete social theory (Thomas, 2004). Retaining the politics of the social model can, in a more elaborate theory, contribute much to challenge 'individualist policy frameworks' (Morris, 2011: 3) and recent policy concerned only with individual aspects of disability (Yates and Roulstone, 2013). It is potent in its capacity to expose individualising views of disability, drawing upon antecedent historical materialist analyses (Oliver, 1990) that locate disablism in shifting social relations and the disabling tendencies of unfettered capitalism. The relevance of the social model will remain while it continues to be the case that social care in the UK is informed by a concern with individual rather than social determinants of disability (Morris, 2011).

In my analysis of enforced individualism, I argued that its ideological challenges included a failure to address structural disablism, and a tendency to construe empowerment in individualistic terms that assumed individualised funding was sufficient for empowerment to occur, meaning collective user control was largely ignored. Factors such as these, and the general focus upon the individual disabled person, function ideologically to mask the collective oppression of disabled people, meaning that 'speaking about disability and disadvantage as an individual problem prevents us from discussing the removal of barriers in the wider social world' (Priestley, 1999: 48). The social model of disability, then, continues to have value as an ideological corrective that unmasks and challenges individualistic conceptions of



disability, revealing historically contingent, and potentially removable, relations of disablism.

## **Thomas' Social-Relational Development of the Social Model of Disability**

I will argue that what is most valuable about the social model is foregrounded in the social-relational theory of disability developed by Thomas (1999; 2004; 2007; 2010; 2012). Before I do this, it is important to clarify that Thomas does not believe the social model itself can satisfy the demands of academic theory. For Thomas, the social model has served at times to simplify the social relational analysis contained within the UPIAS statement (1976) of the fundamental principles of disability. The enormous political value of the social model has come at the theoretical cost of encouraging 'thinking in shorthand—to assert that, for example, that disability equates with 'social barriers'' (Thomas, 2004: 579). Following the need to find alternative means with which to theorise disability, Thomas' contributes a social-relational theorisation of disability. This approach is consistent with the 'disability as oppression' (ibid: 577) foundations of the social model, but it goes beyond it to encompass other factors in disabled people's lives such as the role of 'impairment effects' and 'psycho-emotional disablism'.

A continued focus on the politics of 'disability as oppression' is essential to Thomas' project and is what she values about disability studies in general, distinguishing it from other approaches through its 'explicit commitment to assist disabled people in their fight for full equality and social inclusion' (2004: 571). The social model is insufficient for the requirements of the development of a social oppression paradigm, but it can serve as a symbol of the need to maintain a focus on politics and oppression. In this light, it is significant that many academics believe attacks on the social model open 'the door to, and begins to hint at, an as yet ill-defined rapprochement with "medical model" and "individual model" thinking' (Thomas, 2008: 15). Thomas and academics sympathetic to the social model do not seek to wholly disown and reject it but develop a theory consistent with the political conviction symbolised by it. This is what seems to be at work when Thomas observes of the international journal *Disability & Society* that one can find in it a 'rich mix of

sophisticated research and theory-based academic papers inspired by the social model' (ibid: 16). The use of the word 'inspired' is significant in that the work Thomas refers to is 'inspired by' the political conviction most commonly represented by the social model. Thus while Thomas rejects the use of the simplified social model as an academic theory of disablism, her work can be read as a political intervention 'on the same side' as the social model against disablism, fulfilling Oliver's (1992) requirement that EDR clearly takes the side of disabled people.

Significantly, in light of participant concerns that the social model could be a vehicle for dogmatism, Thomas' multifaceted approach is more open and harder to translate into a dogma. This is relevant because a minority of participants, echoing critics such as Shakespeare (2006) feared the dogmatism associated with the social model. For example, Kate argued it had been adopted by some "purists" as a "religion" and was being used as an exclusionary measure of whether someone could be "in our gang". Thomas' approach retains the political commitment symbolised by the model but is more carefully formulated, meaning it can address participant concerns regarding the possibility of it overreaching its relevant scope.

Thomas subtly develops the original disability/impairment dichotomy as previously seen in the work of UPIAS (1976) and Oliver (1983). Here greater weight is placed on the 'social relational' character of disablism than the more familiar emphasis on disabling barriers in the social model. For Thomas, the social relational definition of disablism means it 'constitutes a form of social oppression in contemporary society – alongside sexism, racism, ageism and homophobia' (2010: 37). Enduring social relations equate to structures and this is complementary to the stress I placed in my analysis of enforced individualism on the failure to understand the structural nature of the disablement that individual disabled people face and that DPOs can challenge. As an example of the relevance of the social relational and structural view of disablism developed by Thomas, I have noted in my analysis of enforced individualism how the role of DPOs in combating entrenched structural disablism was not adequately recognised in the procurement environment. Furthermore, I noted how individualistic conceptions of empowerment cannot grasp structural impediments to individual empowerment, instead assuming changes in the way support is delivered would

deliver empowerment. Thomas's social relational notion of disablism complements my analysis of enforced individualism because it involves a structural conception of disablism as a set of enduring patterns of social relations (structures) which constitute disablism.

Arguably a structural analysis like this could also have been made within the original version of the social model. An advantage of Thomas's social relational approach over the barriers reading of the model is that it better reflects the bivalent nature of disabled people's struggle and the cultural disablism of misrecognition. Disablism involves misrecognition in the mass media (Briant *et al*, 2013) but also at the level of individual human relationships and how disablism can be internalised by disabled people (Reeve, 2002). This was shown by interview participants who voiced the "fears" that changes in policy had caused, or when Mary expressed the sense of "guilt" she felt for receiving more "substantial support" than her friends. In Thomas' approach, viewing disablism as relational adds to the focus on barriers and structures an important additional emphasis on the inter-subjective misrecognition that co-characterises disablism. This type of disablism, and the impact it has on disabled people, is referred to as 'psycho-emotional' disablism (Thomas, 1999). The social relational definition of disability requires that one pay attention to *all* restrictions socially imposed on disabled people. This includes psychological and emotional as well as political, economic and environmental restrictions. For Thomas, 'psycho-emotional disablism' shapes personal identity, including who we are and who we are prevented from being. Thus while restrictions on doing are of great significance, 'that is not all there is to disablism; there are additional, often intangible, dimensions to the social exclusion of people with impairments, which may in turn have behavioural and practical consequences' (ibid: 48). This extension of the social model may make its central political message more appealing to other people who might be considered 'disabled' such as people with mental health needs for whom structural barriers may not be their main concern (see Anderson *et al*, 2012). The lack of this sort of analysis in a traditional reading of the social model may suggest its historical materialist origins were less equipped to reflect the misrecognition that co-characterises disablism along with economic subordination. A stress on relations and psycho-emotional disablism is

consistent with a stress upon structural disablism, but can also prevent this from excluding the individually experienced politics of misrecognition. This aspect of Thomas' approach is complementary to the independent living movement's stress on the politics of recognition and the changes required in relationships required to fulfil disabled people's rights (Morris, 2014b). It also helps to counteract the lack of attention given in Fraser's approach to 'face-to-face' interaction and its role in the development of the self and identity (Danermark and Gellerstedt, 2004).

The advances made by Thomas on the social model flow from her definition of disability as a social relation, between people, or as 'disablism'. Disablism is an unequal relation between impaired and non-impaired people, akin to the way in which 'patriarchy refers to the relationship of male ascendancy over women' (1999: 40). Thus disability is 'a particular form of unequal social relationship which manifests itself through exclusionary and oppressive practices – disablism - at the interpersonal, organisational, cultural and social-structural levels in particular societal contexts' (ibid: 40). For Thomas, the social relational conceptualization of disability 'changes the meaning of disability itself rather than simply switching attention to the social as opposed to biological causes of restrictions of activity' (ibid: 44). By this she does not mean that all restrictions of activity experienced by disabled people are caused by social factors, or simply that disability is socially, rather than individually, caused. She fears such an argument could be read as an over-socialised understanding of disability that denies the role of 'impairment effects'. Rather, by 'changing the meaning' of disability itself, she is redefining disability as 'disablism' or as a relationship between people. This does not refer to the social causes of restrictions of activity, but is redefined to refer to 'the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as 'impaired' by those deemed 'normal' (2010: 37). In this sense, one might describe the relational definition of disablism as the political redefinition of disability.

Thomas could not have developed this conceptualisation of disablism without identifying the direct impact of impairments on the lives of disabled people. Her acceptance of a role for impairment is consistent with my argument in the last chapter that the non-social dimension of impairment limits the applicability of deconstruction

to disability politics. Thomas proposes the category of 'impairment effects' to denote 'the direct and unavoidable impacts that impairments (physical, sensory, intellectual) have on individuals' embodied functioning in the social world' (2010: 37). This is significant because the social model has been criticised in the past for serving to exclude experiences of pain and restriction not attributable to disablism (Morris, 1991). This was apparent in interviews as participants expressed their concern at the tendency towards dogmatism associated with the social model. This, and concerns that the social model may subsume all disability experience into oppression (Shakespeare, 2006), can be resisted if one appreciates that disablism should always be understood in reference to a role for impairment effects. The category of impairment effects prevents Thomas' approach from subsuming everything into a politically reductionist account of oppression, enabling one to acknowledge that there are restrictions of activity that 'may be directly associated with, or 'caused by', having a physical, sensory or intellectual impairment' (Thomas, 1999: 42). Placing limits on the scope of the social model and demarcating the boundaries of a social relational approach may therefore help to limit the dogmatism that concerned participants.

The separation of impairment effects from disablism is an analytic distinction which cannot be neatly applied in practice. For example, impairment effects 'may become the marker for other restrictions of activity that do constitute disability' (Thomas, 1999: 43), meaning particular impairment effects may be associated with greater disablism. Thomas points out that 'care must be taken, of course, not to mistake impairment effects for what are, in fact, disabilities' (ibid: 43). Distinguishing impairment effects and disablism is useful in the context of the threat of enforced individualism where I stressed the structural forces of disablism at work. By analytically distinguishing impairment effects and disablism, Thomas' approach can help to avoid the mistaken identification of the individual effects of structural disablism identified by interview participants, such as individual isolation, marginalisation and deprivation, for what is frequently attributed to the 'tragedy' of impairment. It is able to do this by separating out disabling social relations from impairment effects.

As the basis for further studies, Thomas' approach invites attempts to explain the 'particular form of oppressive social relationship between those who are

designated impaired and those designated non-impaired, that is, the relationship which constitutes disability' (1999: 40). Key questions then arise, such as are 'how is the social relationship which constitutes disability generated and sustained within social systems and cultural formations, and why does it exist?' and 'how does this social relationship operate and manifest itself?' (Ibid: 44). Through my theorisation of enforced individualism I hope to have contributed to this task by providing a means of theorising the tripartite nature of the challenges of isolation to individual disabled people, problematic conditions for DPOs, and obstructive ideology. Such a theorisation also provides historical insight by drawing upon the historical movement between enforced collectivism and enforced individualism as a means of thinking about the prevalence of differing forms of disempowerment and the forces which shape their emergence.

In this way I believe my theorisation of enforced individualism has been consistent with Thomas' analysis of disablism. I also believe that Thomas' analysis complements my application of Fraser's analysis of injustice and resistance and my analysis of independent living. In the following section I seek to clarify the scope of the social model by engaging with participants' concerns that it could be adopted dogmatically. I also respond to some prominent academic criticisms of it.

### **The Scope of Thomas' Social-Relational Theory of Disability**

To gauge the value of Thomas' approach it is important to neither overstate nor underplay its significance. It is helpful here to clarify what can be expected of theories in general. Consistent with the account given of open systems (Bhaskar, 1986) and critical realism in chapter four, theories can only illuminate a relatively small number of aspects of society, bracketing other social mechanisms, and creating logically coherent abstractions which isolate the relationship of a small number of social mechanisms in order to animate them. In doing so, theory provides an explanatory window onto society. Societies are open systems of multiple mechanisms exhibiting features that cannot ever be captured by one theory alone (ibid).

The lack of comprehensiveness of a model can be detrimental for particular groups, by excluding their experience. For example ethno-cultural minorities (Vernon, 1998) or impairment specific groups (Scott-Hill, 2004) may feel that the social model imposes an alien meaning of disability onto them. On the other hand, theories such as Thomas' are indispensable for explanation, and complete comprehensiveness is impossible for any particular theory. Application of any theory results in some social complexity inevitably being lost, but the question is whether the explanatory power gained from using a given theory outweighs the complexity lost in the process. In this light, the phrase "the map is not the territory" popularised by Korzybski (2010), expresses the insight that we unavoidably analyse the world through abstractions. Critics of the social model (such as Scott-Hill, 2004; Shakespeare, 2006; Watson, 2012) complain it is a simplification, but it is demanding too much even of a more sophisticated theory such as Thomas' to hope it can capture the 'true' reality of all disability. Perhaps there can be no single comprehensive model of something as complex as disability. As Robinson remarked 'a model which took account of all the variegation of reality would be of no more use than a map at the scale of one to one' (1962: 33).

This description of the limited scope of individual theories can be used to further strengthen the case for the value of Thomas' approach. The more simplistic social model has been commonly criticised for setting up problematic dualities or binaries (Shakespeare, 2006). Bearing the above in mind, this quality can actually be seen as a virtue of Thomas' approach. By setting up different conceptual relations, it yields insightful 'windows' onto disability. This possibility is illuminated by Harvey's analogous interpretation of Marx's dialectical method:

Marx sees each relation as a separate 'window' from which we can look in upon the inner structure of capitalism. The view from any one window is flat and lacks perspective. When we move to another window we can see things that were formerly hidden from view. Armed with that knowledge, we can reinterpret and reconstitute our understanding of what we saw through the first window, giving it greater depth and perspective (Harvey, 1982: 2).

In the case of Thomas' approach we can see the perspective gained by setting up relations between social and individual models of disability, impairment effects and disability, and psycho-emotional disablism and structural disablism. Alone, these conceptual relations give a very partial view of disability but, by moving from one to the next, the possibility is created of developing a richer view. The windows analogy is apt because it demonstrates that Thomas' approach is less reductionist than the social model is said to be, and may be open to the addition of further windows through which additional perspectives on disability may be gained. Seen in this way, the conceptual elements of Thomas' approach provides fertile ground for theorising the current challenges of disablism, providing windows through which anti-disablism can better grasp its task. The inclusion of these additional 'windows' makes Thomas' approach open to importing more general knowledge into consideration of disability, meaning it need not act as a static dogma as was feared of the social model by some participants.

Looked at in this way, Thomas' approach can elude the criticism made of the social model that it is adopted exclusively and tends to reduce all of disabled people's lives to oppression, inevitably finding oppression in any research informed by it (Shakespeare, 2014). Thomas' approach is not excessively reductionist, preserving a role for biology through the category of impairment effects. This is not to essentialise biology. Rather, through the disablism/impairment effects distinction, it names these two interacting strata. Biology is not reduced entirely to social factors, nor social factors reduced to biology. The separation here is analytic and in reality these dimensions will be blurred in numerous ways. As I argue in chapter four, the argument is that the analytic seperability of impairment and disability is a useful basis for analysing their interface.

Participants such as Kate provided compelling examples of the way in which the social model *could* be adopted dogmatically, as she described how people with learning difficulties were excluded because they wished to be known as 'people with disabilities' rather than 'disabled people'. Examples such as these show how the social model and its associated language can serve to exclude. On the other hand, the influence of the model has not prevented a vigorous debate from occurring about its



merits. For example, scholars such as Morris (1991) complained of the exclusion by proponents of the model of experiences of 'private' pain and distress. Subsequently, Thomas, without entirely dismissing the social model, developed the category of impairment effects. The social model is not without drawbacks, such as the examples described by Kate in which the model has been over-stretched. However, clarifying the scope of her approach and carefully analysing its meaning, as Thomas has done, can help to avoid these traps.

I have argued that because Thomas' multifaceted approach is open to further additions, it is harder for it to become closed and static. I have also argued that the analysis of disablism as a social relational phenomena helps in analysing the structural disablism that emerged in my identification of the threat of enforced individualism in current conditions of disablism. The structural nature of disablism was apparent in the frustration of participants with the failure of funders to accept the need to fund DPOs which could challenge and mitigate the existence of disablism. Social relational patterns of disablism were not accounted for in the obstructive ideas highlighted by participants which construe empowerment in strictly individualistic terms, lacking reference to enduring relations of disablism that limit the participation of individual disabled people and underpin their isolation. Much of this analysis of structural disablism would have been possible without Thomas' particular reading of disablism but, positing the model in relational terms adds an emphasis on the bivalency and misrecognition that also characterises disablism. This is highlighted by her category of psycho-emotional disablism which identifies the individually experienced effects of misrecognition. Finally, Thomas' category of impairment effects is another valuable addition to a traditional social model analysis, preventing the exclusion of 'private' experiences of impairment, and allowing one to unpick the relative role of impairment effects and disablism instead of them being conflated (and disablism blamed upon impairment).

Having explained the relevance of Thomas' approach to theorising and resisting enforced individualism, I will close by reflecting on how Thomas' relational social model complements Fraser's analysis of injustice and resistance.

## Linking Thomas' Social Relational Theory of Disability with Fraser's Analysis

In the previous chapter, we saw how arguments for independent living can be read, in Fraser's terms, as a bivalent claim for affirmative redistribution and transformative recognition. In addition, Fraser's analysis sheds light on Thomas' approach because it also reflects the bivalency of disabled people's struggle. One of the strengths of Thomas' approach is that, in analysing structures of relational disablement, it refers to both redistribution and recognition. Such an approach is pitched at a high level of generality and refers to the full breadth of disabling relations which constitute disablism, ranging from economic exclusion, marginalization and deprivation through to misrecognition in the mass media and individual relationships. In a sense it is transformative in both cultural and economic terms, analysing disablism as a set of contingent social relations that can (and should) be changed, but in the sphere of recognition this does not go as far as deconstruction. Like the independent living approach, it is resistant to a thorough-going politics of deconstruction, again relying on a definable category of disabled people who are disabled by social relations.

Thomas' approach is consistent with Fraser's analysis because both are concerned with the forces which restrict the participation of whole groups or, in Fraser's terms, the 'externally manifest and publicly verifiable impediments to some people's standing as full members of society' (Fraser and Honneth, 2003: 31). The idea of barriers is close to Fraser's emphasis upon cultural and economic injustices that block parity of participation. In this way, Fraser's analysis may be similar to a traditional reading of the social model which stresses the social barriers that disable people. Applying Fraser's analysis to disablism could suffer from some of the same problems as a social model concerned only with barriers.

I argued in chapter eight that whilst Fraser's analysis could help in understanding and resisting enforced individualism, it was limited by focusing solely on cultural and economic injustice which could lead to sociological overreach and reducing all disability into an account of oppression for which the social model has been criticised (Shakespeare, 2006). Critics have often complained in the past that the social model marginalises or ignores impairment and excludes its important role from

the study of disabled people's lives. It would be a mistake to repeat this through the use of Fraser's analysis. However, by combining it with Thomas' approach, and the role reserved within it for impairment effects, this misapplication of Fraser's analysis can be resisted.

Thomas' approach can also guard against another possible misunderstanding that could emerge from applying Fraser's analysis. It will be recalled that Fraser's core objective is parity of participation, of which status subordination is one key barrier. If one applies this approach to disablism it could easily lead one away from a consideration of the 'internal' costs of this subordination and to consider it only in light of the costs to one's externally manifest status. Thomas' category of psycho-emotional disablism is vital here as a reminder that disablism can be felt as much in one's psycho-emotional wellbeing and not simply externally in one's status. The bivalent struggle against disablism extends into one's individual existence. By adding Thomas' relational approach to Fraser's analysis, the application of Fraser's analysis can evade a preoccupation with 'externally manifest' equality of status and avoid repeating the traditional social model's mistake of excluding individual experience.

Earlier, I argued that Thomas' approach is consistent with combining it with other knowledge. An example of this is Vehmas and Watson's (2014) critique of critical disability studies' application of deconstruction. This is of note because of Fraser's endorsement of transformative redistribution and deconstruction. Vehmas and Watson argue convincingly that deconstruction is unhelpful in the face of impairment and social disadvantage. Deconstruction cannot address the challenges of disablism merely by challenging the binary construction of disability identity. Vehmas and Watson concur with Thomas on the importance of impairment effects and argue that applying deconstruction to disability cannot address the non-discursive aspects of impairment. This is consistent with a social-relational analysis that includes a role for impairment effects and an independent living analysis which assumes a relatively coherent, definable group of disabled people who demand a redistribution of resources and transformation of culture to facilitate their independence.

I have emphasised throughout the bivalency of disablism. Thomas' approach, combined with Fraser's analysis can allow the struggle for anti-disablism to focus upon the structural basis of disablement, and discern its cultural and economic components. Thomas' approach complements Fraser's analysis by allowing a role for impairment effects and for the individual experience of psycho-emotional disablement. It is beneficial that the two are also combined with an independent living approach. Without a focus on demands for independent living, other forms of analysis could miss the shifts required in human relationships and patterns of distribution for the right to independence to be secured. Equally, without a social-relational analysis of disablism, calls for independent living could fail due to changes in political-economic structures, which could undermine progress toward independent living and which independent living can contribute little to understanding. This is arguably what personalisation has developed into in recent years.

For all of the potential of Thomas' approach when it is synthesized with Fraser's analysis, fusing them together can only ever act as an invitation to probe the enduring relations that constitute disablism, what supports and sustains them, and how they can be overturned. In the following chapter I will further analyse the drivers of current forms of disablism. I will restrict my analysis to factors of political economy because I could not comprehensively theorise the totality of contemporary disablism. Political economy is an under-theorised aspect of disablism and a 'window' through which I will endeavour to offer fresh insights on current challenges. It is also important because of the situation reviewed in chapter two and because most participants - whether 'radical' or 'gradual' - agreed on its importance.

## Chapter 10: Orientating Disability Studies to Activism and Neoliberalism

In this penultimate chapter I will build on my analysis by introducing some theoretical insights from contemporary thinking in feminism and Marxism to the current situation of disability activism. In contrast to earlier theoretical discussions, the following will be less directly relevant to the interview analysis, but will serve to develop the arguments made thus far and help to theorise the broader context in which my analysis is located. At a time when the independence and autonomy of many disabled people may be threatened, developing novel and revealing ways of viewing the situation can shed new light on aspects of current challenges and on possible responses.

In the first section I will apply John Holloway's political theory to disability studies, offering a means of conceptualising the uneasy relationship between academia and activism and their differing requirements (Holloway, 2005). In the second section, I draw again on Nancy Fraser's work, offering a means of understanding the broader political context in which disability studies and disability activism is located. I argue that applying both these theories aids analysis of the role of activism in a time of resurgent disablism, and develops analysis of the way in which forces of neoliberal political-economy have exerted a powerful influence on prevailing contemporary forms of disablism and created the most urgent challenge facing disability studies today.

### Part One: Open Marxism

In the first of two theoretical contributions in this chapter, I will draw on 'Open' Marxism (see Holloway, 1991; 1993a; 1993b; 2005; Bonefeld, 1987; 1994; Bonefeld, Gunn, and Psychopedis, 1992) and particularly the political theory of John Holloway. Before doing this, I first want to argue that many debates in disability studies can be understood in reference to two poles which pull theory in opposing directions. On one hand arguments are made against the social model and associated work because it is perceived to lead to excessive simplification and distortion of the complexity of

disability (e.g. Shakespeare, 2006). On the other hand, disability theory is criticised for its abstraction and abstruseness, as critics question how useful the resulting work is to disabled people and to political efforts to combat disablism (e.g. Oliver, 2009). Thus there is a divergence between those who perceive disability studies as the ‘academic wing’ (Thomas, 1999) of the DPM, with an obligation to contribute politically useful knowledge, and those who perceive it as their role to engage in the detached ‘scientific’ (Vehmas, 2008) pursuit of knowledge, whether or not it directly benefits the DPM. In my view this tension tends to pervade much debate in disability studies, particularly in the seemingly never-ending debates on the value of the social model.

To respond to this tension I will draw on Holloway’s endorsement of ‘negation’ as a key theme for political action and political theory. By stressing negation, Holloway is arguing that anti-capitalist theory (his chief area of concern) should express the constant effort that must be made to contain the subversive and destabilising movement of the oppressed to go ‘against-and-beyond’ (2005: 266) the existing social order. The constant presence of this ‘against and beyond’ or ‘negation’ within capitalism means that theory should capture the instability of the system and avoid descriptions of it as a static monolith. A theory based on ‘against and beyond’ is befitting because political theory attached to projects for social change begins from a standpoint of negativity to the status quo, not a detached comprehension of it. Here Holloway gives an apt description of the emergence of theoretical reflection:

The starting point of theoretical reflection is opposition, negativity, struggle. It is from rage that thought is born, not from the pose of reason, not from the reasoned-sitting-back-and-reflecting-on-the-mysteries-of-existence that is the conventional image of the thinker. We start from negation, from dissonance. (2005: 265).

Social theory informed by this perspective should not be a detached or ‘scientific’ analysis of continuing domination, but should give a means of understanding the urgency of social change and the ever-present possibility of sudden shifts in social relations. This approach sits comfortably within autonomist or quasi-anarchist schools of Marxist theory, and in the past Holloway was known for espousing ‘Open’ Marxism. Open Marxism can be seen as a reaction against determinism and structuralist theory,

distinguishing itself by developing theoretical categories that are more befitting of the openness and unpredictability of societies characterised by constant instability and conflict that is often hidden. This stress on constant and sometimes hidden conflict reflects the conviction of Open Marxists that capitalism's stable appearance belies a reality of constant resistance. This sensitizes them to the political nature of seemingly apolitical and unconnected acts, imbuing the disparate acts of individuals with a common force of political negation.

The emergence of Open Marxism was partly a reaction against the application of critical realism to Marxism which was perceived by critics to fail to foreground the dynamic potential of the oppressed, losing their self-activity in accounts of ever greater structural complexity (Gunn, 1989). In response, an Open Marxist alternative was developed which stressed struggle and resistance and the dangers of reifying structures of exploitation and oppression. It is similar to Hardt and Negri (2000) who see resistance as having an autonomy which cannot be read off from, or accounted for, in the terms set by structures of oppression. This is because labour has its own force of 'self-activity' that capital depends on to reproduce its power, unlike labour which is potentially autonomous from capital (Hardt and Negri, 2000). Thus the emphasis in Open Marxism is on theory which reflects instability and fragility rather than one which portrays a timeless and stable structural prison of oppression.

At present in disability studies, critical realists (Shakespeare 2006; Watson 2012) call for accounts of greater complexity and the construction of a theoretical edifice that can express the complex interaction of different factors at different levels in the lives of disabled people. It might be, however, that support for this approach could lead to similar weaknesses to those identified in critical realism by Holloway and his contemporaries. That is, in building theorisations of disability that seek to reflect the rich complexity of interacting forces at work, critical realists risk reifying structures of oppression, omitting from their accounts the autonomy of resistance, as the possibility of change moves further away into the distance.

This focus on negation heightens our appreciation that anti-disablism is occurring now in the form of millions of acts of resistance, and not in a far off time

when the structures of society have allowed an opportunity to challenge disablism. The path by which a convergence of these millions of negations can take place is unknown or open and therefore an effort must be made to ensure theoretical categories remain 'open' and reflective of the instability imposed by the unpredictability of struggle.

This approach to social theory has not previously been applied to disability studies, but it is potentially a novel means of interpreting some of the tensions within disability studies. Concerned with developing theory of immediate political significance, Holloway's approach is particularly valuable for the insights it can offer a thesis such as this, based on working with activists. Having briefly introduced Open Marxism, I now go on to apply some of the relevant ideas from this school of thought to disability.

### **'Open' Categories**

It may be useful for proponents of a theory of negation or struggle such as that which is found within the social oppression paradigm in disability research to draw upon Holloway's notion of open categories. An open social-relational view of disablism requires a coherent explanation of what constitutes disability in order to establish what it is that political actors share opposition against. The point of 'open categories' is to otherwise use a theoretical apparatus that is as open to new developments as possible. Another way of putting this is to say that we know that we want to end disablism, but we don't necessarily know how to achieve this. Not knowing creates a politics of dialogue, listening and discussion and promotes consideration of the multiple dimensions of oppression and resistance (Holloway, 2005).

The 'openness' of Open Marxism refers to theoretical categories themselves. This can be seen in contrast to a closed Marxism which:

Accepts the horizons of a given world as its own theoretical horizons and/or it announces a determinism which is causalist or teleological [...] This being so, a central target for Marxism with an open character is fetishism. Fetishism is the construal (in theory) and the constitution (in practice) of social relations as 'thinglike', perverting



such relations into a commodified and sheerly structural form (Bonefeld *et al*, 1992: xii).

Applying this to disability, accounts of disability which aim to introduce ever-greater structural complexity (Shakespeare 2014; Watson, 2012) risk demoting the importance of politics, freezing fluid social relations into elaborate theoretical edifices and accepting the givenness of the world. By contrast, theory that builds on the urgency of the social model, such as Thomas' social relational approach to disability, emphasises the temporal and spatial specificity of disablism and the way in which it is continually re-inscribed onto disabled people in differing ways in specific contexts, serving as a warning against seeing fluid relations as static, immutable and 'thinglike'. Construal of disability as 'thinglike' can prevent us seeing anti-disablement in everyday practices.

The social oppression paradigm in disability research does not refer to disability as a closed, ahistorical and static category, but is open-ended, referring to how oppression is imposed, meaning it is dynamic and expressive of the antagonisms of disablism. If disablism is viewed from the perspective of struggle, there can be no permanence or certainty in our theories. This is to say that negation or struggle means openness of social development and the inadequacy of concepts and their incompleteness in the face of ever evolving conditions of struggle (Bonefeld, 1987). A focus here on struggle and an opposition to the errors of fetishism is valuable, again sensitising us to the ever-present possibility of resistance and the openness of a society characterised by this dynamic effort to control resistance. Applying these ideas to disability studies means theories that guide resistance must be reformulated as continuously as disablism is reformulated and re-inscribed.

### **Holloway, Negation and the Self-Activity of Anti-Disablism**

I have noted in brief above that a key point for Open Marxism is the antagonistic presence of labour within capitalism and the need to contain the self-activity of an autonomous force at the heart of the system. I will go on to apply this insight to anti-disablism, but will first need to briefly depart from it to explain further what this involves.

Drawing influences from autonomist Marxism and Adorno (1992), Holloway (2011) argues that it is important to break with most discourse on 'the left' which begins theory from a concern with domination. What is important about his approach, and others in the autonomist Marxist tradition, is that it inverts these approaches and begins with resistance. Holloway (2011) puts this in the following context:

This is an inversion of fundamental importance, simply because to begin from domination means to enclose oneself within the categories of domination, so that the only possible way of breaking from domination is through the intervention of an external force<sup>49</sup>.

In other autonomist accounts (such as Hardt and Negri, 2000) the self-activity of the working class replaces capital as the driving force of changes in capitalism. Due to the subversive and dynamic power of the working class 'capital responds, trying to decompose the working class, which leads to a recomposition of the working class and a new wave of struggle, a new decomposition, and so on in a constant movement of composition – decomposition – recomposition' (Holloway, 2011). Holloway values this way of analysing capitalist development, but for him it can too often lead to a static concern with characterising the present stage in the composition-recomposition and periodising previous discontinuities between different paradigms of labour and accumulation. This slippage can undermine the central achievement of autonomism and distract from its original intention to put struggle back to the forefront of analysis.

To protect the status of struggle within analysis, Holloway argues that the insight of autonomism must be combined with a 'conceptual revolution'. This means viewing capitalism from the point of view of its 'negation', not just replacing the power of domination with the power of the working class, but further changing our theoretical vocabulary to reflect the dynamism, instability and crisis-creating goals of the working class. Holloway puts this in the following way:

The working class exists as negation of capital, that is, as crisis. The emphasis, then, is not on the restructuring of capital (as tends to be the case in positive autonomism), but on crisis [...] Crisis is the centre

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<sup>49</sup> <http://www.johnholloway.com.mx/2011/07/30/negative-and-positive-autonomism/#sdfootnote1sym>

of thought because what interests us is not the stability of capitalism but its instability, its fragility. Marxism is not a theory of the reproduction of capitalism, but of its crisis' (ibid).

I think a similar point of view can be applied to disablism and anti-disablist resistance. Clearly there are important differences between anti-capitalism and anti-disablism in many respects. Referring to Fraser's (1995; Fraser and Honneth, 2003) analysis of injustice, the configuration and degree of economic and cultural injustice facing either group will differ. Furthermore, while the goals of disabled people and the working class may overlap, there may be important differences in their ultimate goals. For example, autonomous Marxists like Holloway would take an extremely suspicious view of the state as a vehicle for progressive social change, whereas most disabled people would see elements of the state as indispensable and as fundamental to their attempts to prevent marketization of the welfare state.

Nonetheless, I think elements of Holloway's analysis can be applied to anti-disablism, shedding a different light on the struggle involved. In the first instance, the inversion from analysis that begins with domination to analysis that begins with resistance has parallels with the beginnings of the modern DPM in Britain, as anti-disablist activists disrupted their oppression in institutions, through their struggle creating fissures in the fabric of disablism as it then stood. To further apply this inversion, it could be argued that the resistance of disabled people to institutional disablism forced disablism to reconfigure and take new forms, mutating into a more commodified and individualised form which I have expressed as enforced individualism. This highlights the fragility and instability of disablism as it struggles to respond to opposition.

In this light the ideas of the movement can be seen as an expression of the negation of disablism. For example, the social model could be seen as emerging directly out of negation, expressing the opposition of activists to disabling barriers and structures. This is to say that the social model did not grow out of detached contemplation of oppression, but expresses a prior political process of opposition *already at work*. This speaks to the origins of disability studies in the theorisation of disabled activists. Their development of theory was not for its own sake but from a

position of dissonance with the disabling world. Just as Marxism may be understood as an articulation of what Holloway calls the 'No' or 'Scream' against capitalism (2002; 2005) so too can the social model of disability be understood as an articulation of the negation, or 'No' against disablism. A reading of the social model as negation does not impose this view onto the social model, but recognises that the social model evolved from within political campaigns to overcome or 'negate' disablement. Therefore, the social model and work in the 'social oppression paradigm' (Thomas, 2012) can be seen as expressing negation, viewing disablement as an on-going process, analysing it from a point of view which assumes the possibility of non-disablism.

The urgency of negation suggests that disability theory should not be an academic exercise in theorising the stability of disablism and domination of disabled people. As it becomes embedded in academia, there is a tendency for disability studies to become detached from activists and their organic knowledge of their struggle, contemplatively and uncritically accepting the givenness of disablism which many disabled people are actively resisting. In this context, theorists who offer a structural analysis of the reproduction of oppressive social structures can fail to adequately account for the central role of resistance, and risk slipping into prescribing what is necessary for the reproduction of oppression to continue (Holloway, 1991). Theory informed by the negativity of struggle runs against this, giving the social model the quality of 'movement relevant theory' (Bevington and Dixon, 2005).

## **Unity in Diversity**

Of final relevance to applying Open Marxism to disability studies is the promise it holds for balancing unity and diversity in the politics of disablement. A persistent and telling criticism of the social oppression paradigm is that it excludes difference, assuming a common process of disablement and common identity in opposition (Vernon, 1996; 1999; Dowse, 2001). Importantly in this context, thinking in terms of negation can help to reconcile unified resistance with diversity of experience and identity. In Holloways terms: 'No is unity, yes is multiplicity, one no, many yeses' (2005: 266). By starting with the 'No' against disablism and individual models of disability, the social oppression paradigm gives internal unity to the diverse expressions of positive identity contained

within disability politics. This can help to overcome barriers to unified political action such as the perception among some disabled people that there are 'hierarchies of impairment'.<sup>50</sup>

Negation is more difficult to assimilate than the yeses of positive cultural identity as it is constantly preoccupied with movement beyond disablism in its manifold forms. According to Holloway, if you begin with the yeses of multiple positive identities, unity will quickly break down and the forces of anti-oppression is weakened. By beginning with negation, the question of a positive alternative is posed, as those united in negation consider what alternatives they endorse, leading to a process of dialogue (ibid). This is not to deny the importance of the yeses, but 'to understand that they must be understood within a negative logic' (ibid: 266). In order to illustrate this point, I use the following quote from Holloway, replacing his use of 'capitalism' with 'disablism':

Our no [to disablism] is something we share, something that invites us to connect with other expressions of the same no, a coming together that is not a question of building alliances but of extending our own no. The yeses invite us to focus on our own autonomous spaces or movements, to strengthen and deepen them, that is important, but we need more than that. The no leads us rather to

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<sup>50</sup> Scholars such as Deal (2003) and Reeve (2004) discuss hierarchies of impairment. This term refers to the way in which both disabled and non-disabled people can draw distinctions between those in different impairment groups, ranking them on criteria such as functional limitation (Deal, 2003).

Deal explains hierarchies of impairment through the human tendency to base one's ego and self-concept on in-groups and out-groups. In other words, placing other people into an out-group can raise one's esteem by locating oneself in a group that is ranked above the out-group. Thus when in a group made up only of disabled people, disabled people often identify with impairment specific groups (ibid). Of possible significance at a time of greater scarcity in disability benefits and social care payments, Deal notes that hierarchies of impairment can create suspicion of the use of resources by members of other impairment groups. It might be argued that this risks undermining the collective opposition of disabled people to shared challenges. Deal suggests that such problems can be overcome by disabled people choosing not to identify with an impairment-specific group, but as part of the broader category of disabled people. This, he asserts, can facilitate challenges to common problems and the identification of those groups which are treated worst in contemporary society.

Reeve (2004) describes the damaging impact hierarchies of impairment can have in practice, highlighting the experience of a research participant who had been made to feel isolated and excluded because her impairment had been judged by other activist to not constitute a 'real' basis for her to be identified as a disabled person. In this way, Reeve shows how the functioning of such a hierarchy can mean the DPM excludes disabled people perceived to be different or less disabled. For Reeve (2004) this behaviour is an example of internalised oppression, as disabled people absorb the categories into which society has placed them, adopting them uncritically and using them to exclude others. This, in turn, can be an important part of psycho-emotional disablism (see chapter nine).

think of our struggles as cracks or fissures in the texture of [disablism], cracks that derive their strength from spreading. Where the yeses invite us to build beyond [disablism], the no reminds us that the only beyond that makes sense is an against-and- beyond, and that although we may have different dreams of the beyond, we all share the same against (ibid: 266).

In this reading, negation of disablism opens up a new world of possibilities and concepts, but in a world of disablism we must begin with negation. Practical examples of negation could potentially include DPOs. To think of anti-disablism territorially, it may be that these spaces, in which the negation of disablism finds practical expression, are places where the ideas of disablism do not apply to the same extent. Growing from this perspective, alternative practices may develop in spaces characterised by other values. Such practices may be asymmetrical to those in more disablist environments and may even prefigure those of non-disablist futures. However, when these spaces begin to break down and integration into the state-corporate nexus occurs, their independence is weakened, the asymmetry of practice disappears, and the refusal articulated by the social oppression paradigm becomes more affirmative of the status quo. This brings to mind concerns about the closeness of some DPOs to government (see chapter one) and the difficulties that DPOs must navigate in maintaining political independence while securing contracts through the process of competitive tendering that were raised by participants.

## Summary

I have suggested that the application of an Open Marxist approach to the social oppression paradigm can highlight why negation and politically relevant theory continues to be important. Through an emphasis on negation and struggle against disablement, theories are rendered more flexible because they are subject to change at any moment through political struggle. This can also help to guard against theorists becoming overly enchanted with the elegance of their theories and the complexity of their constructions, constantly reminding them of the need to produce work that theorises the instability, and not just the reproduction, of disablement. Arguably, an anti-disablist social oppression paradigm, based on negation, can be valuable in reconciling both a degree of political unity and diversity. Because it is founded above

all on the conceptual importance of struggle and resistance, it may also be endowed with qualities of urgency and movement-relevance. It may then be appealing as an approach around which resistance can occur.

In closing, I argue that although the idea of negation may seem pessimistic or depressing, its strength is that it invites unity between diverse groups who share an opposition to a force of oppression. Diverse positive alternatives are essential, and negation would be nonsensical if something else could not be done instead, but beginning with positive alternatives can lead to a focus on where actors differ rather than what they share. Celebration of positive alternative micro-cultures can do little to challenge more general patterns of oppression that constrain the wider creation of positive alternatives. In this context it's important that negation breaks with disablism, informing prefigurative practices that could herald non-disablist futures. Even if alternative positive practices partially reverse widespread patterns of oppression within a limited territory or group of minds, wider patterns of oppression, such as those of isolation, enforced individualism, and economic or cultural disablism will persist unless they are challenged. Creating positive alternatives to a society characterised by disablism is the ultimate goal, but struggle and negation unlocks the potential latent in alternatives. Applying these ideas, the 'social oppression paradigm' in disability research could continue to embody this negation of disablism.

## **Part Two: Fraser and Orientating to the Present Conjuncture**

In this section I will again draw on the social theory of Nancy Fraser for a quite different purpose than my use of Holloway and Open Marxism in the section above. I believe that Frasers' analysis (2013) offers a powerful means of conceptualising the political situation in which current struggles against disablism are located, characterised by the significant challenges facing disabled people and disability activists. It is my contention that Fraser's analysis of feminism holds relevant lessons for disability theory and that many of her conclusions can be read across into disability studies.

Within interviews for this study it was apparent that broader and more complex strategic dilemmas occupied participants' attention, along with more immediate goals. In the following interview excerpt Nancy gives a good example of this, noting the difficulties of advocating individual rights in a neoliberal environment:

"I think there is a problem [...] with asserting individual rights and demanding autonomy, which is what choice and control is about, in the context of neoliberal economic policy and rising individualism. I think there's an enormous contradiction between that one encounters and it's too easy to fall into a position which would support privatisation and the market, because the market is supposed to deliver choice and it doesn't. And that was the contradiction that was inherent in the demand for direct payments, which is based on the idea that if you give disabled people purchasing power, that's how they achieve autonomy, but there's problems with that. But that's not to say choice and control are bad ideas or that direct payments are a bad idea, just that we shouldn't be sucked into the neoliberal individualist framework."

The difficulty in avoiding support for greater privatisation and neoliberalism when demanding greater individual rights is arguably indicative of broader dilemmas concerning how to orientate to contemporary political-economy. It is Fraser's (2013) belief that the current crisis of neoliberal capitalism is leading to changes in feminism as it attempts to grasp the changes driven by the current crisis. As a prolonged recession affects production and employment in many parts of the developed world, the human cost is paid for by many in the form of impoverishment and growing inequality. Fraser asserts that this crisis of capitalism serves as the 'inescapable backdrop' to feminist theorising which must take heed of the pressures it brings for many women. From the evidence in chapter two of this thesis and the contributions of participants, it is clear that the crisis and its affects are having a similar or even worse impact on many disabled people in Britain. Those who experience compound injustice such as disabled women may experience additional oppression, meaning intersectional analysis may be of relevance to understanding the combination of injustice they face.

Fraser (2013) is not merely arguing that the capitalist crisis is an increasingly important backdrop to feminist theorising, but also that it has come as a shock to many feminist theorists who have avoided the 'large-scale' type of theorising needed



to address the global forces that have driven the economy to near collapse. Instead, Fraser argues, feminism has tended toward ever greater specialisation, as feminist theorists have eschewed the type of theorising associated with political–economy in favour of disciplinary niches. To some extent this has been driven by legitimate concerns that large-scale theorising of political-economy has tended to be reductive and/or deterministic, holding that other domains of inquiry should be understood as secondary to the theorisation of the ‘objective forces’ of the economy (ibid). This may have been a reasonable motivation for leaving behind large-scale theorising, but it has served to distance feminism from political-economy, meaning it is ill-equipped to deal with the ‘unavoidable questions’ of the nature of the crisis, ‘as well as the prospects for an emancipatory resolution’ (ibid: 277).

I think many of these insights can be applied to disability studies. Just as feminism has grown away from political economy and large-scale social theorising, arguably, so has disability studies. In some ways this has been a sign of the maturation of the field, as theoretical diversity has grown and diverse methodologies have been brought to bear on disability issues. Combined with the roots of disability theorising in Marxism and historical materialism (Finkelstein, 1980; Oliver, 1990) the maturation of the field may have led some to conclude that theorising the relation of disability to political economy and capitalist crisis is outdated or necessarily reductionist. With little contemporary discussion of political-economy and disability remaining in disability studies, it has, like feminism, been poorly positioned to theorise the unavoidable importance of the economic forces which have driven public sector cuts, and in turn, driven multiple challenges for many disabled people.

Again taking my cue from Fraser’s analysis of feminism, I argue that disability studies requires a means of responding to the significance of capitalist crisis without returning to economistic approaches that subsume non-economic factors within accounts built upon the assumed deterministic power of economic forces. To develop an understanding of the crisis of capitalism that conceptualises crisis as a social process, involving a wealth of non-economic factors, Fraser turns to the work of Polanyi (1944). Polanyi’s theory of crisis is ‘less about economic breakdown in the

narrow sense than about disintegrated communities, ruptured solidarities and despoiled nature' (Fraser, 2013: 228).

## **The Value of Polanyi's Work**

Polanyi's work (1944) is massive in scope, concerning the historical period in which capitalism grew throughout most of the world. Within this, he provides a compelling theory of crisis which does not locate the ultimate cause of crises within the economy, but in the relationship between the economy and society. For Polanyi, this can most productively be theorised by reference to the 'double movement' between two conflicting forces. On one hand, there is the force of marketization that seeks to disembed markets from the social institutions and ethical/cultural norms in which they have historically been embedded. This is the product of attempts by proponents of the self-regulating market to construct societies which are subordinate to market forces. Polanyi shows how these ideas came to prominence during the birth and subsequent growth of a distinctive nineteenth century set of economic beliefs, usually known as classical liberalism. As proponents of these ideas set to applying them in economic policy, Polanyi charts how the goal became to commodify more and more of what had previously been seen as beyond the scope of market forces. This runs counter to much of earlier history in which markets were embedded within social and ethical rules such as the idea of a 'fair wage'. The political project instigated by proponents of the self-regulating market to overturn the embedding of markets in social institutions in turn provokes a counter-movement for the protection of society. Polanyi views those in support of 'social protection' as engaged in a struggle to shelter and protect elements of society that are newly exposed to the ravages of the free market. The conflict between 'marketisation' and 'social protection' forms the 'double movement' of conflict at the centre of Polanyi's theory.

Polanyi's analysis is clearly relevant to today's crisis, and especially the challenges facing disabled people. In the present day neoliberalism is commonly understood as a renaissance in the ideas of classical liberalism that Polanyi describes. Again free-marketeers seek to commodify ever greater tracts of social life. For example, the marketisation of social life is arguably apparent in the development of

the work capability assessment (WCA) for recipients of PIP and its implementation by the private sector firm ATOS. The WCA has been the subject of significant criticism by disabled people, one reason for which has been the high number of people declared fit to work who have previously been classified as disabled (Guardian, 2014). The reaction to the WCA and related reforms could be read as the emergence of an oppositional force dedicated to 'social protection', as they mobilise to protest against the erosion of sensitivity and the welfare safety net that is manifest in the success of attempts to commodify previously publically provided services. This opposition, and contemporary marketization, appear to fit well with Polanyi's double movement.

Fraser finds much to recommend Polanyi's analysis to feminism. In particular, the centrality of social reproduction to his account avoids economic determinism. For Polanyi, crisis is not just a question of the destruction of social values underpinning the market. Capitalist crisis is at one and the same time a social crisis as unconstrained market forces destroy social bonds. This aspect of Polanyi's theory also has something to offer disability studies. Recalling data concerning the social impact of austerity policies from earlier in this thesis, it is apparent that the current economic crisis is as much a social crisis, breaking apart fragile provisions necessary to maintain independence for many disabled people. The existence of social crisis is also arguably apparent in the forms which opposition has taken, through the telling of individual stories, showing how the economic crisis is also a social crisis, as individual lives are devastated by the impact of austerity and marketisation on disabled people (e.g. Benstead *et al*, 2014).

Another valuable element to Polanyi's analysis is that it does not reject markets entirely but only criticises disembedded markets. He is against markets that are unconstrained by moral and social rules and form part of a wider political project to marketise ever greater elements of social life. This means his theory can align with the conviction of disabled activists that empowerment is possible through markets in 'care' and support, provided they are embedded in moral norms, which ensure disabled people have adequate guidance and resources with which to navigate markets and gain the most from them. Social care market conditions at present, characterised in part by the absence of sufficient resources to gain from purchasing services, could be

described as disembedded markets. The functioning of such markets is increasingly divorced from the norms which disabled activists have articulated, and are arguably part of the project to marketize ever greater tracts of social life.

Having established some reasons for which Polanyi's analysis can be applied to the current situation of disabled people, I now go on to explain the critique of it given by Fraser, and the resulting 'quasi-Polanyian' alternative she offers.

### **The Shortcomings of Polanyi's Analysis: Fraser's Quasi-Polanyian Framework**

For all of the initial value of Polanyi's non-economistic analysis, there are definite shortcomings to his approach. His is a clearly evaluative framework in which embedded markets and social protection have a positive role, protecting society and individuals from the ravages of the market. Conversely, disembedded markets and marketisation have a clearly negative role, removing social protection and exposing society and its constituent members to the market. Although this captures an important dynamic, Fraser claims that it 'tends to whitewash forms of social protection that are at the same time vehicles for domination' (2013: 229). This is an important point for disability studies/disability activism. Some forms of 'social protection' have often been seen as functioning in the lives of disabled people as oppressive institutionalisation or paternalistic 'care' (Barnes, 1990). Contrary to Polanyi's strictly evaluative framework, marketisation in such a situation can serve to undermine oppressive and entrenched arenas of public sector provision of 'care' in which power is held over disabled people. This is possible because society, as well as the economy, can be a vehicle for oppression. In line with this reasoning, Fraser criticises Polanyi for romanticising society and uncritically accepting it as the sanctuary from the ravages of the market

For Fraser, this requires a revision of Polanyi's theory, which can follow his lead in avoiding economism, but also avoid romanticizing society. Fraser's revision of Polanyi's framework introduces a third force into his double movement, adding 'emancipation' to marketisation and social protection to form a triple movement. Emancipation can be reduced to neither marketisation nor social protection. As a third

force, emancipation opens up both the economy and society to critique, with both viewed as arenas in which domination can potentially operate. It can attend to the values in which markets are embedded, for example through a critical analysis of hierarchies of disabled and non-disabled identities, or it can attend to the disablist norms which underpin distribution or social protection. Equally, it could address more clearly economic questions such as access to the jobs market, to one's own property, or to the elite professions (Fraser, 2013).

In other words, whereas social protection is against the exposure of individual and society to market forces, emancipation is against domination in both market and society. This better describes the struggle against the forms of domination I described, using Fraser's theory, in chapter eight. Here we saw how the challenges facing disabled people could neither be understood as purely economic in nature, nor only as cultural or status subordination. Responding to these challenges requires not only a response to economic subordination, as Polanyi might endorse through greater social protection, but also Fraser's category of emancipation to address domination in both forms.

Grasping the triple movement at work gives a richer perspective on capitalist crisis as a three-sided conflict. To understand what is at work within a crisis requires an appreciation that marketisation, social protection and emancipation are 'conceptually irreducible, normatively ambivalent and inextricably entangled' (Fraser, 2013: 235). They cannot be grasped alone and must always be seen as inter-related. To be more specific, the relation of any two must always be mediated by the third (ibid). Thus the movement between marketisation and social protection cannot be understood without reference to emancipation. Without reference to emancipation, domination could emerge with social protection that 'shelters' people from market forces. Equally, the movement between social protection and emancipation cannot be understood without reference to marketisation. For Fraser, feminism has failed to grasp that the struggle against domination in social protection is played out in a context in which the forces of marketisation also exist. Fraser's point here is that attempts to dismantle domination in social protection can lead not just to the erosion of a specific form of social protection but can contribute to erosion of social protection in general. That is,

as domination through social protection is rightly attacked, forces of marketisation, which are far from benign, seize the opportunity to create new forms of marketised domination. This means that feminism needs to recall Polanyi's original warning of the deleterious effects of marketisation and understand the background of marketisation against which campaigns against oppressive social protection are forged.

Applying this to disabled people's situation means that although the marketisation of social care could be questioned, this doesn't have to undermine the autonomous involvement of disabled people as participants in markets for the support services they use. Marketisation in the case of disabled people's support takes a form that disempowers many disabled people, but arguably doesn't have to characterise the provision of *all* social care via market transactions. The process of marketisation in disabled people's support services has taken the form of 'accumulation by dispossession' (Harvey, 2005), meaning the state has reduced benefits and provision of services while steadily increasing the funds awarded to a small number of private sector providers of services and assessments accessed by disabled people. The preferred contractors tend to monopolise the provision of benefit assessment and care provision. Their increasingly empowered position vis-a-vis the position of many disabled people characterises the marketisation of disabled people's services. A consistent power imbalance and the relative enrichment of providers via accumulation by dispossession risks putting private sector monoliths in positions of undue influence over disabled people who lack the resources to interact with the providers of support services on an equal footing.

It is important to consider whether the criticism Fraser makes of feminism opening the door to marketisation could also be applied to disabled activists and their attempt to dismantle institutional domination in favour of direct payments. It might be argued that by demanding the erosion of institutional domination disabled activists played a role in eroding social protection for disabled people in general. However, I think this would be a mistaken conclusion. The DPM was from an early stage informed by historical-materialism and Marxism, so it was already well-attuned to the background presence of market relations in the struggle against institutional domination. By consistently asserting the importance of the social interpretation of

disability, the presence of disablist social structures, and the requirement for resources adequate to deliver independent living, it could be argued the movement has always combined critique of institutional domination with demands that markets are embedded in non-economic values which demand disabled people have what is needed to successfully navigate markets. The DPM could therefore be seen as an exemplar of Fraser's triple movement, criticising domination through social protection and marketisation, while displaying an awareness of the political-economy of marketisation against which these criticisms were made. The predominant influence of neoliberal ideas in recent decades (Harvey, 2005) may have meant that political powerful proponents of marketisation were more receptive to the DPM's criticism of domination through social protection than its criticism of domination through marketisation and its demand for greater social protection.

Orientating to current challenges, disabled activists may be well placed if they are able to retain their historic commitment to theorising emancipation, social protection *and* marketisation, recalling early seminal texts in disability studies. In the present climate, this means taking account of the fact that Neoliberalism is a project of marketisation. This would mean that future critiques of disablism must avoid undermining social protection in general while they critique institutionalisation and professional control (Morris, 2011).

## Summary

Navigating this territory can be difficult and complex. Criticism of neoliberal policy narratives, marketisation and enforced individualism must be expressed in a way that cannot be mistaken for a failure to assert individual rights/autonomy or be seen as a flawed endorsement of the excesses of paternalism. An analysis of disability within political economy is best placed if it can also sustain demands for autonomy and individual rights within an analysis of neoliberalism that prevents any misunderstanding that support for individual rights and autonomy could mean support for neoliberalism.

To better negotiate these tensions, it is useful to draw on Fraser's (2013) argument that all of the three forces at work in her triple movement are 'ambivalent'. Marketisation can work precisely as Polanyi described by undermining valuable social protection, but it can also be valuable on the occasions when it dislodges social 'protections' that are oppressive. Social protection plays the role attributed to it by Polanyi by restraining and embedding market forces, sheltering society from the ravages of the market. At the same time, it can function to oppress and control in the name of protection. Even emancipation is ambivalent. It produces liberation but also 'strains in the fabric of existing solidarities. Even as it dismantles domination, it can dissolve the solidary ethical basis of social protection, clearing the way for marketisation' (2013: 236). That is to say by challenging domination in economy and society, emancipation can fragment aspects of solidarity tied up in systems of social protection, thus creating opportunities for marketisation. Each of these ambivalent aspects of the triple movement provides an important means of theorising disablism and its context in neoliberal societies. Progress has been made against domination in social protection but perhaps less against marketisation. As I note above, proponents of the self-regulating market are ready to hear critiques of social protection in disabled people's lives, but are largely deaf to criticism of marketisation and the progressive destruction of social protection. Orientating to contemporary disablism today may mean that the role of marketisation is attended to with renewed scrutiny.

For Fraser, feminism needs to address marketisation, and the project to 'autonomise and extend markets'. In her terms, this requires a coalition between forces of emancipation and social protection against marketisation, at the same time remembering that social protection can also operate as an arena for domination. Arguing that feminism needs to do more to adequately theorise neoliberalism and marketisation, Fraser is not, of course, claiming that struggles against domination through social protection were mistaken. To argue against marketisation is not argue that emancipation from oppressions in the social sphere led causally to neoliberalism. Fraser's case is that the critique of domination and oppression present in social 'protection' operates on a terrain also populated by marketising forces. Increased



awareness of this, both in feminism and disability studies, can orientate these disciplines to prevalent contemporary forms of injustice wrought by marketisation.

Coming to a close, we have seen that Fraser's analysis help us understand why divisions and tension have emerged in the movement, as prevalent forms of activism struggle to adapt to changing challenges. We have also seen that Holloway's ideas encapsulate the nature of responses to current challenges, and show how disability studies can struggle to adapt to the urgent form that activism takes. Holloway and Fraser's ideas are therefore complementary. Fraser's analysis helps analyse the challenges facing the DPM, and Holloway's Open Marxism aids our understanding of strategies and positions taken by activists. In the next and final chapter I conclude by summarising the thesis as a whole, before turning to potentially fruitful future avenues for research.

# Conclusion

## Summary of the thesis

At the outset of this thesis I charted the rise of the DPM and summarised the mounting evidence of challenges to disabled people, describing some prominent responses and disagreements that have emerged in reaction to this situation. Building on this background, I set out to offer an original account of current challenges to disabled people and the DPM, while also theorising the positions taken by activists, and the political implications of this. As a result of engaging with these questions, I believe I have also contributed towards an understanding of the relationship of disability studies to the DPM.

Central to my account of current challenges to disabled people and the DPM, was my use of Roulstone and Morgan's (2009) notion of enforced individualism. I used this idea to describe shifts I identified at individual, collective and ideological levels. To be specific, this involved the challenge of the growing isolation of individuals, problematic conditions facing DPOs in the 'care' and support marketplace, and obstructive notions of empowerment. The notion of enforced individualism was of further use in expressing the dynamic movement in prevalent forms of disablism, as I suggested that disablism had changed from being characterised by enforced collectivism to a situation in which this coexists with enforced individualism. At the ideological level, enforced individualism also conveys the difference between the DPM's grasp of power inequalities in its notion of 'choice and control', and ideas of 'choice' underpinning policy, which lacked an analysis of power or inequality. I inferred from this analysis that popular narratives of empowerment such as personalisation lacked the necessary grasp of structural disablism and power inequalities that have in the past been articulated by the DPM and disability studies. Building on this analysis, I contextualised these changes by attempting to integrate and apply Thomas' social relational approach and Fraser's notion of bivalency, in both cases offering valuable ways of grasping the nature of contemporary disablism.

In my attempts to give an account of responses to these challenges, I noted apparent cleavages and points of differentiation at work within the movement. Among important points of contestation were views taken on the social model, the primacy of economics and the importance of cooperation with government. I brought out the implications of these positions and analysed how the movement could respond to current challenges, by drawing on Fraser's account of the difficulty feminism has had in responding to resurgent neoliberalism. In this case I suggested that the DPM and disability studies might benefit from engagement with political economy, allowing a deeper interrogation of the causes of, and justifications for, austerity economics. In my view, Fraser's analysis of feminism and her adaption of Polanyi's work can offer much to those wishing to consider future political theory and strategy. I also argued that Open Marxism and particularly the work of Holloway offers a compelling means of articulating the requirements of movement-relevant theory. Research into disabled people's lives does not have to be concerned with politics, but disability studies has historically been the one area of academia primarily concerned with the politics of disablement. Open Marxism reminds us of the birth of disability studies in dissonance and in the negation of disablism, and warns of the damage that can result from ignoring disablism. Of course, this is not to say that studies of a multitude of factors, including the study of discourse, are not legitimate areas of inquiry. Indeed the language and discursive construction of current challenges to disabled people is a vital and complementary area to what I have discussed in this thesis.

### **Future possibilities for research**

When I described the development of my approach in chapter three, I explained the broadening of topic to encompass a wide range of disabling challenges that many disabled people currently face. Even within the broader approach I have taken, there have been important current threats and challenges which have been omitted. Among the more obviously significant topics that I have omitted are disabled people's position in the labour market (Yates and Roulstone, 2012), and the growth of disablist hate crime (Roulstone and Mason-Bish, 2014). If I were to pursue further study of disabled people's situation in a more holistic manner, I would try to integrate these topics

within my work. Their absence in this thesis was in part driven by the concerns of my participants, and in part by the need to limit the number of topics discussed to a manageable number.

Theoretically, the greatest omission may be the lack of intersectional analysis of the impacts of austerity. Analysis of this sort could illuminate the way in which cuts and reforms are experienced differently by disabled people of varying characteristics, situations and identities. Deepening my own understanding of intersectionality might allow me to better grasp how the basic insight of intersectionality can be applied in analysis. By focusing on disabled people in this thesis, I do not mean to have diminished the importance of other political struggles or to imply that disabled people are not in many cases part of these struggles. Indeed, the impact of the challenges I have described will also interact with other forms of oppression and privilege. For example, it may be that working class unemployed disabled women may have been particularly affected by recent changes to government policy. The evidence collated in chapter two of this thesis and in interviews suggests profound and multiple challenges for some disabled people. This does not mean that I endorse a hierarchy of oppression in which disabled people are assumed to experience the greatest degree of oppression. A sensitive intersectional analysis is enriched by drawing upon more specific and detailed studies of the oppression experienced by particular groups.

Another area in which I believe my work could be further developed is through additional insights from social movement studies and political theory. Surprisingly little is drawn from these disciplines in disability studies considering that the field has a close relationship to the DPM. Finally, I also believe that further work could be directed towards the empirical aspects of the current challenges to disabled people and the DPM. In this light, it is noteworthy that non-academic researchers have published the most systematic studies of this sort (see the work of Young, 2014 and Duffy, 2014 that I reviewed in chapter two). Disability studies would be well served to engage in this crucial area of research, and I would personally like to be involved in the production of future research into the impacts of government policy on disabled people.

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