These Days Are Ours:

Exploring Young Disabled People's Experiences and Views of the Disabled People's Movement

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The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

This thesis explores challenges encountered by young disabled people participating and engaging within the UK Disabled People's Movement (DPM). Challenges they face were identified following a qualitative investigation. Seventeen semi-structured interviews were conducted with both young disabled people and established members of the Movement. The thesis argues that, for the Movement to be inclusive, remain committed to the social model of disability and accessible to young disabled people, the DPM must provide young members and newcomers with the resources and support to offer a vision for a new and inclusive society. To achieve this, the social model should be repositioned: from a tool/strategy to an "oppositional device" (Beckett and Campbell 2015) that provides counter-rationalities and disrupts the normative practices inherent in the political, economic, and cultural realms.

The thesis opens by exploring prominent debates pertinent to the situation of disabled people in contemporary society. It focuses on the politicisation of disability and the intrinsic aspects affecting young disabled people's participation within activism and campaigning. Then follows a review of social movement literature charting the development and existence of (new) social movements, and how the DPM is understood in this field. An Emancipatory Disability Research approach is employed. It led into an original account of key challenges articulated by young disabled people as they attempt to participate in the UK DPM. These are positioned around three central themes: membership, organisation of the Movement, and future considerations that will affect the DPM's sustainability. Through existing literature, the research delineates a way forward; its emphasis lies on oppositional devices. The thesis addresses directly the concerns raised by respondents. It will prompt discussion - within and outside of academia - on the standing of young disabled people within the DPM. The research contributes towards an understanding of youth and disability activism.

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List of Abbreviations

ALLFIE – Alliance for Inclusive Education
DAM – Disability Arts Movement
DPAC – Disabled People Against Cuts
DPM – Disabled People’s Movement
DPO – Disabled People’s Organisation
EDR - Emancipatory Disability Research
ENIL – European Network on Independent Living
ICIDH – International Classification of Impairments, Disabilities and Handicaps
IEM – Inclusive Education Movement
ILF – Independent Living Fund
ILM – Independent Living Movement
LDA – Leeds Disability Archive
NDACA – National Disability Arts Collection and Archive
NDY UK – Not Dead Yet UK
ROFA – Reclaiming Our Future Alliance
The Movement – Disabled People’s Movement
UK – United Kingdom
UN – United Nations
UNCRPD – United Nations Convention on the Rights of Persons with Disabilities
UPIAS – Union of the Physically Impaired Against Segregation

1. Scope of the Research

1.1 Introduction

Accounts by prominent disabled activists, reinforced by literature from Disability Studies, states that the Disabled People's Movement (DPM) is in crisis; furthermore, there are questions regarding its diversity, sustainability, and effectiveness. The thesis highlights challenges encountered by young disabled people as they participate in and engage with the Movement. The thesis argues that for the Movement to be inclusive of young disabled people, it should remain committed to the social model of disability. Furthermore, it needs to provide young members and newcomers with the resources and support to offer a vision for a new and inclusive society. To achieve this, the social model should be repositioned from a tool/strategy and, rather, be recognised as an "oppositional device" that provides counter-rationalities and disrupts the normative practices inherent in the political, economic, and cultural realms. The thesis predicts that if this were not to happen, the challenges identified will intensify; young disabled people will disengage from the Movement, leading to its occupation by individuals who will undermine or reject the social model of disability.

This chapter introduces the research, explaining the scope and structure of the thesis. It begins by acknowledging how the DPM is an integral entity for challenging the oppression and exclusion experienced by disabled people. Nevertheless, there is insufficient literature on and research into the role of young disabled people within the DPM. Here, “the DPM” is understood as a term to describe the collective political action of disabled people in Britain. The Movement is organised to challenge disabled people's marginalisation, a phenomenon that emanates from the political, economic, and cultural realms within the social world. It has a commitment to the social model of disability (UPIAS 1975; Oliver 2013) that provides the basis for the organisation of the Movement, despite certain concerns and reservations. The chapter argues that the thesis is well placed both to review the challenges experienced by young disabled people as they participate within the Movement, and to produce recommendations that will ensure it remains a sustainable and effective Movement. At this point, the originality of the research and contribution to the existing body of knowledge is provided. The chapter then outlines why I intended to embark on a PhD. It highlights the significance of reflexivity and my commitment to ensuring the research produces outputs that are meaningful and helpful to disabled people's emancipation. The final section provides for each chapter of the thesis a description and summary of the respective key points.

At the outset, it is necessary to outline the terminology used within the thesis. Although respondents and pockets of the literature refer to disabled people as a "person with a disability/people with disabilities", for the purpose of uniformity of language this thesis uses the term "disabled person". This is for reasons of consistency with the social model of disability. The use of person first language will be employed only when a direct quotation is offered.

1.2 Introducing the Topic and Research

Social movements and activism are considerable points of interest for those working within Disability Studies; they provide an opportunity to explore how the premise of disability is articulated from the perspective of human and civil rights, illustrating the methodologies and agendas employed by disabled activists, campaigners, and their organisations to question the root causes of marginalisation. The collective organisation of disabled people within the UK is well documented in historical and contemporary accounts. Media outlets (Briant, Watson and Philo 2013; Pearson and Trevisan 2015; Disability New Service), art productions (Taylor 2005; Kuppers 2014; Millett-Gallant and Howie 2016) and academic literature (Campbell and Oliver 1996; Williams-Findlay 2011) document the trajectories taken by individuals and groups to create solidarity in order to achieve disabled people's emancipation.

Since the 1970s, globally, Disabled People's Movements (DPMs) have played a vital role in highlighting disabled people's exclusion and disability as a social justice issue. Activists involved in "disability politics" have framed disability as a form of social oppression perpetuated by political, economic, social, and cultural structures. Thanks to the resistance practices of disabled people, disability is now recognised internationally as a human rights issue (*see* UN Convention on the Rights of Persons with Disabilities [UN CRPD]). The struggle for social justice for disabled people in all societies is, however, far from over: there is need for on-going work by disabled activists to ensure that disabled people's human rights are indeed respected. The sustainability and effectiveness of DPMs around the world relies upon the inclusion and participation of successive generations of disabled people. Worryingly, there is a lack of research exploring young disabled people's interests and ability to engage with established DPMs. This problem is not unique to DPMs. Many "traditional" social movements struggle to captivate young people (Gordon 2007; Taft and Gordon 2013), despite the existence of important questions about their futures and, sociologically, about differences between generations in the context of engagement with grass-roots politics (Castells 2015). The European Network on Independent Living (ENIL - an international Disabled People's Organisation [DPO]) and Council of Europe highlight the importance of young disabled people's participating in DPMs and the development of future movement leaders (Todd *et al.* 2012). They noted that young disabled people's inclusion in DPMs was essential for ensuring that not only are movements sustainable, but also that they reflect the aspirations and ideas of younger generations.

The establishment of an influential, functioning DPM is not without difficulty. Barriers that restrict choice and control, as well as attitudes that undermine disabled people's participation, are extensive, with individuals restricted from or denied access to exploring aspects of citizenship and political engagement. The various barriers emerge from a plethora of reasons, including how Social Security and assistance schemes fail to accommodate the essential need for people to explore and engage with social movements; similarly, the built environment and policies that ultimately sabotage inclusive practice, such as the removal of the bias towards inclusive education (Runswick-Cole 2011), combine to hinder the effectiveness of the DPM.

The DPM attempts to address disabled people's reduced life chances by focusing on the causes of extensive marginalisation and isolation. Nevertheless, the DPM continues to build solidarity among disabled people by scrutinising the dominant political ideology and economic decisions that perpetuate the notion of "ableism" (Campbell 2009; Reclaiming Our Future Alliance [ROFA]). This is a term implicitly suggesting that disabled people are inferior to those labelled as non-disabled; disabled people disrupt the illusion of normality and should remain passive in order to protect the current ways of being. The Movement, however, also offers an opportunity to develop and strengthen a culture of pride, thus demonstrating disabled people's passion to create change. This is achieved not by conforming to contemporary practice, but by demonstrating how a sense of pride may serve as inspiration for the creation of a socially just and inclusive world (Oulds 2017).

Within Social Movement Studies, the issue of diversity and representation requires constant investigation and analysis. The DPM, too, has come under examination. Influential scholars and activists have questioned the ways in which the Movement seeks to incorporate the views and actions from a broad range of experiences, such as younger and older disabled people, and minority ethnic communities. The intersectionality of disability, mental health, and neurodiversity (Hugemark and Roman 2007; Spandler, Anderson and Sapey 2015; Carling-Jenkins 2014) is another aspect under consideration. There is thus a need to consider how young disabled people experience, perceive, and interact with the DPM and how their participation within social movements is affected by the wider discourse surrounding disability, political ideology, and social structures. Social movements cannot exist externally to the social, economic, and political happenings within society.

Here, power is understood in a relational capacity. The definition of power used within this research follows the trajectory offered by Beckett and Campbell (2015) in their arguments for the transformative potential of oppositional devices. As a starting point, Foucault's understanding of practices and technologies is adopted in order to emphasise the ways in which power, resistance, and discipline are understood. Foucault (1997) proposes that power is best understood not as a tool to be utilised in order to achieve disciplinary outcomes; rather, it is a web of conditions and relations, each interacting with the others to produce the conditions for oppression – and also for resistance.

This is significant because Foucault (1988, p. 12) highlights that the possibility of freedom exists and has to exist in order to ascertain the extent of various forms of power and authority: "in the relations of power, there is necessarily the possibility of resistance, for if there was no possibility of resistance – of violent resistance, of escape, of ruse, of strategies that reverse the situation – there would be no relations of power." According to Gordon (1999), this understanding of power positions humans as beings in the world who are exposed to an interconnecting web of relations and positions within a context of background practices and structures. This is useful as it brings to the attention ideas of activity and passivity, agency and structure. The DPM is engaged with competing discourses surrounding why and how disabled people are oppressed, what strategies should be implemented to challenge such forms of oppression, and what should be the priorities. Therefore, through suggesting that power be understood as a set of relations with particular emphasis placed on the need and potential to resist, the analysis is able to engage with the various perspectives offered by new and existing members within the DPM. Positioning the DPM as an effective social movement to challenge the extensive oppression experienced by disabled people assumes that its relevance is continuing, thus developing. It also emphasises the need for young disabled people to locate their ideas and strategies within the context of resistance, illustrating to disabled and non-disabled communities that freedom is possible and preferable. According to Beckett and Campbell (2015), there is a certain affinity between this understanding of power and the significance of the social model. The social model, thus, presents a description of the process (disablement) that requires resistance by disabled activists and the DPM. This final point is expanded in Chapter Two, where the concept of oppositional devices is explored in greater detail.

Further to explain the conception of power that underpins the research analysis, I take inspiration from Gabel and Peters (2004) and propose that power is circulating based on the interactions of individuals, their position within current social structures, and the extent of social processes that become evident in their results. Doing so may result in domination by one group over another. However, it also has the potential to provide capabilities for individuals who wish both to challenge and to disrupt the micro and macro aspects that perpetuate marginalisation in any given form (Proust 2000). Such an approach to understanding power is useful in the exploration and critique of existing challenges to young disabled people's direct involvement with the DPM. Considering how the Movement operates within a society of fluctuating power relations, as well as opportunities to enact resistance practices, is also involved. Whilst the hierarchy within the DPM must of course be reviewed and usefully deconstructed, individuals participating in all aspects of society need to be presented with the opportunities to follow their interests in engaging with social movements, activism, and protest. Positioning power within this research was extremely difficult due to the competing arguments within the DPM with regard to understanding power. As highlighted further in this chapter (*see* My Experience of Activism) and Chapter Four, established members and groups typically engage with the structural analysis that prioritises understanding power as a property that is or can be possessed. This means there is tension in the research, as it tries to grapple both with acknowledging the existing, historical position taken by activists to describe and understand disability, and with the new path being laid by emerging activists. My decision to conceptualise power in this way was primarily so as to understand young disabled people's commentary on reshaping the discourse surrounding how and why disabled people are oppressed, and what should be done – and by whom – to challenge and destabilise the social practices that perpetuate disabled people's oppression. At the point of introducing a definition of power, it is appropriate clearly to define three concepts pertinent to this investigation: the social model of disability, ableism, and safe spaces.

The social model of disability is contested within the fields of activism and academia, and has led to competing discourses surrounding how it is to be understood, utilised, and evaluated (Owens 2015). Such discussions are expanded in Chapter Two; however, for the purpose of this study, the definition of the social model is rooted in the interpretation offered by the Union of the Physically Impaired Against Segregation (UPIAS): "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 1975, p. 4). Thus, the social model becomes an effective way of describing the process of disablement. It provides a window of opportunity to consider how and through what means disabled people are denied opportunities, excluded from communities, and oppressed within society. However, it also has the capacity to promote and instigate resistance against the actions, behaviours, and strategies that seek to perpetuate the marginalisation of disabled people. Articulating it in such a way may lead to claims that I am suggesting the social model is a tool, an argument discussed extensively within Disability Studies literature (Kallen 2004). This is not necessarily problematic, yet does require careful consideration. I agree with Beckett and Campbell (2015), who suggest redeploying the social model from a tool to being an oppositional device, in order to gain greater analytical insight. Nevertheless, I would argue that activists and the DPM should also understand the social model as being an oppositional device that ensures greater clarity as to what can be achieved by describing and then resisting disablement. The significance of the social model rests upon its definition as a way of describing the process of disablement *and* of facilitating ideas, strategies, and actions that resist such injustice.

Defining the social model in this way means rejecting the premise that the social model explains disability. To provide an explanation of disability, it is appropriate to reference Campbell's work on the notion of ableism. This research defines ableism as articulated by Campbell (2009, p. 44), in that it is a "network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human." Disability, understood as the extensive and continuous discriminative practices against disabled people, is reinforced due to the troubling notion of "normality" inherent within the social, political, economic, and cultural structures within society. Thus ableism seeks to unpack the "networks of association that produce exclusionary categories and ontologies." (Campbell 2009, p. 20). Such focus on the category of "normal" unlocks the potential for disabled people to challenge and resist the celebration, reinforcement, and disciplinary nature of normality. Through this research, it is important to acknowledge that the social model and ableism are connected. Although this is an area underdeveloped within the literature, there is traction in recognising the potential contained within both these concepts for reinvigorating disabled people's activism. Whereas the social model provides a mechanism for describing experiences of social injustice encountered by disabled people, ableism prompts disabled activists to consider the extensive patterns and relations existent at the micro, meso, and macro levels within society that construct, celebrate, and idolise the so-called norm.

With regard to safe spaces, the fact that literature surrounding disabled people's access to safe spaces for the purpose of activism and social movements is non-existent must be acknowledged. Such significance to social movement literature is outlined in Chapter Two. The term "safe spaces" is problematic. Scholars have outlined the problems inherent in this term (Wallin-Ruschman and Patka 2016). Not discounting the implications brought with the use of the term, it remains in this research. This is justified on the basis that it is intended to provoke response and consideration from the limited research exploring disability and safe spaces, albeit outwith an activism and social movements context. Evans and Boyte (1986, p. 17), although they use the term "free spaces", write, "[these] are the environments in which people are able to learn a new self-respect, a deeper and more assertive group identity, public skills, and values of cooperation and civic virtue. Put simply, [they] are settings between private lives and large-scale institutions where ordinary citizens can act with dignity, independence and vision." Using this definition ensures the research is framed around the idea that disabled people are marginalised yet still, through the collective, have the mechanisms and resources to resist and challenge their oppression. This complements the conceptualisation of power that underpins this research, as resistance is understood ontologically prior to power – therefore, the safe space reflects the idea of the "heterotopia" (Foucault 1986). The safe space opens up the possibility of a narrative or vision that is different, in that it embeds the ideas or practices to realise an inclusive, accessible, and fair society. However, the use of safe spaces here has a dual purpose. On the one hand, it provides activists with a network, set of skills, and solidarity to sustain a social movement and penetrate the extensive networks that produce categories of exploitation, oppression, and injustice. Secondly, it can offer members a haven in which to reflect, discuss, and explore ideas and positions that may be deemed disruptive to existing members within the DPM. The definition of safe spaces in this research, as articulated by Evans and Boyte, has the potential to be utilised for these dual purposes.

It is now over ten years since the dawn of the UN CRPD, an ideal moment to investigate (a) young disabled people's experiences of disability and social injustice across a range of social and political contexts; (b) their aspirations for disability politics and activism, and (c) established DPM members' ideas and perspectives on young disabled people's contributions to disability activism and social movements. The proposed research departs from existing, limited, research on disabled people's activism by specifically examining young disabled people's engagement in and aspirations for disability activism in the UK. It investigates how they think about: (a) becoming a member of the DPM, with particular reference to the positions occupied by established, influential members of the Movement; (b) the organisation of the DPM and how young disabled people are supported to develop and participate in campaigns and strategies, and (c) the resources and infrastructure required to promote the significance of the DPM and improve its sustainability and effectiveness. To achieve this, the research process started with an initial investigation of existing literature to understand current debates surrounding how disability is understood and the key issues affecting the development and sustainability of a DPM. This included a wider review of Social Movement Studies in order to comprehend how such movements are organised, how members connect, and the fluid nature of relationships between social movements and the cascade of events that establish the social world. The result was the development of four research questions:

- What constitutes young disabled people’s position in the DPM?
- How are people included and what is required to ensure participation within the DPM?
- What is the overall organisation of the DPM, including a commitment to specific values or ideas?
- What do people want to highlight and what requires addressing in order both to increase participation within the DPM and to ensure young people can influence the overall direction and agenda?

In considering the research objectives, I differentiated between two outcomes: that which the research intends to achieve with regard to debates emanating from the relevant academic disciplines, and the impact that the research will have upon disabled activists in the UK. It will be the first such study to ask the specified research questions; therefore, it will be significant in Disability Studies: it offers insight into young disabled activists’ contribution to disability activism in the UK, barriers limiting their participation, and their vision for the future of disability activism. To achieve this, the research makes an intervention into the emerging discourse surrounding oppositional devices, which to date contains no investigation or reference to young disabled people’s contribution to activism. Beckett and Campbell (2015) are the only authors to consider the potential of oppositional devices within the context of disability and social justice. The present research develops further understanding of oppositional devices by arguing that this aspect has the potential for repositioning young disabled people within the DPM and ensure their belonging to disability activism.

This research offers empirical findings that illustrate the essential need for an investigation into young (disabled) people’s understanding and ideas pertaining to the organisation of social structures within society. Again, this is a somewhat underdeveloped area within Disability Studies. Contemporary work by Slater (2015) and Goodley, Runswick-Cole, and Liddiard (2017) are examples of research attempting to reinvigorate Disability Studies by introducing a specific focus on young disabled people’s contribution to communities and civil society. The findings here illustrate the substantial and important impact young disabled people can have in raising the visibility and awareness of social injustice encountered by the disabled people’s community. Furthermore, this will challenge scholars within Disability Studies and Social

Movement Studies to reflect, investigate, and capture young disabled people's creative and challenging ideas and strategies towards addressing social injustice.

It will also make an original contribution to Social Movement Studies in two respects: (a) contributing to understandings of youth engagement with social activism today, in particular in the social-media-age, and (b) providing a still rare investigation into DPMs. This is important because Social Movement Studies have failed to capture the experiences of young disabled people within activism; key debates pertaining to the development of social movements have not included research from Disability Studies. Notable research attempting to bridge the divide between the two disciplines, such as Shakespeare (1993), Oliver (1997), Beckett (2006a), and Dodd (2014), remains useful. However, further contemporary research is required.

The impact of this research upon disabled people's activism and the UK DPM is equally as important as its contributions made to academia. As outlined in the following section, the research is significant to disabled people through its attempt to recognise and address the crisis emerging within the DPM. The Movement is currently regarded as weak and ineffective, given the competing priorities and strategies proposed by its membership (Sheldon 2005; Shakespeare 2006). Although attention should be paid to the literature highlighting this crisis, there is a significant lack of ideas and alternatives to the concerns raised. The problems must be articulated and necessary space provided for activists and their organisations to engage, critically, with the issues that affect the sustainability and effectiveness of the DPM; however, it is equally essential that action be taken to move the dialogue forward and consider what is possible and preferable in the context of improving the situation.

My contribution is through the findings of this research, suggesting emphasis be placed on young disabled people's contribution to disability activism – with particular attention to the strategies and activities to improve recruitment and participation within the DPM. This will go some way towards addressing the friction between members, which has – according to the data presented in this research – led to young disabled people's distancing themselves from the Movement. The research matters to young disabled people because it emphasises that their contributions are important, should be valued, and will shape the future of disability politics in the short and long terms. The young disabled people who participated recognise the significance of the DPM and remain committed to having a role in its ever-evolving development. As a result, this extensive investigation serves as a reminder that we – disabled activists – risk furthering the crisis and reinforcing the hostility within the membership until and unless alternative ways to improve young disabled people's participation are considered, stipulated, and acted upon.

Interviews with seventeen disabled people who were either involved with or had a keen interest in the DPM (eleven young disabled people and six established figures within the Movement) were undertaken. Although the research focuses on the perspectives provided by young disabled people, it was desirable and necessary to include the ideas and opinions of established figures, given that both groups are pertinent to the evolution of the DPM. The position of established and influential figures has a direct impact on the participation and inclusion of young disabled people. Furthermore, the challenges raised by young respondents influence the role and actions of established members within the Movement.

To understand the complexity of the issues under investigation, there is a need to capture perspectives from different groups within a social movement in order to highlight areas of commonality and of contrast. Doing so strengthens the overall arguments produced through the research and provides a better understanding of the actions required to improve young disabled people's participation within the Movement so as to protect its sustainability and effectiveness. Interviewing both groups is a reflection that there is a notion of interdependence among members of a social movement. The research findings will have limited potential for activists if there is a failure to recognise the importance of reciprocity within the DPM, i.e., the mutual benefits that are gained by acknowledging and reacting to the challenges outlined. By accommodating both groups, strategic links are made between the issues highlighted by the respondents, and there can be an awareness of how the personal experiences are contextualised within the historical and political actions of the Movement. Thus, addressing the position of young disabled people within the DPM requires incorporating the views and experiences of both those who are affected by a restriction on and those who have responsibility for improving youth participation.

An Emancipatory Disability Research (EDR) design was employed, ensuring the research was founded on the social model of disability. Furthermore, the purpose of this research is to avoid becoming fixed on the investigative procedures; rather, it offers proposed actions in order to become part of the production of the social world. The research draws explicitly upon disabled people's collective experience and, in doing so, challenges directly the widespread oppression experienced by disabled people. Whilst this means encompassing the personal experience, it is how the Movement can affect positively the disabling structures within society – which is its focus. The notion of personal experience, here, is to highlight how, collectively, disabled people frame the key issues that contribute towards oppression. Using a coding process, it was possible to identify themes and patterns produced by the respondents and researcher.

The analysis section of the thesis offers a collection of challenges faced by disabled people as they attempt to engage proactively with the DPM. The challenges were grouped around three key areas: membership, organisation, and future considerations. They are unpacked further, with the inclusion of direct quotes. They highlight the following issues:

Membership: the contemporary explanations of youth are rooted within the dominant display of normative practices, which has consequences for young disabled people's position and status within the DPM. This highlights the perception of authority within the Movement, as younger people's desire to engage in activism depends solely upon their acceptance by others involved. The purpose of participating within social movements also necessitates how young disabled people have opportunities to explore their ideas on disabled people's route to emancipation, particularly when their ideas run counter to the dominant aims, strategies, and agendas currently adopted by the DPM.

Organisation: the essence of interlinking movements illustrates the competing discourses associated with the overall purpose of the DPM. Whilst contingents within the Movement demand a rights-based approach, others call for further radical action. This brings attention to the influence of social model thinking and how it is embedded within the overall direction and purpose of the Movement. It provides a mechanism to identify within society the conflicts that perpetuate disabled people's marginalisation. However, attempts by young people to question or critique the model are perceived as an opportunity for them to weaken its position. The organisation of the DPM is further rendered problematic when considering the significance of socialist ideas within the Movement, especially when young disabled people do not identify with that specific political ideology.

Future Considerations: there is a substantial risk that the DPM will struggle to establish a legacy, which also means that new members will struggle to participate in the Movement. Of particular importance is the archiving process that, currently, young disabled people find difficulty in accessing. This leads to young disabled people's isolation and pressure to remember certain amounts of knowledge regarding disability activism in order to participate within the Movement. The issue of legacy is further affected by local and online mobilisation, as this may have an impact upon the recruitment and retention of young disabled people. The DPM must consider supporting members at the local level to develop the skills, resources, and confidence to mobilise effectively. A failure to address the concerns will result in young people's becoming disengaged from the Movement.

The analysis sets up the subsequent discussion surrounding what can and must be transformed within the DPM in order to ensure it is sustainable and effective in confronting a disabling society. To achieve this, the research argues the Movement is grappling with various political issues that remain unresolved and, as a result, have led to contradictory and conflicting campaigns and strategies. Young disabled people, in resolving such situations, should be supported to occupy safe spaces and challenge the "notion of youth" to assert what is required to realise disabled people's emancipation.

1.2.1 *Originality and Contribution to the Body of Knowledge*

This is the first study on young disabled people's contemporary position within the UK DPM. It critically assesses young disabled people's understanding of the Movement, including aspects of membership and organisation, and describes the barriers that prevent participation and hinders young disabled people's attempts to influence the DPM's agenda – these are articulated as challenges. The thesis extends Beckett's and Campbell's (2015) idea that the social model should be understood as an oppositional device, as is outlined and explored in Chapter Two. It is the only study to use empirical evidence to suggest how activists and the DPM should reposition the social model as an oppositional device. This can be achieved only if established figures and influential networks within the Movement support young disabled people in going beyond discussions that pertain solely to youth issues. Furthermore, the DPM must prioritise the facilitation of young disabled people's counter-rationalities surrounding what is a preferred and possible future in the context of disabled people's social position. Such a measure would ensure that the DPM is focused on a direction that encourages dialogue about societal and collective futures, positioning disabled people as challengers to the contemporary social practices of normality and ableism. If the barriers to participation within the DPM, raised by young disabled people, are left unaddressed by the Movement, it is argued that the DPM risks becoming non-representative of the current approach to addressing disabled people's marginalisation.

The current research, through the collection and analysis of the data, contributes to the emerging literature on oppositional devices by arguing that if the social model is subsequently framed as an oppositional device, activists will be able to produce the counter-rationalities required in order to transform the status of disabled people and the social world of which disabled – and non-disabled people – are part. The repositioning of the model can provide opportunities for young disabled people to be resourced and supported to form a sustainable collective that resists the current ways of being, i.e., the individualising tendency produced through neoliberalism[1] and the normative practices that attempt to silence disabled people and value ableism. As highlighted by the existing literature in Chapter Two, the social model is currently utilised as a tool that is implemented within current structures, weaponised by the machinery of government to promote the agendas and direction of the State. This has led to contingents of the DPM becoming incorporated within government infrastructure, with a focus on aligning existing policy development with social model principles. Furthermore, as mentioned through this study, the social model remains core to the organisation of the Movement, yet young people argue they are not in a position to critique its influence. Any criticism or questions regarding its operation results in accusations – by established figures – of naiveté or attempts to undermine the DPM, rather than being simply a wish to comprehend. The research argues that the Movement must be an accessible place where young disabled people may invent a new way of life, one in which disabled people not only resist the

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[1] I contend that neoliberalism does not advance social justice and equity. It has emerged out of the principles of classical 18th and 19th century liberalism (Braedley and Luxton 2010) and influences political decision-making and social policy. States are guided by market principles, open trade and investment regimes as they attempt to address poverty and the marginalisation of communities. The focus on accumulating capital reinforces the drive for competition within all aspects of daily life, and personal responsibility becomes a mechanism to suggest people who are marginalised are at fault for their situation.

materialities that perpetuate their exclusion, but, more importantly, offer a vision for a new and inclusive society.

Here, the DPM is understood as an affective movement that can produce radical change by supporting young disabled people to mobilise and explore the materialities that dominate young people's lives. If the Movement is committed to including young disabled people, then it must assist young disabled people to make sense of the cascade of events that continuously reproduce the actions and behaviours that perpetuate normality and support them to document how, where, and what they want to resist.

From the data, it is inferred that a failure to act on this will lead to further disengagement by young disabled people, who will argue that the Movement is not in fact accessible to them and does not reflect young disabled people's demands. Ultimately, this will lead to the assumption that the DPM is “dead”, dismissed by young disabled people or occupied by individuals and groups that no longer represent the approaches taken by the pioneers and initial architects of the DPM: to identify and oppose injustice.

1.2.2 *Why Is This Research Significant?*

A useful starting point is to consider the political, economic, and social context of the study. The UK is the first country to be investigated for human rights violations of disabled people (Pring 2017). The United Nations inquiry concluded that austerity policies have disproportionally and adversely affected disabled people – particularly in relation to the cuts in funding social care and the Independent Living Fund, the flawed medical assessments associated with employment support, and increase in disabled people’s experiencing debt, eviction, and other avoidable distress. Disabled people were portrayed as being “lazy and putting a burden on taxpayers” (UN 2016, p. 14). In response, the UK government rejected the findings; it dismissed the recommendations to address the violations, stating the government continues to improve the support available to disabled people”. The UK government is in breach of human rights, committing violations towards disabled people, yet no significant action has been taken by policymakers.

The Equality Act legislation is insignificant: it is founded upon the subjective stance of "reasonable adjustments", whereby those with considerable power determine whether the marginalisation experienced by disabled people can be justified. The grounds quoted are of too great cost, too many resources or too much disruption to everyone else (Harwood 2014; Schwartz and Elder 2018). Opportunities to reflect, develop, and propose radical or reformist approaches to improve disabled people's rights depends on whether these align with the current political and economic objectives of the State. With consideration of the detrimental impact of the British exit from the European Union, notable commentary has been provided by Baroness Jane Campbell and Lord Low (House of Lords 2017); their comments, which suggest deep concern for disabled people's social position in a post-Brexit United Kingdom, echo the views from established campaigners throughout the DPM.

The prospect of ensuring disabled people have the appropriate level of support in order to participate in the education system has continuously been questioned and undermined. The Coalition Government in 2010 called to end the "bias" towards inclusion, focusing, rather, on the diagnostic assessment tools to detail school children's medical needs and to shift policy to undermine an inclusive education approach (Runswick-Cole 2011). The recent Equality and Human Rights Commission (2017) highlighted disabled students as having lower attainment rates in school, twice as likely as their non-disabled peers not to be in education, employment or training. Also, the proportion of disabled people with no qualifications was three times that of non-disabled people. Currently, disabled people and their organisations are raising awareness of the government's millions of pounds'-worth of cuts to the Disabled Student Allowance programme (Lewthwaite 2014). The cuts continue to be extensive; no funding for expensive assistive technology, no funding to pay for additional staff to provide academic support (note-taking, sign language interpreters, examination support or study skills mentoring), and no funding to meet the additional transport costs incurred because of disability. These examples, combined with the recent developments surrounding disabled people's being forced into institutions because of care costs (Brennan 2017), illustrates the importance of a DPM that resists such practices and offers alternative visions for the way society should necessarily be organised.

Such varieties of view justify medical interventions. Contemporary service provision is based upon the assumption that the problems facing disabled people are a result of their medical condition. Prevention, rehabilitation, and re-enablement to take account of the needs and aspirations of disabled people take precedence over adjusting the existing structured social environment. Access to support is determined solely by medical assessments and medical professional scrutiny. This reinforces the perspective that disabled people's marginalisation is a direct consequence of their physical impairment, learning disability, and/or health condition. Not only does acting upon the perspective lead to further exclusion and isolation; it has also led to the deaths of people placed within institutions – such as that of Connor Sparrowhawk, who drowned in an assessment and treatment unit (Rogers 2015).

The present thesis is built upon the argument that the DPM is indeed important and relevant to young disabled people. However, it must be acknowledged, by the existing membership and their organisations, that if no action is taken to improve young people's participation then there is a severe risk of newcomers' and potential activists' disengaging from the Movement.

During the interviews, respondents discussed their interest in the DPM and deliberated as to whether they care about its existence. Such a discussion is essential because a failure to identify and address existing barriers that hinder young disabled people's participation in social movements can result in contesting the DPM's importance. With regard to the continued existence of the DPM, it is possible to separate the findings into two aspects: importance, and effectiveness. Young respondents equated "importance" with the level to which they felt valued and respected by established figures and organisations. They questioned how the Movement supports their involvement, arriving at a conclusion that suggests they are being neither valued, supported, nor protected. This will leave the DPM in a dangerous position of not encouraging and facilitating future generations' participation within disability activism. In terms of caring about the Movement, there needs to be a critique of the current relationship between youth and established members, with further understanding of how the DPM cultivates youth engagement. This is an extensive problem across social movements, as research shows young people fail to be captivated by established social movements and turn instead to local, community-based youth organisations (Gordon 2007; Taft and Gordon 2013).

Determining whether young disabled people consider the Movement to be effective requires consideration of how the key demands are aligned with the priorities and ideas of younger members. Murer (2011) notes that youth participation within social movements is driven by a desire to improve people's living conditions. Motivation to care about the existence of social movements depends upon young people's sense of belonging to the membership and their access to a means of self-expression within the Movement's organisation. This is particularly the case when the social condition of precariousness affects young people. According to Mattoni (2012), young people are encountering an unstable future with uncertainty surrounding employment and their access to social security, alongside the apparent devaluation of academic achievement. This leaves people desperately attempting to unite with a shared collective identity, which may be provided by social movements as long as there are opportunities for young people to mobilise. For the DPM, the issue of precariousness – especially within the neoliberal context – is represented in the daily struggles encountered by disabled people. If young disabled people are not supported to participate in the Movement, which means their not having opportunities to influence the emergence of key demands, it will adversely influence whether the DPM is perceived as an effective social movement through which to address disabled people's marginalisation.

Both of these issues affect the prominent concerns surrounding its continued existence. Addressing the challenges highlighted in this research will go some way towards protecting the DPM's longevity, bearing in mind that established figures must collaborate with existing young members to improve recruitment strategies. Any strategies would have to take account of the concerns raised by respondents with regard to the pressure they feel under to espouse the ideas of existing leadership figures. The DPM must be proactive in exploring the issues raised by young disabled people. Demonstrating the current importance of a social movement is not to assume that its historical achievements will suffice. It is necessary to provide contemporary examples as to why young people should engage in activism and focus on politicising their personal experiences (Nolas, Varvantakis, and Aruldoss 2017).

To frame this discussion around a particular issue, it is useful to consider the extent of biotechnology and how medical advancements in genetic modification and screening will lead to the eradication of certain impairments. This will, undoubtedly, have an impact upon the future make-up of the DPM. Young disabled people’s role in activism will require action to address the concerns pertaining to biotechnology. How the DPM responds to this issue will affect the existence of the Movement, including how young disabled people engage with and respond to it.

In exploring the literature associated with social movements, a notable point was raised: there exists pressure by certain social movements to focus on cure and rehabilitation as an approach towards addressing the barriers experienced by disabled people. Such movements, typically referred to as health movements (Brown and Zavestoski 2004; Hughes 2009), are strengthened by the advancements in biotechnology. The DPM has attempted to challenge these arguments through a human rights narrative (Amundson and Tresky 2007; Miller and Levine 2013) and by prioritising how disabling barriers are a consequence of the existing social structures. Although the arguments raised by the DPM in this context have received critical attention, there is little to no exploration as to how advancements in biotechnology and genetic screening will influence the future demographics and aspirations of the membership basis within the DPM. Respondents were not asked to explore this issue specifically; however, it has emerged as a concern following the analysis of their future considerations that will affect the Movement's sustainability and effectiveness. This issue must receive wider attention and be incorporated within the subsequent development of strategies to recruit and engage with newcomers to the DPM.

Advancements in biotechnology, essential for the identification and potential eradication of impairments, are challenged by the ethical and human rights debates associated with them (Rigaud 2008). State institutions and international organisations are regularly debating the implementation of the technology and appear receptive to the voices of health activists and parent representatives of traditional charities, which operate from a medical model approach (Lwoff 2009; Kalokairinou, Borry, and Howard 2017). The campaigning typically follows a narrative of demanding choice and reinforcing the notion of suffering on behalf of the disabled individual. This contradicts the demands and actions put forward by the DPM, in their attempt to raise concern over the consequences of such medical practices. The technologies are described as progressive, but they, in fact, reinforce the beliefs pertaining to ableism. Little attention is offered to the consequences that such medical advancements will have on the dignity and freedom of disabled people.

This is extremely dangerous to the DPM, as the improvements made to genetic modification and screening effectively constitute a reinforcement of eugenic principles (Reindal 2000; Podroužková 2014). The Movement is tasked with demonstrating how this discourse is aligned with the pursuit of normality and the protection of the existing social structures that perpetuate disabled people's marginalisation. It is required to resist how the technological innovations are presented; they emphasise the health and humanitarian benefits, instead of drawing attention to how they are forms of control – used to regulate the social order of society. Supporters of the technology will often reduce the debate to individual accounts, emphasising how it is linked to personal freedom. Disabled activists employ similar tactics, yet it is imperative that the Movement frame this as part of the historical and contemporary discourse associated with the pursuit of eugenics. The narratives that focus on eradicating specific impairment groups, such as Down syndrome, spina bifida, and neuromuscular conditions (Madeo *et al*. 2011; Kendal 2015; Groskop 2016), exist because medical professionals, and individuals with no direct experience of the politicisation of disability, conclude that experiencing impairment effects equates to tragedy within the existing social world. Such concerns are captured by activists who challenge the implementation of assisted suicide policies (Not Dead Yet [NDY] UK). The presentation of biotechnology is deliberately offered as improving choice and autonomy; however, it is essentially about prioritising the elimination of people who pose a threat by their apparent failure to conform to the demands and expectations of an ableist society.

The reason for highlighting this particular issue here is because the DPM is facing a catastrophe with regard to its existence. There will be extensive changes to the membership of the Movement if members and their organisations do not prioritise the impact of biotechnology on the future of disability activism. The existing membership, comprised of individuals with hereditary conditions and congenital impairments, will disappear as individuals with such conditions and experiences of disablement are screened out. To prevent this requires supporting young disabled people to participate in the development of strategies that resist such practices, drawing attention to the implications and consequences of how this technology is a method of regulating people's lives and protecting the existing social structures. Measures are implemented unilaterally under the guise of being advancements beneficial to people's freedom of choice. If young disabled people and newcomers to DPM are to be future leaders and become established figures then there must be opportunities now to articulate ideas about the future: ideas that will challenge these existing practices and propose alternatives to improve disabled people's social position. It is essential to question why it is permissible that such decisions to promote and implement the technology are occurring when it is evident that disabled people neither have choice and control, nor are they provided with the right level of support to participate within their communities (Ratzka 2007; Elder-Woodward 2013).

The premise of biotechnology is a contemporary example that requires action from the DPM, if it is to address the social injustices that are and will become apparent as a result of this technology. It will affect the organisation of the Movement, now and in the future, and will weaken the position of the DPM, as members pass away and the aspirations of health social movements gain further traction. For this reason, it is essential that young disabled people have an active and valued role within the Movement, which extends beyond the limited appeal of exploring youth issues. Understanding the social model as an oppositional device will ensure members are able to reflect upon the previous actions of the DPM further to challenge the extent of discrimination. This will help to provide new ways to resist and demonstrate the significance of disability activism. If ever there was a need to ensure young disabled people are supported to have prominent positions within the DPM, it is now.

1.3 My Experience of Activism

Mills (1959) argues it is imperative to explore the relationship between history and biography in order to understand contemporary social problems. As a result, it is critical to explore my personal experience of activism and how it is positioned within the context of youth, activism, and social movements. I have identified as an activist since the age of fourteen although my earliest memory of experiencing disablement and injustice came when I was navigating through the primary education system. Every time a test was imposed, I achieved a low score; it was not unusual to find the answer boxes blank after page two. I would become frustrated, embarrassed, upset that I could not perform as expected and receive scores that mirrored those of my friends in the classroom. My parents were requested to a meeting with representatives from the local education authority and a social worker. They were unanimous in their decision:

I should go to a segregated "special" school because I was unable to meet the demands and expectations of the local comprehensive. They argued that I struggled to learn, did not understand the lessons, and became withdrawn during reading and writing exercises. I remember my father’s asking if they had ever engaged with me to recognise and address any access requirements related to participating within the classroom. The answer was “no”. My father continued by suggesting it was the parameters of the education system, as well as the expectations placed upon the child, that created this outcome, not the individual. He argued that the necessity to examine my performance and knowledge through a written, timed test was flawed because I struggle to hold a pencil, take twenty minutes to write nine words, and am unable to turn pages in a book. The local authority reluctantly conceded that such an argument had not occurred to them; I was spared segregated schooling, provided with individualised support, and offered alternative approaches to assessment.

I came to realise that the barriers experienced on a daily basis are manifested not because of the limitations of my body, but as a result of the way society is organised and the expectations placed upon individuals by a ruling group. In later years, it came as little surprise that my parents had begun to research extensively after I had received my diagnosis. Rejecting the notion of tragedy and medical discourse to explain discrimination, they came across Disability Studies and its approaches to identifying and addressing disabled people's marginalisation. My father told me he was irritated and dismayed that the local education authority was not taking a social model of disability (Oliver 1990) approach to addressing disabling barriers. Subsequently, I began to understand the model and recognise its significance in my daily experiences. I became aware of the vision outlined in the Independent Living philosophy (Evans 2008). In my early teenage years, I lost focus and became uninterested in the ideas and vision offered by disabled activists, campaigners, and teachers. I remember feeling anger and hurt: angry that society was bloated with injustice and would disregard those who are isolated and marginalised, and hurting from being told that I was not normal or feeling ridiculed when it was advised that I should develop friendships only with disabled people and never engage in sexual experiences. Even though I could reference the "twelve pillars of independent living" (SPECTRUM 2018) and had a basic grasp of Pride Against Prejudice (Morris 1991), I felt a disconnect between the hope articulated by prominent scholars and activists, on the one hand, and my personal experience of oppressive structures and attitudes on the other.

A number of years later I immersed myself in the ideas and strategies offered by activists and campaigners. I became politicised and could articulate disability as a form of social oppression. What followed was academic, professional, and personal commitment in the area of disabled people's emancipation. I researched issues pertinent to the lives of young disabled people (Griffiths 2010; 2012), advised governments on the impact of policies and initiatives upon young people, and developed toolkits with human rights organisations to facilitate young disabled people's involvement in political and cultural matters (Todd *et al*. 2012; Council of Europe 2016; ENIL 2018).

I became interested in how young people recognise and address oppression experienced on a daily basis. I wanted to know how young disabled people accessed, participated in, and influenced the agendas that are pertinent to disabled people's emancipation. Within the DPM, and the wider discourse surrounding Disability Studies and activism, there are lasting concerns regarding diversity within the DPM membership (Campbell and Oliver 1996; Barnartt and Altman 2013), the sustainability and effectiveness of the Movement (Sheldon 2005; Shakespeare 2006), and prominent challenges – as well as opportunities – within the realm of disability activism (Beckett 2006a; Dodd 2014; Beckett and Campbell 2015). To address this, it is necessary to dedicate time, energy, and resources to understanding young disabled people's position within the DPM and the challenges that hinder their inclusion and participation. I believe it is my responsibility, as an activist attached to the DPM and a supporter of the social model of disability, to capture the ideas and views of those who are or may be integral to the future direction of disability activism.

The status I have as an existing member of the DPM has led me to reflect on the significant dilemmas inherent within the contemporary functioning of the Movement. One notable issue is the background of the established, influential members. I have regularly thought about my personal development within the DPM and how, on occasions when conversing with prominent members, they have articulated at considerable length on the importance of Marxist tools of analysis. There has been continuous friction between members who incorporate a Marxist analysis in their assessment of the existing structures within society and those who will not explicitly embrace such a perspective. I remember feeling uncomfortable, sitting in discussion groups, reading messages or attending presentations, when established members repeatedly demanded that the DPM focus only on the material factors associated with our exclusion and marginalisation. Anything else, they argued, was a waste of time and resources. Furthermore, I would talk to fellow members of the DPM, most notably young people or newcomers, and share discontent over the suggestion that young disabled people were weakening the activities of the Movement by not committing to a historical materialist analysis of disability.

This, I believe, is reflected in the interviews conducted for this research. Problems continue within the DPM because young disabled people attempt to resist absorbing an implicit Marxist approach to understanding power and the role of the state. Where younger members want to consider alternative ideas, strategies, and influences surrounding disabled people's marginalisation, their ideas are challenged by existing members and their organisations. On a personal level, I have struggled in my attempt to shake off the expectations and demands to commit only to a radical Structuralist approach, instilled into me by years of learning about disabled people's activism. I do not deny the significance of Marxism, but our activism does not begin and end with this particular analysis. It is not conducive to our cause for members to insist that one particular approach will lead towards emancipation. In fact, as a Movement, we have no coherent vision for an inclusive, safe, just society. The question remains whether we should indeed be trying to locate and embrace a singular vision. This is why this research is useful for suggesting that the DPM should commit to supporting young disabled people: to create alternative visions for the way society should be organised, not in an attempt to compound such visions into a singular trajectory, but continuously to push forward with challenging and resisting the extensive attempts to bring about our oppression.

The reason for providing this level of detail is to highlight how my personal experience of activism has led to the point of developing and producing this research. My involvement in activism and my affiliation to the DPM meant that I could connect with fellow members and campaigners to identify key issues encountered by the activists and social movements, which also bear a resemblance to aspects of my personal trajectory into activism.

Whilst this chapter outlines the research, providing insight to the aims and objectives, it should be noted, however, that I am neither willing nor able to distance myself as a researcher throughout the production of the research. The position I have taken, and the methods adopted, reflect somebody who belongs to the environment explored. I research disability activism and social movements whilst also identifying as a functioning constituent of the DPM with a history of campaigning. This also means participating in the process of ongoing mutual shaping between myself and the research topic (Attia and Edge 2017). My personal experiences of disablement and activism are not assumed to be reflective of the narratives provided by other disabled people. Therefore, I am in the position of learning and becoming aware of the intrinsic issues affecting those who are interested in or integral to the DPM. Ultimately, my role as a researcher and activist is to theorise on what is taking place while also remaining an active contributor to the activities and strategies developed by fellow activists and campaigners.

1.4 Outline for Each Chapter

The thesis is divided into nine chapters. Chapter One introduces the research.

Chapter Two begins with an overview of the DPM, drawing on aspects most pertinent to the research questions. It then unpacks scholars' understanding of disabled people's marginalisation and oppression within the social world, with a reference to the importance of activism and social movements towards realising emancipation. As acknowledged by scholars (Oliver and Barnes 2010), the development of Disability Studies is connected to the rise of the DPM. This factor is important because it provides a base from which to explore the significant development of the social model of disability, as is crucial for the activities and demands emerging from the DPM. Although criticism and limitations of the model are highlighted, the chapter argues it is essential that the DPM remain committed to the model. Here, the concept of oppositional devices is outlined – emphasising the importance of the Movement's adopting resistance-based practices. The chapter shifts focus towards the notion of youth, questioning the position of young disabled people in activism and campaigning.

Chapter Three details the key aspects of Social Movement Studies most closely applicable to the research questions. Initially, the chapter provides an overview of terminologies used to define how social movements exist - with particular reference to the formulation, continued impact, and (potential) decline of social movements. The chapter specifically highlights the work of notable scholars. Following a general overview of the life-cycle of social movements, the chapter introduces the notion of new social movements and how this differs from traditional social movements; such difference is relevant as there is much debate regarding how to define the DPM. It also allows for a discussion regarding the approaches taken by social movements to operate within resistance or revolutionary politics. Although the chapter explores how the DPM is situated within social movement theory, it draws to a close by situating the DPM within new social movement theory, making reference to the limitations imposed by taking a rights-based approach. The implications for how the DPM supports young people and newcomers in participating and influencing its overall direction and strategy are demonstrated.

Chapter Four outlines the development of the research and details the steps taken to justify the selected methodological approach. It also demonstrates the ways in which the views of respondents are related and other factors were addressed as the research design evolved. This provides clarity with regard to the decision-making process and illustrates how the research is situated in relation to both past and current discussions regarding research methodologies into topics concerning disabled people. To achieve this, the chapter begins by specifically outlining how the research was conducted. The chapter then situates the methodological approach taken within the wider discourse surrounding disability research, arguing that emancipatory disability research provided the most suitable framework within which to conduct an investigation of the research questions.

Chapter Five uses the analysis of interviews with young disabled people, and with established members of the DPM, to identify three significant aspects that affect young disabled people's relationship to the Movement. This chapter argues that the current, dominant conceptualisation of youth, found within the DPM and wider social world, represents young people as passive, dependent upon the ideas of older, established figures, and has two particular purposes: firstly, to learn from existing figures, with the expectation of continuing their work and legacy, and secondly, to become involved only in discussions and activities pertaining to youth-related issues and agendas. This creates frustration amongst young people, as they thus experience a sense of marginalisation by certain members and organisations within the DPM, who suggest they are as yet naive to the various discourses surrounding disability politics. Initially, this chapter explores how young disabled people relate to and are affected by the terminology surrounding youth and activism; this is positioned alongside the perspectives of established members and their articulation of the purpose and importance of young people's engaging in the DPM. The second aspect centres on the notion of authority and command, with specific attention drawn to how young disabled people suggest how their position and status within the DPM is dependent upon the actions, behaviours and ideas of the established, most notably older, members. Finally, the trajectories of membership – including how the definition of "member" affects participation in a social movement – are discussed. Attention is paid to how the purpose of a social movement is recognised and the consequences of the DPM's operating from a soft leadership approach.

Chapter Six explores the challenges identified by young disabled people in the context of how the DPM is organised around specific ideas. The chapter argues that the emergence of interlinking movements reflects the concerns experienced by activists and scholars regarding the approach taken by the DPM to address disabled people's emancipation. This highlights the limited potential of a rights-based approach; further, it questions the effectiveness of the DPM, as contingents and members seek a professionalised role and collaboration within the current governmental infrastructure. With the social model of disability remaining at the core of the DPM, it is clear how this concept facilitates the collaboration of disabled people to unite; however, its influence as a vision for social change requires consideration. This is because young disabled people perceive it as a condition of their inclusion within the Movement and they are unable to question or critique its parameters, with such activity being regarded as an attempt to dilute or weaken the model's position. The present chapter initially explores the recognition of interlinking movements, which coexist and draw attention to the competing discourses associated with the overall purpose of the DPM. Secondly, it discusses the influence of social model thinking and application within the DPM's organisation, direction, and agendas. Finally, the chapter explores the significance of socialist ideology within the DPM and how this affects young disabled people's participation in and access to the Movement.

Chapter Seven explores what challenges exist that are associated with the sustainability and effectiveness of the DPM, and which would affect their participation within the Movement.

Three themes emerge: archiving, local and online mobilisation, and whether young disabled people care about the existence of a disabled people's social movement. The chapter argues that without a clear and coherent strategy to support young disabled people's participation, which includes taking account of the issues raised here, the Movement will lose traction in resisting current, normative perceptions of disability. This highlights the importance of capturing disabled people's experiences in order to support future generations in their understanding of the history of disability activism and the potential for emancipatory action. Without addressing aspects of elitism and academic imperialism within archival practices, young disabled people do not feel empowered by the opportunities available to learn about the DPM. The issue of a clear and coherent strategy also requires consideration of how the Movement operates at a local level, and whether it indeed facilitates the involvement of young disabled people. The chapter explores the significance of archiving activism, with reference to the process of the collection, interpretation, and publication of the DPM's history, current issues, and debates. The chapter moves on to highlight the importance of local mobilisation of young people; also, there is the significance of grassroots activism, as a way for newcomers and young disabled people to feel engaged and able to participate. Finally, the chapter reviews whether young disabled people do now or will continue to care about a DPM, and the consequence of their opinion; most notably, questions are raised as to how young disabled people inherit leadership positions.

Chapter Eight sets out why the DPM should disrupt the current normative, disabling rhetoric and practices surrounding young disabled people. The DPM requires the use of safe spaces, as this will ensure that young disabled people have the freedom and encouragement to explore their ideas about disabled people's emancipation. The research argues that the DPM should seek to provide safe spaces and to encourage debate amongst young people. This assists in facilitating the assertion of young disabled people's perspectives on realising disabled people's emancipation. The chapter moves on to argue that this is to be achieved only if there is a commitment to recognising the social model as an oppositional device. Achieving this will require discussion as to how the social model may be used to promote the importance of disabled and non-disabled people establishing resistance-based practices, which means the DPM must consider how it can articulate a vision that addresses the marginalisation and discrimination encountered by many – not just those who identify as disabled people. The research highlighted a number of key themes affecting young disabled people's participation within the DPM in three areas: membership, the organisation of the Movement, and the issues that affect the future legacy of the Movement. The themes should be read as challenges and barriers serving to restrict young disabled people’s access and overall inclusion within the Movement. I argue that young disabled people encounter challenges when attempting to engage in the DPM, particularly surrounding their involvement in the development and dissemination of key demands to realise disabled people’s emancipation, as well as opportunities for them to critique the social model of disability.

Chapter Nine, the conclusion, provides a summary of the thesis. It charts the significance of the chapters; it also reinforces the overall argument. The chapter concludes with future possibilities for research, asserting that I have intended the research to be transferable into other areas of research production and hope this will be part of a wider discourse surrounding the future of disabled people's activism.

With the research aims and objectives defined, it is necessary to explore the literature surrounding disability and social movements. Such an exploration will provide the context for understanding the arguments outlined throughout the thesis.

2. Understanding Disability Activism and the Social Model

2.1 Introduction

The chapter begins with an overview of the DPM, drawing on aspects most pertinent to the research questions. It then unpacks scholars' understanding of disabled people's marginalisation and oppression within the social world, with a reference to the importance of activism and social movements towards realising emancipation. As acknowledged by scholars (Oliver and Barnes 2010), the development of Disability Studies is connected to the rise of the DPM. This factor is important because it provides a base from which to explore the significant development of the social model of disability, as is crucial for the activities and demands emerging from the DPM. Although criticism and limitations of the model are highlighted, the chapter argues it is essential that the DPM remain committed to the model. Here, the concept of oppositional devices is outlined – emphasising the importance of the Movement's adopting resistance-based practices. The chapter shifts focus towards the notion of youth, questioning the position of young disabled people in activism and campaigning. This allows for young members to envision preferred and possible futures that disrupt ableism and offer solutions to current practices perpetuating the marginalisation of disabled people. Young members will focus on offering reflections on the future of disabled people's social position; this in turn may influence the key demands and activities of the DPM.

As an introduction, defining disability is key to understanding the actions of disabled activists who attempt to politicise their experience of disablement. The International Classification of Impairments, Disabilities and Handicaps (ICIDH) review "impairment" as a biological health condition, with "disability" defined as the functional limitations of their impairment, and "handicap" refers to the social consequences of acquiring a disabling impairment (Brandsma *et al.* 1995). The ICIDH interpretation is associated with the individual model, as is explained later in the chapter. For those working towards building solidarity within various DPMs, the ICIDH is considered terminologically problematic, given those multiple meanings associated with the terms "impairment" and "disability" (Simeonsson *et al.* 2000). However, the World Health Organisation (WHO) has now adopted the International Classification of Functioning, Disability and Health (WHO 2013). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2007) is recognised as progressive, with a focus on human rights protection and on the full and equal participation of all disabled people in society. The UNCRPD has been used alongside the social model to bring about emancipatory change (Fraser Butlin 2011).

2.1.1 *Framing the DPM in this Research*

There is no intention of providing a comprehensive history of the Movement, especially as other writers have captured historical and contemporary accounts of disability activism in the UK (Campbell and Oliver 1996; Dodd 2014; Leeds Disability Archive[2] [LDA]; National Disability Arts Collection and Archive[3] [NDACA]). Rather, it is worthwhile drawing out specific points that highlight how the DPM understands, describes, and explains disability. Achieving this will provide clarity as to how activists and their organisations both develop strategies and envision demands. Also, the participation and experiences of young disabled people is under consideration thus it is necessary to contextualise an understanding of the Movement alongside opportunities to increase the involvement of young members.

The various networks and organisations present in the United Kingdom during the 1970s and 80s illustrated the necessity for personal politics to influence the initial development of a movement for disabled people. The politicisation of disabled people was, arguably, coordinated by two organisations – UPIAS and the Liberation Network of People with Disabilities, both instrumental in structuring disabled people's collective identity (Sutherland 2006). An essential element of the organisations was to share experiences, with the expectation that they would politicise individuals and support disabled people to consider the roots of disablement, as well as indicate the direction for change. UPIAS adopted a policy statement that was seen as excluding learning-disabled people and mental health conditions, and was comparable with left-wing political factions (UPIAS 1975). The Liberation Network facilitated the transition from articulating personal circumstances into collective understanding. Whilst both groups are now defunct, networks have emerged to support similar strategies – particularly ROFA, Sisters of Frida, and Disabled People Against Cuts (DPAC). The literature on participation within

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[2] Leeds Disability Archive emerged out of the Centre for Disability Studies at the University of Leeds in 1990.

[3] National Disability Arts Collection and Archive was launched in 2018. It is delivered by Shape Arts and hosted by Buckinghamshire New University.

Disabled People's Organisations (DPOs) focuses on matters pertaining to self-empowerment and disability radicalism. As Sunderland notes (2006):

> The Liberation Network was a really important and effective entry point to disability radicalism […] It recognised that people who have been oppressed and isolated are likely to have a lot of feelings of distress, but gave them a way of dealing with that. It was open to a wide range of disabled people who consequently learnt about each other's situations.

As Perry (2017) notes, the DPM is persistently highlighting and seeking to destroy the barriers faced by disabled people in society. To join the Movement is to acknowledge and claim a group identity, which requires politicising individual experience and gaining the recognition that to be disabled is, in and of itself, a political statement. The DPM is a multitude of various concerns, priorities, and tactics. The Movement exists to prompt action and express evident dissatisfaction against the current hierarchies. It is constantly evolving and challenging the extensive practices that perpetuate disabled people's experiences of marginalisation and oppression. This reinforces Szende's (2011, p. 5) argument that social movements do not "idealize some historic point when the groups they represent were not oppressed. Instead, these movements look forward to a point in time when the society of which they are part will be more just, and therefore struggle towards that goal".

Sheldon (2009) argues that further links must be drawn between disability and the capitalist mode of production, which will emphasise the economically informed interpretations pertaining to disabled people's oppression. She goes on to highlight how the DPM's commitment to progressive change could lead it to becoming insular and focused on short-term, crisis-driven agendas. This is because of the urgency of immediate problems such as access to social care, health, and participation in the community. Additionally, Sheldon's point is reflected in current examples of how the DPM participates in key issues affecting disabled people. Numerous DPOs have had opportunities to coordinate local authorities' self-directed support schemes, albeit significantly reduced given the recent cuts to local government budgets (Duffy 2013; Harwood 2014). It is necessary that action be taken to protect and improve disabled people's living standards; however, this will have implications for the sustainability and effectiveness of the Movement. As a result, this research explores how young disabled people can become involved in creating possible and preferred futures that will address the concern through a combination of long-term planning and short-term action.

Irrespective of the actions taken by the DPM, the Movement has developed also to address ableism. The notion of ableism is key to the development of disability activism, especially when considering disabled people's experiences of marginalisation and oppression. Ableism, according to Campbell (2009), is a network of social practices, processes, and deep-rooted beliefs that aims to produce the "ideal" being. This reinforcement of the perfect, essential, and functioning human relegates disability to an inferior level. Existing social structures promote and accommodate the normative individual, whilst disabled people encounter discriminatory practices and reduced living standards. The DPM is important and necessary because it offers a form of resistance that challenges the extent of ableism. Wolbring (2008) describes how ableism leads to the distinction between ideals and attributes that are valued and those that are not - being able to walk is the preferred, appropriate, and appreciated method for moving, as opposed to the use of a wheelchair. Disabled people's contributions, presence, and aspirations are permanently questioned by those enforcing normality, for example: an inclusive educational approach is undermined (Griffiths 2017), disabled people experience hostility for requiring support (Burch 2018), and facilitating disabled people's death is prioritised over addressing disabling barriers within society (Colleran 2017). To explore disability is to question how the social world produces and maintains ableist values. This pursuit to eradicate difference, whilst promoting the desire for normality, positions disability as a disruptive category. In her explanation of ableism, Campbell suggests her perceptions are an extension of those that have emerged from Disability Studies. Her ideas challenge the premise of difference within the social world – and, importantly, provide ways to resist ableist narratives and practices.

Such an approach must not ignore the social practices and structures that reinforce ableism. For disabled people, the process of internalising an attribute that is perceived – by society – to be an object of tragic consequence may lead the person to be identified as undesirable (Wendell 1996; French and Swain 2008). Ensuring that non-disabled people recognise the prevalence of ableism is key to advancing disabled people's emancipation. The DPM has a documented history with regard to challenging the marginalisation and oppression experienced by disabled people. Whilst ableism is expressed in numerous ways (Friedman and Owen 2017), in the present research, respondents discussed disability activism as an approach to address disabling barriers within the current political, economic, and cultural structures. As noted by Barnes (2013), the DPM is instrumental in creating positive change and challenging the structural oppression encountered by many; however, the Movement's reach is limited. Many disabled people remain oppressed by and dependent on the conditions imposed upon them within society.

2.2 Social Model of Disability

The majority of disabled people are socially excluded, oppressed, and, regardless of the international variations in the definition of what it means to be disabled, live within societies that disadvantage and deprive their existence (UN 2018). The social model of disability is essential to the organisation and activities of the Movement (Owens 2015).

The origins of the social model are key to the development and continued existence of the DPM. However, it is important to distinguish between the social model, as formed by activists, and the later academic interpretation that continues to be instrumental in Disability Studies. The core values of the social model were first established by Paul Hunt (1966), and later came to be considered fundamental to the principles of UPIAS (1975, p. 4). Disability would be considered a product of social conditions, requiring a holistic assessment of existing barriers, then, potentially, taking it for granted that disabled people have a degree of independence:

> Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation in every area of social life, such as education, work, mobility, housing, etc.

Although UPIAS no longer exists, there was always concern over their "inclusion criteria", resulting in key individuals', such as Finkelstein (1986), introducing a clear narrative for explaining disability culture and the importance of the collective identity. It is evident that the Union recognised that all disabled people experience isolation, segregation, and various forms of oppression. The necessity for disabled people to come together and challenge the conditions that perpetuate marginalisation remains. For the Movement, the social model is considered instrumental in mobilising political activism and advancing disabled people's rights (Anastasiou and Keller 2011), and in demonstrating how disabled people were marginalised historically (Longmore 2003). The social model is celebrated as a way towards emancipation (Hughes and Patterson 1997). Among activists, it is regarded as an essential tool for establishing the dignity, rights, and structural changes needed in order to guarantee the removal of disabling barriers (Kallen 2004). The outcome, i.e., actions taken for social change to occur, is the product of the analysis (Flood 2005). This use of "tool" is key to understanding how the model is used, currently, by the DPM. The aim of UPIAS (1975) and the Disability Alliance was to propose the ways in which disabled people could have self-determination and be active contributors to society. Using a social model approach, they challenged the collective organisation of society and how it produces dependency, which results in the marginalisation of disabled people.

2.2.1 *A Materialist Approach to Understanding Disability*

The materialist approach may consider disability to be a product of the Industrial Revolution. The valuing of disabled people as responsible community members decreased in line with the introduction of a labour market, which created competition within, and amongst, those communities. There was inadequate or no provision to support the participation of disabled people within this new socio-economic climate (Russell and Malhotra 2002). As a system adopted by the majority of globalised nations, it is only with the radical transformation of society, which will follow from changes to the relations and forces of production, and a rejection of capitalist ideals, that the social oppression of disabled people can be prevented. Oliver (1999) argues that capitalism demands a workforce that is physically and intellectually able to conform to the demands of industrialisation, which means contributions by disabled people are questioned. Social structures reflect a desire to exclude disabled people, legitimised through the mode of thought (ideology and hegemony). In his assessment, Oliver suggests disability is not created because of capitalism, but takes a specific form – the barriers encountered by the individual are a consequence of impairment, health condition or neuro-typical label.

Abberley (1987) draws upon four points through which to understand disabled people's experiences of oppression. Firstly, industrial capitalism has positioned disabled people as inferior to those who are non-disabled. Secondly, this notion of inferiority is reinforced through social practices. Thirdly, it is neither natural nor inevitable that disabled people should experience such oppression. Finally, it is imperative to recognise that there exist those who benefit from ensuring disabled people are positioned as such. Abberley frames oppression within an historical account of the ideological forces that accompanied capitalist development. He suggests the present social order denies disabled people their complete participation within economic and community life. Abberley's work predates the Coalition and Conservative governments, which have introduced and continue to implement extensive austerity policies that have deleteriously affected disabled people's living conditions. However, his arguments reflect current United Kingdom social policy, i.e., the incorporation of marginalised groups within the labour market.

Finkelstein (2001) employed a Marxist analysis to outline his commitment to the original principles of describing disability, as devised by UPIAS (1975). Within Disability Studies discourse, there has been considerable interest in the theoretical approach of Marxism to explain the State's role in the oppression and exploitation of disabled people (Armer 2004). Previously, the emergence of key disability theories used such analytical frameworks to interpret and explain disabling barriers to various aspects of daily living.

Marxist analysis has been used predominantly when disablement is framed within a materialist approach. Oliver and Finkelstein, two scholars inspired by Marxist political economy, articulate a cycle of conflict between disabled people – a minority – and a controlling social regime that is intentionally oppressive. Oliver (1990, p. 42) states "if a situation were to occur, where the distributive dilemma was resolved on the basis of need, then this would surely mark the transition from capitalism to socialism as predicted by Marx". Materialists have argued that disabled people could be rejected from society based on their perceived cost (Handy 1990; Harrison and Davis 2001). This is highlighted by examples showing how deinstitutionalisation programmes are fragmented (Bulic-Cojocariu and Kokic 2018), as well as by impact reports on austerity measures (Mattheys 2015).

It is important to note the development of post-Structuralist accounts of disability, which has questioned the notion of understanding impairment as an essential truth. Scholars, taking inspiration from the ideas of Foucault and Butler, have sought to challenge the divides between impairment and normal (Feely 2016). Significant debates and criticisms of materialist theory, and their links to the social model, are outlined later in the chapter. Prior to this, it is important to highlight prominent issues raised by activists with regard to the social model and its influence within the DPM.

2.2.2 *Activist Debates Surrounding the Social Model and the DPM*

Here, three specific points are raised. The significance of hierarchies of impairment, establishing solidarity and addressing intersectional aspects between disabled people, then how the model has been co-opted by the State, has led to DPM members' engaging collaboratively with State infrastructure. Hierarchy of impairment refers to people with certain impairments' being perceived to have an enhanced entitlement to identify as disabled and typically assume influential positions (Deal 2003). Shakespeare, Gillespie-Sells and Davies (1996) state that the hierarchy is a product of internalised oppression, which prevents utilising collective self-organisation to develop a positive disability identity. This has led to the emergence of interlinking social movements associated with disabled people's emancipation – such as neurodiversity activism (McGee 2012) and Mad Pride (Beresford and Russo 2016). The failure to adopt a collective identity (Watson 2002) may have negative consequences for the overall representation within the DPM. This because the Movement, ultimately, embraces individuals who are "disabled and proud" and dismisses those who associate disability with a failure to achieve "non-disabled status".

Moving to solidarity and intersectionality, Charlton (1998) argues for a DPM that recognises oppression as a totality of lived experiences; however, the DPM's history is littered with examples of failings to include a diverse range of experiences and identities – particularly young disabled people and learning disabled people (Campbell and Oliver 1996). As recognised in this research there are limited studies on how young disabled people are included within disability activism, which means it is difficult to ascertain the challenges that restrict or deter potential young members from joining the DPM. The lack of a diverse age range in the Movement has reinforced calls for the DPM to increase the diversity and various backgrounds within its membership. For the Movement to do so is important because disabled children and young people lack its support and opportunities to participate in decision-making processes (Franklin and Sloper 2004). The DPM is an essential movement through which to advance children's and young people's rights as well as to ensure they are involved in influential and leadership positions. O'Mahony (2010), in collaboration with Alliance for Inclusive Education

(ALLFIE), reported the ways in which DPOs can support young disabled people to take part in leadership development. Their findings showed that general development projects either are aimed at non-disabled people or they focus on improving participation within local government decision-making. DPOs are best placed to encourage and inspire young disabled people to become future leaders. However, such organisations require resources and improved networking opportunities so that they are best able to share good practice.

The opportunity to identify as disabled and, by extension, to adopt an affirmative stance on disability, will facilitate "the development of a politics of personal identity" (Campbell and Oliver 1996, p. 20). This is essential for building solidarity among social movement members. The DPM needs to prioritise the celebration and recognition that difference should be valued (Tollifson 1997; Cameron 2010), as it should not be assumed that newcomers will immediately identify with the politicisation of disability.

Disability scholars have used the principles of oppression to illustrate various intersectional aspects of disability discrimination, such as disability with gender (Wendell 1996, 2006; Morris 1991, 1996; Thomas 1999), 'race' and ethnicity (Ahmad 2000; Bell 2006), sexuality (Shakespeare, Gillespie-Sells and Davies 1996; Tremain 2000; McRuer and Mollow 2012), age (Priestley 2003) and social class (Jenkins 1991). Exploring social divisions within disability become problematic when different sub-groups of disabled people are perceived to prioritise differing experiences of oppression. Begum believes the "double oppression" of being a disabled woman, for example, yields to the "triple oppression of being a black disabled woman (who experiences) […] racism, sexism and handicapism" (1992, p. 70-71). Although further action is required to improve the diversity within the DPM, the membership does comprise different backgrounds and experiences. It illustrates simultaneous rather than separate oppressive experiences. This reinforces Thomas's point that theorising on disability and women should avoid "bracketing disabled women into one undifferentiated social grouping" (2007, p. 71). Such is not always the case, as highlighted in the comments made by established respondents in this research.

As highlighted in this research and in existing literature, the DPM comprises various actions taken to improve disabled people's contemporary position within society. This can include focusing on and advancing rights-based approaches (Katsui and Jukka 2008), calling for the radical overhaul of the economic and political structures (Gómez Bernal and Roca 2016), and promoting disability pride (Martin 2012). However, membership of a social movement is complex, as is highlighted in the DPM. It is too simplistic to assume disabled people are a homogenous group and will articulate their experiences of oppression within a singular characteristic. This is explored further in Chapter Three.

A concern has been raised with regard to some established activists' becoming incorporated into the structures that they are supposedly challenging (Oliver and Barnes 2012). Arguments have followed that such actions have undermined the Movement, leading to its fragmentation as members become consumed by the internal deliberations as to whether the DPM can exist as an effective and sustainable social movement. This concern links into a wider issue explored in this research: that young disabled people are unaware how they can explore their views about the applicability, limitations, and possibilities of the social model, yet at the same time avoid receiving criticism from established figures within the DPM. If the challenges encountered by young disabled people are to be addressed, then it requires the Movement both to consider how young members explore the significance of the social model and to understand how their doing so can facilitate their involvement in disability activism. Voicing ideas must occur irrespective of whether established figures and their organisations are critical of how some members have become incorporated into working with and alongside Government agencies. As will be discussed later, the oppositional device approach could address such a concern insofar as activists will organise to consider the different ways in which the social model has been understood and used, including its co-opting (and subsequent manipulation) by the State.

It is necessary to explore the criticisms and debates surrounding modern and materialist theory, and its links to the social model. This is key to demonstrating why the oppositional device approach is needed; it constitutes a way to cut across the complex divides and offer fresh insight that will support disabled people to realise emancipation.

2.2.3 *Academic Debates Surrounding the Social Model*

According to Shakespeare and Watson (2002), the social model has created conflicts and tensions within academia. Oliver (2008) has argued it that should be recognised as a practical tool to improve people's lives. Nevertheless, within Disability Studies this model emerged as a challenge to the individual model. The individual model locates the problem of disabling barriers within the individual and within the functional limitations to arise from being labelled as a disabled person. It is associated with a belief that disability is a personal tragedy (Oliver 1990). The medical model of disability, which derives from the "medicalisation" component of the individual model, considers the health of a disabled person to be the primary reason for discrimination and disadvantage. This portrayal concludes that society will view disabled people as abnormal and dependent upon medical professionals and carers. The eradication of impairment groups through genetic screening, cure or rehabilitation, and often the segregation of the individual within an institution, are proposed as a means by which disabling barriers can be overcome (French and Swain 2002). Contemporary examples illustrate how disabled people are still at risk of institutionalisation, such as the recent campaign and investigation into primary health care organisations' unlawful withdrawal of services that would have forced disabled people into institutions (Perry 2017; EHRC 2018).

Throughout its existence, it is clear that the social model has become an international point of debate among policymakers, DPOs, and governments (Albert 2005). Nevertheless, academics continue to discuss the significance of the model, which means questions are raised over the efficacy of the social model with regard to the disability agenda (Hurst 2005). Oliver (1990; 2013), a prominent figure within Disability Studies, summarised the social model by suggesting that disability is rooted within society's failure to provide adequate services and ensure the needs of disabled people are considered such that they allow for inclusion. In this context, medical contributions play a central role in establishing a quality of life for disabled individuals, with an increased life expectancy and the capability to manage the health implications of their impairment far more effectively than the past. Nevertheless, the social model attempts to distinguish between impairment and disability. This distinction challenges the narratives that frame disabled people's marginalisation because of an individual's health, impairment or neurotypical label. It provides disabled activists with a way of describing experiences of oppression and discrimination. Hurst (2005) employs the following example to explain the social model: an individual with a health condition, such as a diagnosis of Down syndrome, will then experience disability (oppression and exclusion), i.e., attitudes, inaccessible transport, and poor employment opportunities.

Through its various interpretations the social model has typically been identified as either a materialist or a rights-based model (Sheldon 2005). Further problems have arisen with regard to the theoretical identification of the social model, particularly surrounding the notion of rights. Finkelstein (2001) acknowledges the campaigns for disability rights yet argues that rights are not dependent upon, nor are a reflection of, the social model. Others (Priestley 1998; Horsler 2003) have argued that the social model may be interpreted differently in identifying the cause of disability.

Two aspects of the rights-based model are problematic. Firstly, considering disability to be caused by traditional beliefs has as a result the overall concept of disability being separated out on the basis of culture, rather than its being considered a “universal” struggle. This can pave the way for certain audiences and academics to impose their priorities on eradicating disabling barriers, rather than their allowing disabled people at the grassroots level to implement their own structure for achievement in their respective cultural contexts (O’Toole and McConkey 1995). As identified in this research, young respondents argued that established figures and their organisations within the Movement have dictated how the social model should be understood in order for it to address disabling barriers. This has led to young members’ feeling ostracised if they attempt to debate how it is understood – and how they understand it. Secondly, concern is raised over the notion of rights: allegedly a natural principle, provided to all, regardless of cultural background or social status (Armstrong and Barton 1999). The rights-based focus on the social model offers practical solutions that seek change through equal opportunities and equal rights agendas in compliance with existing systems (Sheldon 2005). This is reflected in the various directions taken by the DPM to create emancipatory change, as is highlighted in Chapter Six. A focus on rights over the radical transformation of existing social structures is part of the reason for the emergence of interlinking social movements associated with disabled people’s marginalisation – further explored in Chapter Three.

Many support the idea that disability should be embedded within a human rights agenda (Armstrong and Barton 1999; Quinn and Degener 2002), demonstrating the significance of using the UNCRPD to advance social, cultural, and political rights (Harpur 2011). Given that the perceptions of disabled people are still very much embedded within the individual and medical models, campaigning for rights will be seen by politicised disabled people (Drewett 1999) as a suitable option. This is particularly the case when the rights agenda is aligned within a socio-economic and political framework (Young and Quibell 2007).

While these highlighted issues affect the validity of the social model, they do so, predominantly, in relation to those practical difficulties that result from its implementation. Lang (2001) believes the social model of disability should not be considered as a monolithic entity; rather, it could be perceived as a cluster of approaches through which to understand the notion of disablement. At the core of the model is the belief that disability and disablement are socio-political constructions, which may produce variants of the model to reflect the multiple factors associated with experiences of disabled people's oppression and discrimination.

Furthermore, there is a need to consider the relational and psycho-emotional aspects of disablism. Watermeyer and Schwartz (2008) argue that little attention is given to the personal and emotional aspects of disability oppression and impairment. This emerging field has led to notable Disability Studies scholars' suggesting that the social model has tended to disregard the personal and emotional attachment to disability and impairment (Thomas 2007). It is suggested that the UPIAS definition of disability lends itself to demonstrating the importance of both structural and psycho-emotional disablism (Thomas 2007). According to Reeve (2014), the social model has never specifically excluded a discussion on these aspects, but has concentrated on structural barriers as a way to initiate debate on the marginalisation of disabled people. She continues by arguing that it is now time to explore indirect and direct forms of psycho-emotional disablism, those that build upon the concept of internalised oppression.

According to Hurst and Albert (2006), one of the main criticisms of the social model in this application is the ignorance of the reality of impairment for disabled people. The definition of what causes disability may be understood as negating the importance of what causes the impairment, so often a result of social or economic factors. Nevertheless, the social model should not be seen as a rejection of medical intervention, merely as a resistance to the perception of disabled people as medical objects. Disability Studies scholars have explored the inclusion of body experiences within the social model of disability. The model is situated within a context of how institutions, organisations, and individuals interact with disabled people, recognising that many developers of the social model were attempting to eradicate the relationship between impairment and exclusion, yet doing so without focusing on how to resist social practices that reinforce discrimination on the grounds of impairment, health condition, or neuro-typical label. Presently, according to Morris (2013, p. 4), it is necessary fully to acknowledge the experiences of the body before it is possible to demand changes within assessment and criterion frameworks for the person to receive support. If this is not realised, tension will persist between individuals who want to discuss barriers, on the one hand, and those who aim to connect identification of barriers with personal experiences of impairment and, possibly, illness, on the other:

> The crucial point is that we need to take ownership of the experiences of our bodies instead of leaving it to others. If we don't articulate what our requirements are which result from the impact of impairment and/or illness we cannot hope to either get the adjustments we need, or ultimately challenge disabling public attitudes which treat such experiences as tragic at best and, at worst, as manifestations of personal inadequacies and/or of a life not worth living.

Oliver (2013) advises caution over the potential outcome of reinforcing a link between illness and disability, which can perpetuate disabled people's role of tragic victims because of the individual's impairment. This could be perceived as a criticism of some disabled campaigners, who prioritise the impact of ill health and impairment on the ability to exist within an economic and welfare framework that values contribution to labour over reliance on social security. The concern raised by Oliver is valid; it reflects on further discussions continuing within the DPM over terminology and disabled people's association with vulnerability frames (Crowther 2015).

Over time, the field of Disability Studies has introduced a plethora of models to describe disability, such as affirmation model (Swain and French 2000) and social relational model (Thomas 2007). Oliver (1990) expressed concern over the numerous models that exist to explain the concept of disability. There exists a very real risk that the application, or failure to do so, of specific models will come to form the focus of discussion at the expense of the issues surrounding disabling barriers. It would appear such concerns have not been addressed as, more recently, he has called for people to stop discussing the model and either replace it or reinvigorate its use (Oliver 2013). This research attempts to reinvigorate how the social model is understood within the Movement: if young disabled people are to hold prominent and valued positions within the DPM then it is essential firstly to review how the social model is understood and utilised by established figures and their organisations.

More recently, scholars have focused on the cultural constructions of disability and disablism (Waldschmidt, Berressem and Ingwersen 2017). This has shifted understanding of disability away from realist approaches and introduced an exploration of the individual as a composite of biological, psychological and social aspects (Galis 2011). The post-Structuralist approach challenges the idea that the divisions of the human species are natural and inevitable; instead, it proposes that the appearance of "normal" and "impaired" are illusory and manifest through cultural and political distinctions (McRuer 2006). The significance of post-structuralism, within disability research, rests upon the premise of rejecting inherited frameworks that categorise human diversity (Feely 2016). This is reflected in the works of Corker and French (1999), who attempts to render problematic the notion of impairment as a biological foundation, in Tremain's (2005) focus on deconstructing the impairment and disability distinction, and in Kafer's (2013) approach of blurring the divide between normal and impaired. The development of Critical Disability Studies has become instrumental in advancing discussion on the cultural and linguistic construction of disability (Meekosha, Shuttleworth and Soldatic 2013).

Notwithstanding the fair criticism, i.e., that materialist accounts may neglect the significance of culture, there are dangers to embracing a post-Structuralist approach. The focus on discourse and deconstruction may appear to overlook the material factors that perpetuate disabled people's marginalisation (Wendell 1996). This could weaken the DPM because of the risk that the Movement's actions and strategies are deconstructed and rendered unreliable in the pursuit of political and economic change. As a way forward, scholars are beginning to explore the emergence of "new materialism" (Fox and Alldred 2016), which, according to Feely (2011, p. 1): "allow[s] us to consider disability as a material phenomenon without a return to essentialism". Nevertheless, it is possible to return to materialism and attempt to satisfy such academic criticisms by focusing on how the DPM engages with the existing political and economic structures – most notably the effects of neoliberalism. Developing an effective and sustainable social movement, one inclusive of the membership, requires a commitment to understanding how the social model is used politically by activists – and for what purpose.

2.3 Moving Forward – the DPM and the Social Model

More recently, there has been a resurgence of socialism within the DPM. Dodd (2014) provides empirical data to suggest that activists and scholars should explore Open Marxism[4]. This, he argues, will help to understand the extent of disablism and provide solutions that will address the challenges encountered by disabled people at the individual, collective, and ideological levels. Furthermore, Slorach (2015) utilises a Marxist framework to focus on how disabled people have continuously been exploited through the capitalist imperative to maximise profit. His aim is to improve understanding of the material basis that creates and reinforces disabled people's marginalisation. Although not a focal point in this research, respondents acknowledged the significance of the Marxist influence upon activism.

In recent years, Oliver and Barnes (2012) propose situating disability within the ever-changing nature of capitalism. This will provide clarity as to how the perpetual cycles of economic crisis produce and reinforce the social policy and State actions that continue negatively to have an impact upon disabled people's lives. Oliver and Barnes argue that if disabled people are to remain united and resist the severe consequences of capitalism, then the DPM must return to the politics of hope, solidarity, and activism. These are principles that are critically important to the development of disabled people's social movements (Pelka 2013). Such arguments capture the essence of this research, as it sets out to identify the challenges that prevent young disabled people from engaging in the politics of hope and solidarity. If the DPM fails to recognise the barriers that prevent young members from participating in disability activism, it is undermining the opportunities to create emancipatory change.

Whilst debate will continue over the formulation of an economic approach to understanding disability (Armer 2004), scholars from Disability Studies have analysed the relationship

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[4] Open Marxism is a school of thought that rejects the determinist and positivist characteristics associated with Marxist thinking, as outlined in three volumes of text (Bonefeld, Gunn and Psychopedis 1992a, 1992b; Bonefeld *et al*. 1995).

between disability policy and neoliberalism (Grover and Piggott 2005; Roulstone and Prideaux 2012; Grover and Soldatic 2013). Recently, there have been calls for the DPM to engage in a critical study of neoliberalism (Mladenov 2015), supporting academics who call for the inclusion of the Movement within the broader political and economic debates (Morris 2011).

The chapter now introduces a contemporary intervention into the debate surrounding the social model: the oppositional device.

2.3.1 *Oppositional Devices and the Importance of Resistance*

Facilitating disabled people's understanding of the social model is essential to ensuring that the DPM remain committed to addressing the barriers encountered by disabled people and to working towards a fair, safe, and inclusive society. Academics have questioned whether the social model has outlived its effectiveness and requires reshaping (Shakespeare and Watson 2002; Gabel and Peters 2004), yet Beckett and Campbell (2015) have articulated an approach that will support activists to establish specific fields of resistance. They argue this will be immensely beneficial to the DPM, as it will structure discussions on the potential challenges ahead and the strategies required to create progress. The research draws on Beckett and Campbell's (2015) idea of the social model as an oppositional device. This way, the focus is on how the social model may assist activists in developing resistance-based practices to the processes that produce and sustain disablement.

The premise of oppositional devices is influenced considerably by the work of Foucault. Beckett and Campbell (2015, p. 272) suggest "emphasis be given to Foucault's proposition that resistance is, ontologically and chronologically, prior to power". This is reinforced in the work of Revel (2008) and illustrates how resistance opens up possibilities for the individual to challenge the various forms of power. Such an understanding of resistance and power may bridge the divides between materialist and post-Structuralist accounts. It is for this reason that the oppositional device offers a way to build consensus between traditional Disability Studies and the emerging field of "Critical" Disability Studies.

Understanding the social model as an oppositional device requires a move away from understanding it as a tool. Rather than being an entity to implement, it introduces opportunities to question what it means to oppose/resist, how that may be applied, and the implications that this may have. The idea of the oppositional device is inspired by Holmes (2007, p. 3), as a way to describe the "deliberately abnormal, fictional, satirical, delirious, antagonistic or even violent pattern of behaviour that inserts itself into, and distorts, a corporeal, technical and symbolic configuration of normalised social relations, in such a way as to provoke". He draws on Foucault's idea of the Panopticon (1991) through which to show how structures are established to instil a specific pattern of interaction, regulated by a form of technology and supported through deep-rooted logic or rules.

For Holmes, the point is to ensure individuals critique their actions and continuously question where and how to develop collaborations. Creating oppositional devices is a means of opening possibilities, of identifying and challenging the structures that demand and regulate conformity. In doing so, it draws attention from other people thus the chances to disrupt intensify as more people see a need to resist and challenge. What is particularly interesting about his idea is the recognition that some acts of disruption are tolerated; an attempt to fragment any concerted effort that may destabilise the structures being resisted. The aspect of the tolerance of disruption is reflected in the current commentary surrounding the DPM.

The question remains as to how the focal point of resistance may allow DPM members and their organisations to unite. Beckett and Campbell's (2015, p. 275) assessment of an oppositional device offers seven intersecting operations that illustrate the importance of identifying practices as unjust:

- allowing practices, programmes and rationalities to be identified as unjust;
- harnessing and orientating practices of resistance towards such programmes, procedures and rationalities;
- allowing formation of counter-rationalities and the dispersal, proliferation and repetition of practices and statements informed and promulgated by said counter-rationalities;
- facilitating analysis – allowing statements, policies and institutions to be evaluated;
- allowing establishment of a social movement's vocabulary and delineation of what can be said if an enunciation is to be associated with a movement and boundaries that once crossed result in a statement losing meaning for, and possibly approval of, a movement;
- providing a framework of agreed values allowing repetition of resistance-practices in sites different from those in which the oppositional device was formed and for those engaged in seemingly disconnected struggles to recognise their shared purpose; and

- allowing members of social movements to act strategically and as one.

Beckett and Campbell suggest that the social model may indeed align with the various operations outlined above. They draw on literature produced by Finkelstein (1972) to argue that the social model produces sets of distinctive concepts: impairment and disability; disabled and non-disabled persons. This ensures a pathway towards collective resistance, as disabled people become united through their awareness that a politicised disabled people's community exists. It is one that emphasises both the oppression experienced by disabled people and the essential need to resist such practices.

They continue by showing how the social model facilitates the broadening of activist agendas, thus can support DPM members in identifying emerging areas for resistance. As an example, they refer to Linton's (1998) work. Linton highlights how the systematic appropriation of the terms used to understand disability has led to individualised, deterministic, and essentialist accounts through, as Beckett and Campbell state (2015, p. 276), "such statements as 'biology is destiny' and that the assigned role of disabled people is determined by natural inferiority". The social model is then operationalised to challenge such statements and to question the assumed notion of 'truth' that underpins the justification and rationale for such statements. In this way, the social model can be used to draw attention to the policies and practices that perpetuate disabled people's oppression, for example, segregated education systems, institutionalised care environments, and sheltered employment opportunities that promote meaningless work.

To Beckett and Campbell the social model is transformative on a personal level; it can be utilised to redirect "notions of biopower" (Tremain 2008). The social model is regarded as a mechanism to liberate disabled individuals from the oppressive narratives demonstrated in by the personal tragedy accounts (Crow 1996). Framing the social model as an oppositional device offers activists a way to reject such narratives and identify as an oppressed group, that is, of those disabled by the way society is organised.

In their assessment, Beckett and Campbell acknowledge how the social model is also operationalised as a tool for discipline, drawing attention to forces interior and exterior to the DPM. With regard to the internal matters of the DPM's organisation, they reference scholars such as Shakespeare and Watson (2002) and Peters, Gabel, and Symeonidou (2009), who argue the social model is employed dogmatically and is used as a means of determining whether individuals are considered members of the DPM. The findings from this research reinforce these concerns, as young disabled people highlight how critiquing the social model can result in established members' attempting to undermine their position within the Movement. Whilst this is deeply concerning and requires immediate action from the DPM, the research argues, as do Beckett and Campbell, that the social model should be and is significant to the organisation of the DPM. The social model is recognised as being key to the collective identity of DPM members thus is essential for the development and implementation of politicised strategies that bring about social change.

This last point is significant when considering why young disabled activists should understand the social model as an oppositional device. The research found no indication amongst the respondents that the social model should be abandoned; rather, the social model remains essential for the individual and collective politicisation of disability, as well as for challenging the oppression experienced by disabled people. The social model as an oppositional device introduces the importance of resistance practices. It celebrates the collective actions of a political group, disabled people, who attempt to position the organisation and functioning of contemporary society as socially unjust. Through this approach, young disabled people can understand the social model as a mechanism through which to identify what needs to be resisted, to devise strategies of resistance, and to implement activities to disrupt contemporary social practices: these will bring about change. Whether the changes be cultural, political, economic, or social, young disabled people have the freedom to use the social model to establish a style of resistance practices that reflect their aspirations and ideas for disability activism. This is explored further in Chapter Eight.

Determining whether Beckett and Campbell's list of operations is complete remains outside the scope of this research and requires further commentary within Disability Studies literature; nevertheless, within the context of this research, further development of the social model as an oppositional device rests upon its facilitation of alternative, preferable futures that would bring about disabled people's emancipation. Beckett and Campbell refer to this, when suggesting the social model is underpinned by an ontology of the virtual (May 2005). The ontology emphasises the need to introduce counter-rationalities and alternative ideas to address the injustice perpetuated by an ableist society. If the DPM is to remain an effective, sustainable social movement, it requires members to support the young disabled people and newcomers who introduce their ideas for building an inclusive, just, and accessible society. It is clear that the social model remains integral to young disabled people's activism. However, it must be framed around its potential to identify and disrupt normative values and practices. Introducing the social model to young disabled people, as a way to describe, disrupt, and overhaul the conditions that perpetuate injustice, must be incorporated into subsequent discourse surrounding oppositional devices.

Such operations should form the basis of social movement organisation and create opportunities for newcomers to engage proactively with the Movement. By incorporating these operations, new and existing members can understand their role within social movements and work collaboratively to identify and articulate demands. This will help build solidarity within a social movement in order to formulate counter-rationalities to disperse the practices and social structures that are identified as unjust. There is a possibility of taking Beckett and Campbell's idea and using it as a way to facilitate young disabled people's participation within the DPM. This is argued on the basis that young respondents struggle to establish debates about understanding the social model; the expectation is they will passively learn, absorb, and adopt the narratives offered by established figures. Through this research, it is possible to conceive how promoting the oppositional device approach will lead to young disabled people's recognising the importance of the DPM and gaining opportunities to introduce alternative ways of structuring the social world.

It is paramount to address the issue of power in this context. As outlined in Chapter One, I take inspiration from Gabel and Peters (2004) and consider the fluctuating nature of resistance as a way to understanding power. As Peters, Gabel, and Symeonidou (2009) suggest, resistance continues to be harnessed by DPMs to create and sustain change for a more just society. They propose a theoretical paradigm that frames disability as a construction of political action seeking to recognise the power of resistance, both individually and collectively. Understanding power and resistance in this way means the social model, as an oppositional device, reinforces the significance of disability activism and provides young disabled people with opportunities to frame their experiences of marginalisation then to seek emancipatory outcomes.

This section has charted the significant development of the social model of disability, capturing its position within activism and academia. Existing criticism and limitations of the model have led to its being contested as a means of describing the extent of disability. The opportunity to understand the social model as an oppositional device offers a suitable way towards building solidarity within the DPM and improving young disabled people’s participation within the Movement. As the research is primarily focused on challenges encountered by young disabled people, the final section will highlight specific literature that could strengthen their position in activism and campaigning.

2.3.2 *Youth and Identity*

The relationship between disability and society – whether the direct outcome of economic structures or the cultural significance of social processes and interactions – generates a condition of oppression and difference, experienced by the individual or marginalised group. This understanding will, from the individual’s perspective, not only formulate the core principles of their individual-self, but also affect their interaction with a group or social movement. Moreover, the DPM relies upon interactions between members to protect its existence and enhance its influence, which requires individual members to have a comparative understanding of “why am I different?” and common identification with others as to “how do we address inequity and for what purpose?”. Both aspects are a complicated matter for the Movement, with fundamental arguments between members and individuals who disagree on their respective visions and analyses of disability. This is a recognition that many existing and new members are continuously exploring issues associated with self- and cultural identity, which is of particular relevance to young disabled people (Slater 2015).

In order to address diversity within the Movement, attention must turn to how young disabled people are supported to engage in activism and the DPM. Thus far the chapter has explored disabled people's social position, highlighting the extent of marginalisation encountered. This has demonstrated the importance of disability activism and social movements, and is concerned with addressing the social structures producing and reinforcing marginalisation. The prevalence of the social model should not be dismissed, as it is essential to the actions of the DPM and those who participate in its organisation. However, as noted in this research, young disabled people face extensive challenges to engaging in the Movement, which includes their understanding the social model. This final section will draw attention to ideas that can improve young people’s participation within the DPM. Further exploration of these are found in Chapters Five to Eight.

There is wide acknowledgement that disability identity is an unresolved issue. Collectively, the themes emerging from this research are representative and pertinent to young disabled people. Issues associated with the immobilisation of youth identity (Slater 2015), identity (Riddell and Watson 2003; Loja *et al.* 2013), and the importance of participation (Carter *et al.* 2014) are recorded in the preceding and subsequent chapters. Nevertheless, it is paramount to consider how the desired adult is represented and what contributes to the transitioning from child- to adulthood. Lesko (2012) approaches adolescence as a combination of theoretical, political, and strategic frameworks that mould a young person into an adult, rather than relying on a traditional view of biological development. The discourse on adolescence provides an opportunity to explore the aspects that contribute to the definition of adolescence (Slater 2015); thus illustrating that youth and adulthood are understood as a product of social facts operating within a specific context. Lesko's suggestion to perceive youth as "border zones between the imagined end points of adult and child" (Lesko 2012, p. 42) creates an environment that grounds young people into a diverse range of functions – school, support services, and medical assessments – to shape their identity and, potentially, prepare them for social, cultural and political arenas. Although the original research into border zones fails to account for disability issues, Slater investigates this connection within the context of neoliberalism (Slater 2015), suggesting youth and disability are conceptualised within medical and psychological frameworks to suit contemporary, normative understandings. If the purpose of the border zones is to prepare children and young people to meet the requirements of contemporary adulthood, then it is important to consider the experiences of disabled young people participating in a society rooted in ableism.

Contemporary research demonstrates how young disabled people struggle to have choice and control over all areas of their lives (Townsley, Marriott, and Ward 2009; Griffiths 2012). Even with the Government's rollout of self-directed support, there is minimal provision of advocacy and guidance to support young disabled people such that they indeed have choice and control over the support they receive. There is an expectation that independent support services will provide support to young disabled people, in order for them to have active roles within the community. However, strategies to ensure young disabled people have self-determination typically focus on establishing partnership working between external services and local authorities (Keen 2007), rather than on facilitating young disabled people's participation within activism and social movements. Concerns have been raised over how much control young disabled people have over their own support, leading to discussions with regard to who is ultimately responsible for the service provision (Leece and Leece 2010). Furthermore, rigorous guidelines and assessment outcomes create barriers to the flexibility of accessing support (Duffy 2010). Accessing support is essential to ensuring young disabled people can participate in local communities; action is required to identify the support needed for young disabled people to engage in disability activism. Whilst this requires improvements to the assessment procedures and delivery of support, it also necessitates reflection and action by the DPM.

2.3.3 *Safe Spaces*

Polletta (1999) suggests safe spaces are small-scale settings that are part of a social movement while detached from the authority and control of dominant groups; the settings are occupied by individuals who generate the cultural challenge that precedes or accompanies political mobilisation. The role of safe spaces is essential for supporting the inclusion of individuals within wider networks and structures. Contemporary literature on safe spaces tends to explore their use within the teaching and learning context (Gayle, Cortez and Preiss 2013; Darrell, Littlefield and Washington 2016; Harpalani 2017). However, research has explored the significance of safe spaces in supporting activists to explore pertinent issues associated with identity, social justice, and power (Poynter and Tubbs 2008; Lewis *et al.* 2015; Palkki and Caldwell 2017). Ahmed (2015) calls for safe spaces to provide platforms where people can continue to participate on difficult issues.

Within activism and social movements, scholars have suggested that the idea of safe spaces offers a separate and sheltered area to mobilise for social change (Polletta 1999; Wallin-Ruschman and Patka 2016). They are essential for bringing individuals together to raise awareness of particular ideas and avenues of thought, with the intention of building solidarity and creating political mobilisation (Armstrong 2002). Some scholars are cautious, suggesting safe spaces may appear regressive, particularly if they do not celebrate the diversity of the members and fail to focus on offering a critique of existing hierarchies – therefore, also failing to have clear actions to take beyond the confines of the safe space (Reagon 1983). The role of safe spaces is essential for the short and long-term organisation of social movements, as they can facilitate group pride (Polletta 2002); however, this may lead to a destabilised activist base if members are over-reliant on friendship networks.

There is a considerable lack of research into the use of safe spaces and disabled people. Where there is a focus on safe spaces, it predominantly relates to: supporting individuals to form social networks and gain protection from disabling barriers within the social world (Bryant, Tibbs and Clark 2011), creating spaces for disabled people to meet other disabled people (Bertilsdotter Rosqvist, Brownlow and O'Dell 2015), and addressing hostility within the education system (Robinson 2018). Within the context of disability activism, there is no literature critiquing how young disabled people engage in safe spaces in order to establish participation within social movements. This is problematic because, as this research shows, young disabled people want opportunities to critique and challenge the ideas and strategies offered by established figures and their organisations in the DPM. The premise of safe spaces is offered as a potential solution to the challenges raised by young respondents.

2.4 Conclusion

The chapter has outlined key aspects of disability and youth that are most applicable to the research questions. As the research focuses on the DPM, it was appropriate to explore why the Movement was and remains necessary. This introduced political and economic arguments to explain the prevalence of marginalisation encountered by disabled people. Justification for the arguments presented was based on how they are reflected in the points made by respondents in this research. An example is offered to show how the Movement engages with key issues affecting disabled people. The topic of welfare provision was highlighted in order to illustrate the various approaches taken to improve access to support services, particularly in the period of neoliberalism. The DPM is involved in a complex critique of how the State provides support, challenging the extent of austerity measures whilst also demanding self-determination.

The chapter explores the understanding of the social model of disability, a fundamental idea that has inspired disability activism. This is justified on the basis that respondents spoke about the importance of the model for their personal trajectory into activism and its significance for the organisation of the DPM. Furthermore, this research argues that the model is essential for facilitating young disabled people's participation within the Movement. The origins of the social model were outlined, which led to the introduction of key debates and criticisms surrounding how the social model is interpreted within activism and academia. The proposal to understand the social model as an oppositional device, as suggested by Beckett and Campbell (2015), is outlined. This draws on literature proposed by Holmes (2007), which leads to the suggestion that the social model should not be perceived as a “tool” to be implemented. Rather, it is an oppositional device that may facilitate opportunities for activists to question what should be resisted, how that can be realised, and what can happen as a result of resistance. The importance of resistance is a focal point throughout Chapters Five, Six, and Eight. The chapter provides a review of key literature that frames the discussion of a way forward in Chapter Eight. It is essential that the challenges encountered by young respondents be addressed by the DPM in order to improve participation within the Movement.

The next chapter explores pertinent literature from Social Movement Studies, exploring how the DPM may be defined as a (new) social movement and the indications this has for supporting young disabled people to participate in the Movement's overall direction and strategy.

3. Unpacking (New) Social Movements

3.1 Introduction

The chapter outlines key aspects of social movements most applicable to the research questions. As the research focuses on the DPM, it is appropriate to provide an overview of the specific terminologies used in defining how social movements organise. The ideas of Blumer (1969) pertaining to the life cycle of social movements is introduced, despite the fact that Disability Studies scholars have criticised its applicability in understanding and critiquing the DPM. Whilst criticism directed towards Blumer is noted and respected, his framework provides a necessary introduction to understanding people's desire to participate in social movements. Attention is also directed towards the work of Beckett (2006b), who utilises qualitative research to explain prominent debates and issues surrounding the emergence, sustainability, and effectiveness of the DPM. Her work has provided important insight into how to define the Movement, the diversity amongst members, and the implications for its recognition as a new social movement.

The chapter unravels the complexity surrounding New Social Movements in the context of their focus on rights-based issues and identity politics; this is challenged on a number of levels, including the interlinking nature of the DPM and the diverse positions taken by disabled activists to advocate for radical social change over a rights-based approach. With interlinking social movements becoming a focal point throughout Chapters Five, Six, and Eight, it is essential to understand how traditional class-based issues and identity politics may combine and intersect within a social movement.

The final section of the chapter provides an extensive account of the DPM, in particular describing the structural and cultural recognition of the need to address disabling barriers within the Movement. Mention is made of various waves within political social movements. Similarly, the definition of the DPM as provided by Oliver and Campbell (1996) allows for the exploration of diversity within the Movement and the implications this has for the young disabled people participating. Interest in, awareness of, and accessibility into the DPM is highlighted, and shapes the subsequent discussions found in Chapter Five.

3.2 Understanding the DPM as a Social Movement

The issue of social movements has received considerable critical attention, with many scholars exploring various definitions through which to articulate aspects of social conflict and initiatives (Oberschall 1973; Weissmann 2008). Before reviewing key terms, it is essential to distinguish the development of social movements from that of historical movements. Irrespective of the approach taken to understand the role of Social Movement Studies, the study of collective action within social formations from the process of action within historical change must be clarified. Touraine (2002, p. 89) perceives social movements to be "an answer either to a threat or a hope that is directly linked to the control that the social group has over its capacity to make decisions, to control changes"; this, perhaps, reflects a position of attempting to observe the actors associated with a social group rather than being a generic analysis that could explain the transformation of the world, such as economic determinism. For example, within the field of social study, observing social movements of an industrial society is not the same as the reaction to the process of industrialisation: the experiences will not refer to the same reality. Furthermore, there is a need also to consider hierarchal natures of social processes, such as prioritising the impact of political movements within the above context.

The importance of social movements relies upon a defence of existing opposition to actual, or perceived, hegemony; although the mobilisation of social movements can occur to combat capitalism or globalisation, or to promote anarchist revolutionary thinking, the emergence of New Social Movements in post-1960s Western societies is a celebration of post-Marxist thinking and a rejection of the priority given to class struggle (Crossley 2002). This contemporary form of social movements embedded a focus on central conflicts attached to issues of identity and personal politics – such as environmental, feminist or anti-racist movements (Wieviorka 2005; De la Porta and Diani 2006). I have intentionally omitted the DPM from the examples above, because defining the DPM as a new social movement is debatable.

According to Crossley (2002), there are four frameworks within which to analyse social movements: firstly, the pre-1960s European approach was to utilise the Marxist tool of inquiry to understand issues of power and identify the singular key movement to address various conflicts (Barker, Cox, Krinsky and Gunvald Nilsen 2013). Secondly, the pre-1960s American "collective behavior" approach is now recognised as a flawed construct to explain the occurrence and intensity of protests and movements. The comment applies particularly as "collective behaviors" aligned to social movements with manifestations of "mob hysteria", having objective hardship as the root cause of protest formulation; also, it portrays members as isolated individuals detached from social structures. Critiques of this approach have ultimately led to a rejection of the collective behaviour principles used as a method to explain social movements (Tarrow 2011). The American trajectory has now entered, thirdly, a stage of exploring resource mobilisation and political process, which attempts to establish theoretical constructs to advance the inclusion of social movements within social reality and Social Studies. This current approach initially focused upon the structural networking among actors associated with a movement – exploring social relational aspects between members – which led to an examination of resources required to mobilise support in response to oppression (Tesdahl and Speer 2015). Fourthly, recent developments have incorporated the role of political systems and processes to determine its impact on opportunities to establish protest, leading to a reflection of how activism has impacts upon the life course of New Social Movements.

Irrespective of the analytical framework used, attempting to create an inclusive definition is problematic, as the purpose of social movements remains contentious. The social agents attached to various movements are in a position to question the role of a collective group; for example, is it to embed opposition aims and objectives into the actions of a dominant group? Or is it to mobilise support and strengthen various social movements centred on a particular theme? Reflecting on such questions allows for an effective strategy through which to explore issues of resistance, political process, collective action, and identity associated with social movement thinking.

3.2.1 *Collective Action and the Four Stages of Social Movements*

Understanding collective action and group processes involved in social movement organisation is a significant point of interest for scholars (Olson 1965; Coleman 1990; Marwell and Oliver 1993). The extensive literature illustrates differing objectives pursued by those analysing social movements. Emphasis has been placed on highlighting the significance of rational action

(Gamson 1990), political processes (McAdam 1988; Tilly 2009), and resource mobilisation (McCarthy and Zald 1997). An interest in the mobilisation and organisation of social movements has led to the emergence of "new social movement" theories (Touraine 1992; Buechlar 1995), which is explored in further detail in the subsequent sections of this chapter. However, it is important to note at this point that new social movement literature has rendered questionable the historical objectives associated with understanding social movements. Scott (1990) suggests historical objectives within the field of social movements has prioritised an exploration of issues associated with social class (for example, working class exploitation). This is in contrast to the new social movement literature that typically engages with single broad themes or identity issues. According to Offe (1985) and Melucci (1996), New Social Movements are distinctive insofar as they do not develop a total political analysis. As Cleland *et al*. (2018, p. 23) suggest, "[New Social Movements seek] change by lobbying social spheres of society rather than the obvious political spheres of governments."

The notion of collective identity is significant to social movements' organisation, sustainability, and effectiveness (Melucci 1996). Melucci places emphasis on social movement members to engage with creative activities and outputs. These activities represent the opportunities to bring about social change, either by acting within the limits posed by societal organisation or by pursuing possible alternatives that challenge the limitations. Taking into consideration the historical context of studying collective action, in which scholars argued that such behaviours were irrational responses to accelerated social change (Durkheim 2012; Lincoln and Guillot 2004), others have argued that the transition from collective action to social movement occurs when members "reject the boundaries of established institutional rules and roles" (Darnovsky, Epstein and Flacks 1995, p. 12). Furthermore, Tilly's (1978) account of collective action concluded with the creation of four central components: a focus on opportunities to advance an agenda, a recognition of resources required to achieve goals, the clear link between shared interests and group behaviour, and acknowledging the logistical challenges associated with organising direct action. Tilly's argument, therefore, conceptualises collective action as a response to the frustration of a social group that does not have direct forms of communication or influence; a view that is reflected in Olson's "Logic of Collective Action", which explored protesters' rational thought processes when establishing groups and organisations that seek to further the interests of its members (Olson 1965).

With clear acknowledgement of the complexities involved in establishing and recognising the journey of social movements, it is beneficial to consider Blumer's definition:

> Social movements can be viewed as collective enterprises seeking to establish a new order of life. They have their inception in a condition of unrest, and derive their motive power on one hand from dissatisfaction with the current form of life, and on the other hand, from which is and hopes for a new system of living. The career of a social movement depicts the emergence of a new order of life. (Blumer 1969, p. 199)

There are significant developments in the understanding of social movements since the introduction of this broad definition. Blumer's account, though, introduces the general characteristics, issues, and differences that have resonance when aligned with the trajectory of the DPM. Initial consideration of Blumer's ideas and their application to disabled people's emancipation can be found in Driedger's (1989) analysis on the historical development and future considerations of "Disabled People's International" (Hurst 2005). In her assessment, Driedger draws upon the dynamics offered by Blumer and other traditional social movement scholars to explore stages of social movement development, such as emergence, coalescence, institutionalisation, fragmentation, and decline. However, this was not received without scrutiny and criticism; Oliver and Zarb (1989) suggested such theories and frameworks are limited in their capability to assess the multiplicity of issues affecting specific social groups. They continued by suggesting that these frameworks cannot be aligned with the social movements that emerge as a product of late capitalist development. The initial interpretation of Driedger's work was criticised on the basis of DPMs' occupying an internationalist platform that, according to Oliver (1990), should be recognised by their significance in establishing new forms of social relations rather than on how to compartmentalise their legacy. Thus, Oliver argued that the frameworks offered by Blumer, and other conservative US social movement theorists, derived from movements dominated by middle-class elites within one country and focused on singular issues.

Notwithstanding this criticism levelled towards the credibility of Blumer's work, his framework can be a useful introduction to understand people's desire to participate in social movements as well as their demands for social change. This was used by Beckett, during her empirical research, to categorise and depict episodes of collective action by disabled people (Beckett 2006b). Here, Blumer's framework is not read as a prescriptive set of outputs and occurrences that manifest in all collective groups. Rather, he provides a flexible interpretation for understanding the potential actions taken by members and groups during the life course of a social movement. This provides an opportunity to introduce the debates and issues surrounding the DPM and its members. As the research incorporates the views of both young disabled people and established members of the DPM, the various dynamics offered by Blumer are viewed as a continuation of actions, strategies, and behaviours that resemble an ever-changing DPM. Considering that this chapter, and entire research, unpacks the complexity surrounding – for example – a rights-based agenda, alliance with State infrastructure, and the disengagement by potential members, Blumer's ideas are incorporated as a way of demonstrating how a movement is affected by these various issues, and at different times. This research, in further clarification, highlights concerns regarding the decline and "death" of the DPM, which resembles aspects of the framework that denote the decline and demise of social movements. Similarly, the research draws attention to issues pertaining to how influential activists have become co-opted by the State, which has affected how the Movement operates thus has led to the fragmentation and emergence of interlinking movements. This, again, is reflected in the framework. The criticisms offered by Oliver are not necessarily disputed. The parameters of the present research do not reflect the aspirations of the work that was the initial focus of Oliver's concerns; for example, here, the focus is on a social movement within one country and explores its internal dynamics in order to ascertain how to improve inclusion for young disabled people.

Blumer’s notion of “collective enterprises”, which refers to collaborative working and the recognition of a shared project among members, draws attention to the very purpose of a social movement (Crossley 2002). By rejecting traditional forms of collective action – particularly “mob psychology” (Le Bon 2014) – Blumer is stating that movements occur due to the dissatisfaction with the *status quo*, acknowledging a desire to establish a progressive vision for positive change. Whilst recognising that many new social movement analysts would argue that contemporary literature produces an inconclusive link between movement emergence and dissatisfaction, this definition has substantial relevance to the development of the DPM and is explored later in the chapter.

Blumer’s work on collective enterprise is significant for its drawing attention to the relationships between social movement members. This is important for understanding how consensus and conflict emerge between members, and the impact these will have on the organisation and sustainability of social movements. It is possible to draw parallels between Blumer's analysis and Melucci’s (1989). Both prioritise processes of interaction, conflict, negotiation, and compromise in order to understand how collective groupings fail and succeed. Selecting Blumer is justified on the basis that contemporary research exploring the DPM has employed Blumer's approach (Beckett 2006b). Furthermore, there is fluidity in his approach and an opportunity to use his work across a variety of specific contexts, such as disabled people's collective activism. His ideas serve as the best approach to understand the DPM, as it is possible to loosely align the DPM's activities and organisation to Blumer's phases of a social movement life-cycle.

There are three aspects of Blumer's work on collective enterprise that are particularly appealing to this research. Firstly, rather than engaging in a prescriptive attempt to define and outline the parameters of a social movement, Blumer (1969) emphasises the importance of negotiation and interactive processes among group members. This is important in considering how young disabled people engage with established members in order to attain valued and respected positions within the DPM. It also allows for the research critically to analyse the ways in which young DPM members discuss, revisit, and challenge, ideas essential to the strategies within the Movement. Secondly, Blumer highlights the precariousness of organising collective action, drawing attention to factors that may undermine or stabilise the longevity and effectiveness of a social movement. Disability Studies scholars have raised concerns over the sustainability of the DPM (Sheldon 2005; Shakespeare 2006), and this is reflected in the research questions for this investigation. Finally, through Blumer's interest in the production of conflicts and tensions within collective enterprise, there is an opportunity to observe the interactions among group members and consider how their opinions, attitudes, and actions are relational. As Crossley (2011, p. 30) argues, "[opinions and attitudes] are formed and lodged between actors not within them." This provides insight into how young disabled people may engage with resistance practices to bring about change, not solely with regard to the social structures in society, but also within the membership of the DPM.

Continuing with Blumer's influence on this area of research, his initial work on the life cycle of a social movement has been furthered by various scholars and remains an ever-present framework when constructing an overview of social movement processes. The four stages of social movements are: emergence, coalescence, bureaucratisation, and decline (Christiansen 2009).

The initial stage, emergence, denotes the transition from individual or sporadic action to the initial coordination of a reaction to extensive dissatisfaction with an aspect of social functioning (Tilly 1978). Arguably, this stage relies upon the coordination of a social movement organisation structurally embedded within a community, and can utilise its existing membership to raise awareness of the issues to a wider audience. Although established leaders may not emerge at this stage, individuals pertinent to the development of the social movement are starting to consider how they will address the tension between inclusive engagement and organisational efficiency (Choi-Fitzpatrick 2015).

At the coalescence stage, coordinating the mobilisation of supporters or developing a collective consciousness is still in its infancy; rather, the movement is beginning to popularise the marginalisation or discontent experienced by individuals through a process of creating structural solidarity. Equally important is a recognition that the development of coalescence is not *per se* a response to creating a revolutionary movement, but an acknowledgement of others who experience discontent (Benford and Snow 2000), as well as a sense of what the unease is about and who or what is responsible for it (Christiansen 2009). This may result in mass demonstrations or public displays of dissatisfaction in order to highlight a social movement's clear demands and objectives. With a focus on tactics, leadership issues arise, as key individuals are required to influence the coordination and vision of the movement.

As a social movement transitions from intermittent actions – such as mass rallies, coordinated demonstrations or inspirational speakers – to effective, coalition-based strategies to advance their agendas, it enters the third stage known as bureaucratisation. There is now a necessity to identify resources, roles, and responsibilities to protect the functioning and existence of the movement; this may require training for members, the inclusion of paid staff, and the implementation of a framework for democratic legitimacy (Staggenborg 2016). Whilst there is concern that a reliance on paid staff may lead to the "professionalisation" of a social movement, particularly when formalised at the grassroots level (Heideman 2017), many movements cease to exist if there is an overreliance on volunteers to maintain sustainability – such as occurred with the Students for a Democratic Society (Elbaum 2002). Although having paid staff is not a prerequisite for the efficiency and longevity of a social movement, the emergence of leaders is crucial to mobilisation and maintenance. Those in decision-making positions are required to focus on broad representation and to facilitate the inclusion of marginalised individuals and groups associated with the aims of the movement (Diani and McAdam 2003; Baiocchi 2005; Smith and Wiest 2012). Furthermore, Staggenborg (1988) suggests that the "professionalisation" of social movement leaders results in a loss of innovative practices to advance the aims and objectives, which reduces the authenticity of grassroots involvement or ownership.

The final stage is decline, although Christiansen (2009) – in his account of a social movement life cycle – emphasises that this should not inevitably equate to failure. There are various reasons for decline. Firstly, social movements may end due to repressive actions, where authorities or ruling elites instigate the systematic destruction of or oppressive control over a social movement (Boren 2001). Secondly, forms of co-optation may occur, particularly when the sustainability of a movement relies upon an individual's leadership rather than on its structural processes. In such circumstances, the leadership will transition away from the movement and become entrenched within the movement's targets (Trumpy 2008). Thirdly, movements with clear demands decline as a result of their success, if their aims have been achieved; this is reflected in localised movements with specific goals or national movements that split into factions once their initial objective has been realised (McAdam 2000). A fourth reason, explored by Christiansen (2009), perceives decline as a consequence of the movement's becoming included within the mainstream; that is, the values, goals, and ideologies are incorporated into mainstream society and no longer require a separate position to demand change or inclusion.

The framework of the four stages is clearly limited in its application to social movement theory, as is particularly evident when distinguished from discussing movements preoccupied with political or economic change. An overreliance on "structural process" will create a culture of analysing social structures that permit the development of social movements, rather than exploring how activists perceived opportunities to create change or raise awareness (Jasper 1997).

It can be argued that this is pertinent only in a discussion on the status of American social movement theory. Taking such concerns into consideration when exploring the stages of social movements nevertheless demonstrates its relevance to any investigation of social movements, irrespective of geographical location. Generic aspects can be incorporated within the life cycle and determine their application when exploring New Social Movements, which predominantly centre on issues of identity and quality of life (Inglehart 1990; Melucci 1994).

Before moving on to explore *New Social Movements*, it is useful to draw upon the literature that highlights the complexities of how to apply social movement theorising to the UK DPM. It is not possible to outline the extent of such debates within the confines of this chapter. It is sensible, though, to consider the work of Beckett (2006a), who raises important aspects of the debate reflected in the data collection and analysis phase of this research. Beckett draws upon qualitative research to call for a new approach to understanding the demands, agendas, and ideas proposed by the DPM. This, it is anticipated, will lead to a contemporary and comprehensive analysis of the DPM's struggle for emancipation. In her summary of the key areas under investigation, she describes:

> [T]he appropriateness of the term "movement" to describe the "political" activities of groups of disabled people (see for example Oliver, 1997); whether the disability movement can be termed a "new" social movement (see Oliver and Zarb, [1989] 1997; Shakespeare, 1993); the effects of divisions between disabled people, in terms of gender, ethnicity and type of impairment, on the cohesiveness of the movement (see for example, Priestley, 1995 and Vernon, 1999); and the "location" or organisational focus of the movement (see Oliver, 1997). (Beckett 2006a, p. 736)

The present research builds on the work of Beckett and has attempted to understand, explore, and contribute to the discussions outlined above. In particular, the importance of social movement cohesiveness is a key area of investigation because this research explores the challenges outlined by young disabled people in their attempting to be included within the DPM. Attention is drawn to aspects of membership, the political activities of disabled people and their organisations, the significance of the social model of disability within the Movement, and future issues that require consideration in order to address the sustainability and effectiveness of the DPM. Moreover, Beckett's research argues that the DPM is in a process of defensive engagement that reflects the views of dominant voices within the Movement, which may be in contrast to those of other members. This is an issue that undoubtedly affects the development of solidarity. Although it raises concerns as to how the DPM articulates the essence of oppression and marginalisation, there is no suggestion that doing so would necessarily lead the DPM to a position of abandoning the social model of disability.

Beckett (2005; 2006a) has concluded that existing models of social movement theorising do not satisfactorily offer coherent ways to understand the DPM, as doing so includes contesting the basis on which new social movement theory may be applied. This is a result of pressure by academics to adopt new social movement criteria in order to demonstrate the emancipatory potential of the Movement. Beckett’s idea is to focus on the nature of engagement by exploring the notion of citizenship and social movement theory, as these will provide clearer insight. A proposal such as this is not disputed, as it is important to recognise that the present research does not attempt to address this point. Instead, the research aims to understand the contemporary issues affecting young disabled people's participation in and inclusion within the DPM.

Here, it is useful to highlight an issue captured throughout the research findings: the significance of interlinked networks and social movements. Literature refers to the notion of interlinking movements. There is wide debate to determine why collective action may be organised in this way. Whilst scholars, such as Touraine (1985) and Alvarez, Dagnino and Escobar (1998), argue this is a consequence of identity politics’ becoming absorbed within a plethora of rights-based issues, others suggest it is a reflection of social movements’ inability to gravitate towards a single cause (Laclau and Mouffe 1985). This has resulted in an understanding that social movements operate on a platform of intermingled causes and rights issues, which cross the divide between class and identities (Eckstein and Wickham-Crowley 2003). A comprehensive account of the intellectual contributions surrounding how collective political identities develop and shape the organisation of social movements is provided by Stephen (2010).

In her assessment, Stephen (2010) states that post-modern critiques of social movements – particularly New Social Movements – juxtapose traditional, class-focused movements with identity-based movements. By drawing on Harvey (1989) and Hellman (2008), Stephen recognises, too, the emergence of fragmented identities, a reflection of the neoliberal impact upon social movements. This affects the agendas, direction, and reactions of activists in attempting to articulate the issues and create social change. Whilst members of social movements will offer different perspectives as to how to address the focal point of their cause, research continues to illustrate how the affective and emotional dimensions of movements assists in the development of solidarity and continual participation (Collins 2001; Juris 2008). To understand this further, it is useful to consider the development of networks and their significance to the establishment and practice of social movements. Brodkin (2007) writes extensively on networks of activists and campaigners that are drawn together as their work overlaps and changes; this can lead to formalised coalitions as well as to expanding personal networks. Such groupings provide a way of understanding how a social movement may have progressive, interlinking capacities that draw individuals and organisations together, depending on the purpose of their work. The work of Escobar (2003, p. 615), who argues that social movements should be perceived as "meshworks", reflects this. His focus on interlinking social movements (2008) denotes the idea of self-organised networks, developing in unpredictable directions and patterns. Of particular interest is how the networks combine to articulate heterogeneous elements that demonstrate commonality, without the necessity for uniform responses. The networks become self-sustainable based on their agendas, accessibility to newcomers, and their ability to join with other networks in order to provide an effective system – or wider social movement.

The topic of networks, in relation to the emergence of interlinking social movements, is addressed comprehensively by Castells (2011). He provides an account of the relational capacity among networks to create and expand their communicative abilities in order to challenge, produce ideas, and be part of a dialectical process that empowers the separate networks; further, they produce the overarching, recognisable social movement – which he refers to as a meta-network. These writings and arguments, provided by established social movement scholars, bear resemblance to the issues pertaining to the DPM. The Movement contains agendas and strategies associated with the notion of a disabled identity, radical overhaul of the political and economic structures, the promotion and protection of existing legislative frameworks, and the coordination of disabled and non-disabled allies. The DPM thus comprises various interlinking social movements that represent the different directions taken by activists and organisations in order to address the presence of disablement. To understand this further, there is merit in returning to Stephen (2010), as she argues there is insufficient research to demonstrate the ideas surrounding interlinking social movements with specific examples from the field. It could be argued that this notion provides additional insight into the limitations surrounding Blumer's work, as outlined at the beginning of this chapter. I would, however, suggest that the two concepts are not mutually exclusive and may provide a contemporary critical extension of Blumer's argument regarding the trajectory of social movements.

In order fully to understand the position of the DPM and the key aspects reviewed throughout the research, it is necessary to unravel the complexities surrounding the concept of New Social Movements. This is particularly so because it highlights the discourse surrounding the activism that is focused on resisting current practices, as these perpetuate disabled people's marginalisation, and the direction taken by others to call for the radical redistribution of the political and economic structures within society.

3.3 New Social Movements

An analysis of the intrinsic aspects of constructing social movements provides a comprehensive description of the structural process. Of equal importance is the investigation to determine how activists express their goals and how audiences interpret them (Roy 2010). To explore this further, it is necessary to consider the emergence of New Social Movements and examine how they identify and articulate their demands then produce substantial change through the implementation of various methodologies.

New Social Movements provide an opportunity to reflect upon the progress made by conventional ones – which predominantly utilise a Marxist perspective – and, as a consequence, witness the emergence of a new form of collective action, values, and constituent characteristics (D'Anieri, Ernst and Kier 1990). As Starrico (2012, p. 468) explains:

> It did not so much open an era as close one. It was not the beginning of a paradigm, but the end of another one. What comes, after the growing importance of new social movements both empirically and theoretically, can be understood as a consequence, but not as a continuation or progression.

This shift in examining social movements, supported by a growing body of literature, illustrates the difficulty of applying traditional frameworks – such as a Marxist approach of class-based analysis – to understand various forms of collective action (Edelman 2001). Reinterpretations of existing frameworks are still relevant for New Social Movements as, for example, they facilitate our understanding of the internal power and emancipatory elements of movement organisation and development.

While New Social Movements continue to provide an exploration of social relations, the paradigm has encountered criticism (Calhoun 1993; Pichardo 1997). Scholars have noted that issues associated with contemporary movements have historical roots and provide a continuation, albeit with altered priorities, of the aims of traditional "older" movements (Peterson, Wahlstrom and Wennerhag 2015); it is a factor questioning the validity and application of new social movement theory.

Irrespective of the influence of traditional movements upon newer forms of social change and protest, there is a risk of creating over-schematised reflections of reality as a discussion focuses more closely upon the parameters of the various concepts and theories adopted to explain the progression and legacy of social movements. This may lead to a "cul-de-sac", where the fixation is on questioning the validity of the framework used rather than on the culture, organisation, and strategies of the movement encountered. As Castells (1997, p. 4) discusses:

> Since there is no sense of history other than the history we sense, from an analytical perspective there are no 'good' and 'bad,' progressive and regressive social movements. They are all symptoms of who we are, and avenues of our

> transformation, since transformation may equally lead to a whole range of heavens, hells, or heavenly hells.

3.3.1 *New Social Movement Culture*

Various approaches may be taken through which to explore the different dimensions that underpin the mobilisation of New Social Movements; whether scrutinising the aims or limitations of a movement, the focus remains towards categorising their objectives and demands (Starrico 2012). By positioning New Social Movements within a sphere of cultural and identity politics, questions arise over the political aspirations of the movements, including the potential to politicise culture, and where – in society – a cultural struggle may occur.

The politicisation of culture may be explained from the perspective that New Social Movements have depoliticised collective action through focusing on the transformative nature of localised and idiosyncratic matters (Starrico 2012). These focus on establishing a new politics of resistance, as opposed to changing the political and economic systems. There are authors who argue that New Social Movements are politicising the various aspects within the cultural sphere, as there is a multitude of sources who address the emergence of social conflicts (Kauffman 1990; Day 2006). Melucci (1994) maintains this position by exploring the impact of gathering and generating information; for individuals, the potential to produce meaning within a changing environment leads to the development of New Social Movements, as an attempt to search for a constant identity. This leads to the organisation of individuals collectively to shape their identities and challenge those who reject or question their existence.

A focused review on the cultural production within New Social Movements highlights a key dilemma in identity politics: using social movement theory to understand the development of identity-based organising. Exploring Bernstein's (2005) debate on collective categories, it may be argued that the difficulties associated with establishing individual and collective identities results in fragile politicisation processes attempting to challenge the marginalised groups' perceptions of them as being dominant and, perhaps, repressive. This produces three areas of discussion: the content of the collective identity – the definition adopted; the everyday viability of the identity – the individualistic success achieved through adopting the identity, and the political usefulness – a recognition of what impact the identity will have upon existing structures and existing distinctive categories.

The challenge is to determine the level of impact the construction of a collective identity will have upon the social movement, particularly when the boundaries of the group are scrutinised or dismissed by its members and outsiders (McGarry and Jasper 2015). The introduction of queer theory (Santos 2013) illustrates the desire to deconstruct the categorisation process of identity formulation, questioning the social production of labels and binary identities that ultimately serve as the basis of both the oppression of and – potentially – the motivation for the group's demands. Whilst research has explored the constructionist/deconstructionist approaches to this issue, the deconstructionist logic highlights a predicament for those attempting to disrupt the categories: "fixed identity categories are both the basis for oppression and the basis for political power. This raises questions for political strategizing […] must socio-political struggles articulated through identity eventually undermine themselves?" (Gamson 1995, p. 391).

The adoption of strategies to disrupt identity classifications requires established leaders and members within New Social Movements to participate in the academic debates surrounding the deconstruction of group categories. The work of Taylor and Whittier (1992) has studied the formulated and transformative stages of the collective identity journey. Their analysis has pointed to the politicisation process for communities where – through the construction of boundary definitions – they can separate the challengers from the administrators. This leads to the development of an interpretive framework to raise consciousness before entering a stage of negotiation to draw upon strategies that will contest existing systems of domination. It is important not to perceive Taylor and Whittier's analysis along a linear trajectory, as the boundaries are continuously revised and negotiated at different stages throughout a new social movement life cycle. As Nagel (1994) argues, the development of the collective identity does not rely solely on intervention from members within the group; it is also shaped by established institutions, political policy implementation, local resource implications, and access to decision-making structures.

Recognition that culture is of paramount importance to the development and sustainability of New Social Movements challenges the views of those academics who explored traditional theories of resource mobilisation and political process (Goodwin and Jasper 2015). Although it is essential to differentiate between protest and social movement, contemporary research is exploring the significance of culture in the attempt to construct and articulate grievances, which then leads to the development of collective identity and mobilised action (Pinard 2011). By incorporating cultural meaning as an integral dimension of social movements, there is the opportunity to go beyond the materialist understanding of grievances and protests – against the State – and recognise the cultural framing that raises the consciousness of various group members. Then, through a process of polarisation and escalation of conflict (Hisrch and Kang 2015), group solidarity may lead to a sense of ideological purity that, in turn, may produce cycles of movements that are affected by one another (Tarrow 2011).

The perception that social movements, in themselves, are major cultural events is also of relevance (Kenney 2002). If they are, then questions are raised as to how external audiences interpret the individuals who pursue various forms of activism to achieve their goal. Mobilisation scholars explore the factors associated with an individual's journey to participate in activist environments, yet the rhetoric surrounding the categorisation of group members may lead to assumptions that activists belong to a homogenous group. This is refuted by researchers (Wiltfang and McAdam 1991). The perception could, nevertheless, provide part of an explanation for the systemic criticism expressed towards the role of New Social Movements from certain audiences.

The development of New Social Movements, irrespective of their approach, critiqued as adhering to reformist or revolutionary practice, is pivotal to our understanding of the DPM. The remainder of this chapter is dedicated to exploring some of the key issues associated with the study of social movements, within the context of disabled people's experiences of challenging social injustices born out of the construction of disablement.

3.4 DPM

There is long-standing debate as to whether the DPM may be defined as a new social movement. Firstly, it must be clarified that any critique does not imply that the Movement is united with clear bureaucratic structures and boundaries. Rather, it should be perceived as a singular category encompassing the diversity of individuals who identify as disabled (as a politicised construct), their user-led organisations, and particular figures within Disability Studies who explore the validity and reliability of the tools and concepts espoused by the collective membership and identified influencers of the DPM. According to Mallett and Runswick-Cole (2014), the relevance of "disability activism" in explaining how the Movement functions is paramount. Activism demonstrates the various forms and scales of responses, incorporating a range of concerns that reflect the position and priorities of the Movement. There must be caution, however, to prevent any blurring of the distinction between activism and social movement responses then to recognise that both terms account for different interpretations of what the process of demanding and instigating change requires.

3.4.1 *Structural and/or Cultural Recognition*

The complicated nature of the debate over the existence, functioning, and aims of the DPM is largely dependent upon defining the Movement in terms of existing models of social movements. Whilst this has already been explored, including by Beckett (2006b), a significant reflection of the research within this area is to perceive the totality of the Movement as an ever-changing phenomenon. The DPM exists neither to reflect the principles of the framework imposed upon it nor to be constrained by the limitations or implications associated with a particular explanation of social movements. Such an explanation is reinforced by Davis' account of first and second waves within political and academic movements (2013). These originate with the establishment of an identity that challenges the existing negative descriptors imposed by the oppressive State or regime and, subsequently, enters a second wave that redefines the struggle and the parameters of who belongs to the group. Davis, in his account of waves, proposes that the Movement will enter a phase of manifestation that concludes with disability as a subjective position used to challenge the grand, unifying theories of identity and identity politics. However, when critiquing the DPM, it is necessary to distinguish between the episodic nature of collective action, on the one hand, and the continuous development of exchanges to formulate contemporary expressions – by the Movement – toward various, pertinent, issues, on the other.

There is another aspect regarding social movement waves that requires attention: implications caused by the screening out of congenital impairments. Whilst the DPM has campaigned extensively not to conceptualise disability as a medical pathology issue, there are accelerated advancements within the medical field to identify and eradicate specific impairment groups. The literature makes reference to how genetic screening will have an impact upon disabled people's identity (Boardman, Young and Griffiths 2018), how findings should be articulated to parents (Fulda and Lykens 2006), and why screening could be considered part of a eugenics pursuit (Gillott 2001). Disability Studies continue to discuss the ethical implications regarding genetic screening (Sharp and Earle 2002; Shakespeare 2010; Davis 2013), yet there is a substantial lack of literature pertaining to how screening and testing will influence the future make-up of DPM members, the direction taken to address disablement, and what effect this will have upon the recognition of disability as a political and rights-based issue. Shakespeare (2010) provides commentary regarding contemporary policies and practices surrounding prenatal diagnosis, recognising that genetic screening should be part of a wider cultural investigation to ascertain whether disabled people are perceived, valued, and supported to be citizens within society. Even though Shakespeare offers insight into future considerations regarding screening, no consideration is offered as to how this will affect the DPM.

Contingents of the reproductive rights movement (Caeton 2011) are campaigning for the right for a potential parent to have an abortion on the grounds that the foetus is identified as having an impairment. Health social movements (Brown and Zavestoski 2004; Hahn and Belt 2004) are demanding improved access to healthcare services and the treatment of disability and illness. These views combined, the eradication of disabled people with congenital conditions, pre- or post-natal, could become more prevalent. This would lead to a less active membership base of disabled activists and campaigners, as their spaces would be occupied predominantly by people who acquire their impairments later in life. As a result, individuals and groups will take positions of power; they will no longer represent the historical approaches that identify and address disabled people's social injustices. Examples of this may be recognised in the activism surrounding assisted suicide, as well as regarding the investments in searching for cures.

The descriptors for New Social Movements are well documented within this chapter. Classifying the DPM as a new social movement is complex, requiring consideration of various perspectives. Factors have been cited in favour of the classification, such as that the emergence of the Movement was marginal to conventional politics; it continues to be coordinated by user-led groups, and has facilitated the development of a disabled identity (Barnes and Mercer 2010). New Social Movements are centred upon a purpose to support and affirm a group's collective and individual uniqueness, particularly in contrast to the dominant ideology that seeks to or causes oppression and discrimination toward a particular group (Woodward 1997). The advancements within technology and encouragement of various organisations has supported disabled people to share their experiences, reflect on each other's stories, and articulate the intersectional boundaries associated with their lives. This has been an intrinsic value of the Disability Arts Movement (DAM) (Sutherland 2014), which has sought to utilise the arts as a means through which to communicate the feelings and experiences of the individual(s) and to develop links with the wider mechanisms to create change – including political activism.

Another contributory factor in favour of the classification is the progress made by the DPM to address the internationalisation of issues. Similarly to Davis's "waves", it could be construed that the Movement incorporates an assortment of interlinking movements – combining revolutionary and reformist politics (Oliver and Campbell 1996). Whilst it may be argued that the Movement is, or should be, a radical confrontation of the dominant social order, the mobilisation of DPOs and activists across the globe has produced an array of alliances. National differences – influenced by geopolitics and a deconstruction of the issues affecting disabled people and individuals with health conditions or impairments – have also been recognised. For example, the Independent Living Movement (ILM) across mainland Europe is focused on a de-institutionalisation programme and the development of personal assistance schemes (*see* ENIL), the Inclusive Education Movement (IEM) challenging the exclusionary practices of established education systems (*see* ALLFIE), and the reluctance by the North American DPM to take a social model of disability approach (Shakespeare 2010).

The factors outlined provide a convincing argument in favour of the classification, yet Shakespeare (1993) doubts the applicability of new social movement theory for the DPM, questioning the emphasis placed on specific aspects of the process. Furthermore, whilst the debate has advocates for and against conceptualising the Movement within a new social movement paradigm, a possible underlying assumption that it would be beneficial to frame the DPM within this framework is worth noting. This acknowledges how the significance of the Movement depends upon those who question and analyse the power it has. Beckett (2006a) articulated a similar observation, stating that the Movement is drawn to a new social movement framework, as it is perceived to possess greater emancipatory potential.

The inability to position the DPM within the current models of new social movement thinking is a reflection that current priorities and agendas, established by individuals and organisations who identify as members of the Movement, do not embody post-materialist or post-acquisitive values. The original issues formulated through the adoption of the social model of disability still remain. The structural issues continue to arise – even within the realms of late- or post-modernity – yet there remains a danger in aggressively dismissing the focus upon culture and identity in order to find a place for the DPM. Although the life cycle of social movements – according to Blumer and outlined earlier in the chapter – aids understanding of a movement's trajectory, there is a need to balance the desire to formulate a shared ideology within a movement with the recognition of a variance in the shared understandings and social organisation within the group membership. The latter could, arguably, concern the adoption of Tilly's definition of social movements (Tilly 1994). Nevertheless, there is a further risk of dismantling the existing foundations of the DPM in favour of supporting a platform for divided opinions, because doing so may involve failing to realise or tackle the perpetual danger of divisions within a singular movement. As Beckett (2006a, p. 747) argues, "how is it possible to state categorically that it is a social movement as opposed to a political coalition or a loosely structured protest event?" In the context of the DPM's aligning itself with the canon of new social movement theories, this research argues that it is impossible to position the DPM within the existing frameworks if it is hoped that by so doing it will be possible to understand the nature, aims, and organisation of social movements. This is because the DPM has not been sufficiently explored within Social Movement Studies. There is minimal gain in attempting rigidly to force the DPM into existing analytical frameworks, especially considering that the literature has on the whole paid little attention to the importance of disabled people's activism and emancipation. Blumer's approach is therefore useful because he does not influence researchers towards a specific analytical framework; rather, he introduces specific areas of thought and investigation. The fluidity in his approach permits researchers to use his work in various ways, particularly by approaching contexts and topics largely ignored within the existing body of literature. At this point, there is no persuasive argument to suggest the DPM is a new social movement. Instead, the findings in this research should be read as a call for Social Movement Studies to engage with the ideas of ableism and oppositional devices, in order to understand how the DPM is positioned in attempting to resist and open up new, preferable, and possible alternatives to the existing social structures that perpetuate ideas of normality alongside other notions of disability, the latter as an inferior categorisation.

A useful interpretation of the Movement may be found in Ellison's account of "defensive engagement" strategies, which draws attention to the relevant power structures that prevent individuals from both engaging in activities to maintain arrangements or developing new ones (Ellison 2000). This perspective, emerging from a discussion on the nature of citizenship, has particular relevance to the deconstruction of the Movement's functioning and its engagement of members. Research is emerging that analyses the meaning of citizenship within a disablist context (Morris 2005; Ignagni *et al.* 2016), exploring the relationship between the individual, the notion of citizenship (as characterised by different types of activity: defensive and proactive), and the directives within the Movement, which may be key to framing and evaluating its purpose and actions.

By incorporating this definition of what it means to be a citizen, there is an opportunity to provide a space for individuals and collectives to view their activity as a defence mechanism preventing the dismantlement or eradication of social rights. Similarly, the opportunity to instigate proactive engagement allows for the design, development, and demand for innovative practices that will challenge the existing and dominant public agendas. Such an approach will recognise the fluctuating positions that individuals may hold on the divide (defensive-proactive), reflecting the diversity within the Movement when addressing issues and establishing debate. Beckett's (2006a) call for contextualising the DPM as being embedded within a process of defensive engagement is tempting: it establishes a trajectory that supports those rooted within reformist practice as well as suggesting that revolutionary, transformative demands – achieved through proactive engagement – remain a viable option.

There is a need to be cautious with this perspective, especially as it may position the notion of rights as the pivotal conduit towards achieving inclusion – or towards decelerating exclusionary practice. The notion of rights, whether formulated through demands or legislative frameworks, exists as a by-product, surfacing as a consequence of the inequality and marginalisation experienced by groups within an oppressive regime. A celebratory focus on the protection and development of rights may not appease those truly entrenched within the radical left, which could conclude with a "defensive engagement within a defensive engagement" – as members within the Movement challenge the progress being made by others. This is reinforced by Oliver and Barnes's (2006) account of the problems associated with the DPM, including how the Movement has pursued a narrow legalistic approach favouring individuals who work within a rights-based industry. It has led to the "professionalisation" of disability rights and a shift from an oppositional stance to that of a collaborative aide. Another factor is the manifestation of substantial risks for the Movement if it is perceived to align too closely with government proposals or appear unreasonable by remaining aloof to the members of the Movement. This last option would leave disabled people in a position of attempting to influence a system – through the implementation of rights – whilst simultaneously recognising that the power exerted by the ruling elite fails to improve the life chances of disabled people and even questions their existence within society.

This should constitute an acknowledgement of the complexities of the issues being analysed. Providing a critique of a rights-based approach is not to dismiss the current economic failures within an existing system, one requiring the continual recognition and protection of existing rights to prevent individuals from experiencing segregation, marginalisation, and institutionalised services. To reinforce the importance of a DPM it is necessary to balance the activities that focus on upholding existing rights to tackle the immediate, crisis-driven, agendas against the opportunity to sustain dialogue on the longevity of the Movement.

Reflecting on the chapter hitherto, there is a risk of reducing the DPM to a *floating* movement that embodies the principles of certain social movement theories, depending upon the author's (and reader's) interpretations of existing literature and of the overall objective for the Movement. For that purpose it is essential to consider the criteria, introduced by Campbell and Oliver (1996), to assess a social movement:

- the introduction of new political or economic changes
- the implementation of specific legislation
- the altering of public opinion and behaviour
- the establishment of new organisations and institutions
  (the following criteria were suggested when specifically reviewing the DPM)
- the internationalisation of disability issues
- the framing of disability within a human and civil rights context
- the extent of facilitating empowerment amongst disabled people.

The validity and reliability of the criteria (above) should be scrutinised, especially as they – problematically – imply the existence of homogeneity when identifying an agreed definition of disability and disabled people; the principles outlined should, though, be incorporated into our subsequent review of particular aspects within the DPM. Furthermore, Carling-Jenkins (2014) has provided an extensive analytical framework through which to understand the development of social movements pertaining to disability.

3.4.2 *The Movement's Presence – Creating Space and Building Alliances*

The final section of this chapter will explore the intrinsic complexities associated with the individualistic aspect of joining social movements and how these relate to the representational nature of mobilised action – particularly with reference to virtual and physical space. Finally, there is a reflection on the formulation of alliances, especially with academia and with individuals among current experts.

Melucci's influential account of collective identities is pertinent to our understanding of the process experienced by individuals' joining or supporting social movements. His process-based account has been criticised, most notably by Snow (2001), yet Melucci focused upon the consolidation of a collective that was part of a wider network within New Social Movements. Doing so allows for a rejection of traditional thought that perceives individual actors as having a shared and total agreement on a movement's ideology and goal. It is replaced with an understanding that collective identity refers to the complex nature of individuals defining various aspects of a movement's organisation and planned action (Melucci 1996). Of particular interest is the focus upon the emotional involvement of activists and the process to identify a common cognitive framework that positions the individual within a collective self.

As the DPM has often been positioned within the wider examination of identity-based movements, it is vital to distinguish between personal characteristics and collective identities (Haunss 2000). Personal characteristics may be shared amongst those who join a social movement, but this is not the only specific aspect that produces a collective identity; there is a need – within Social Movement Studies – to comprehend the differences between personal, social, and collective identities (Snow 2001). Within the DPM, all members will identify as disabled people with experience of health conditions, impairments, and neurotypical labels. Each individual will have experienced the personal identification process born of structural and historical labels and definitions, yet the collective identity is formed on the basis of a refined notion of what is to be achieved through the collaboration of individuals. This echoes Buechler (2000), who perceives collective identity as part of a continuum, originating from a structural position affecting the individual to the construction of a shared network.

Returning to the emotive aspect of activism, there is an assortment of issues to consider that affect the organisation, strategies, and mobilised support of a social movement. This research is exploring the narrative accounts and interpretations of established figures within the DPM, thus it is necessary to consider the cultural significance of those within leadership positions. Whilst McAdam, McCarthy, and Zald (1996) argued that the interactions between leaders and wider membership was dependent upon the exchange of perceived benefits, Kemper (2006) details the symbolic nature of leaders as being the embodied representations of the movement's aims and objectives; these are interpreted differently depending on the audience (internal members or outside figures). By acting as a conduit, the leader(s) invoke(s) a variety of emotions that can inspire members, arouse suspicion from outsiders, and facilitate the implementation of their strategies. This requires an effective array of tactics to arouse anger, compassion, and joy amongst the membership while simultaneously demonstrating empathy with the members' perspective in order both to prevent and to avoid potential dyadic withdrawal and separation from the Movement (Goodwin and Jasper 2015).

A thematic development within this aspect is the notion of commitment and how this leads to consciousness raising, which subsequently results in a declaration or pledge to the ideology absorbed from the current, established leadership. Lalich (2004) has documented the charismatic nature of leaders and the effects this has on processes of cultural, cognitive, and social control; however, this is not to be construed as social movements' adopting authoritarian measures to achieve their aims. The emotional shaping that occurs is a reflection of the structural necessity to develop a social order within the Movement, which facilitates the direction activists will take as they become further embedded within the activities. Having a social order is also required to produce a coherent frame, a critical component for social movements as it supports the identification of core values and key messages amongst membership (Ryan and Gamson 2006). Although the process is useful for structuring the overall strategy and framework for a social movement, it is essential to recognise that it results in personal sacrifices for the activists (Sellie *et al*. 2015), particularly when operating within online or offline environments.

Chatterton and Pickerill (2010) have explored how activists self-manage and develop models for a better life within the constraints of the very environment that they challenge; similarly, analysis is required to determine how the DPM operates against and beyond the current dominant political, economic, and civil society while remaining a part of it. The geographical aspect of activism, particularly in exploring how activism emerges in particular environments, is relevant to Social Movement Studies because it demonstrates how local mobilised action may signify potential social change on a wider scale (Harvey 2001; Featherstone 2008). When debating the various aspects associated with virtual and physical manifestations of social movements, it is important not to perceive them as being in binary opposition, as both realms will be adopted by movements at various times to reflect their respective positions, activities, and directions.

The internationalisation of the DPM has benefited greatly from virtual networks used to facilitate discourse and further the concepts, resulting in a global reach and the construction of a “shared community”. By utilising technology the Movement has the opportunity to promote shared experiences, which in turn establishes a “transmovement structure” that characterises the potential reach and impact of activist networks (Polletta 1999). Although Polletta focuses on the geographical nature of transmovements, this research will consider the notion of resources to mobilise action within a disability activism – particularly in the context of future issues affecting the DPM. The intrinsic relationships between members or groups may occupy within concentrated locations, as is pertinent to the lives of disabled people, mean that they may gravitate to environments that are most inclusive in meeting the access requirements of the individuals present. This can create implications for social movements, given that they will be judged and valued based on the accessibility and distribution of resources.

A final note on the topic of establishing alliances and generating interest within social movements concerns how to ascertain whether young people – particularly young disabled people – indeed care about the significance of social movements and activism. Whilst there is considerable debate surrounding the extent and role of young people's political participation (Earl, Maher and Elliott 2017), this has predominantly fallen into two groups: those who frame youth engagement around the need for older, established social movement members to lead the politicisation process for younger activists; and those who recognise young people are active and lead their own participation within social movements. Concern has frequently been raised regarding young people's involvement in political issues (Wilkins 2000; Putnam 2000), yet social movements scholars have argued that youth engagement has not declined but shifted towards an engaged citizenship model (Shea and Harris 2006; Dalton 2009). This approach has promoted activity through volunteering, protesting, and politicising the personal (Schlozman, Verba and Brady 2010).

Regarding young disabled people, there is a lack of research and literature on the topic of young disabled people's interest and participation within social movements. Although writers such as Titchkosky (2003) and Kelly (2010) have suggested innovative ways to increase disabled people's participation within activism and protect the future workings of the DPM, the issue of disability pride is pertinent. This is because of the recognised widespread reluctance amongst young disabled people to identify proudly as a disabled person or to consider their own or a general potential to politicise disability. Shakespeare and Watson (2002) have noted that disabled people, *en masse*, do not associate with the DPM, and Watson (2002) indicates disabled people reject the notion of disability pride in exchange for an identity rooted in the discourse surrounding normality. This can have detrimental consequences, as the development and implementation of neoliberal ideals – as mentioned in Chapter Two – may have a severely negative impact upon young disabled people's awareness and support of and participation within the DPM. The analysis and subsequent discussion of the research findings will further explore this aspect.

3.5 Conclusion

This chapter has detailed the key aspects of Social Movement Studies most closely applicable to the research questions. Initially, the chapter provides an overview of terminologies used to define how social movements exist – with particular reference to the formulation, continued impact, and (potential) decline of social movements. The chapter specifically highlights the work of notable scholars. Following a general overview of the life-cycle of social movements, the chapter introduces the notion of New Social Movements and how this differs from traditional social movements; such difference is relevant as there is much debate regarding how to define the DPM, particularly with regard to its analysis and articulation of disablement and how it organises around particular strategies and demands. Although the chapter explores how the DPM is situated within social movement theory, it draws to a close by situating the DPM within new social movement theory, making reference to the limitations imposed by taking a rights-based approach. The implications for how the DPM supports young people and newcomers in participating and influencing its overall direction and strategy are demonstrated.

The chapter specifies the significance of providing theories about social movements, and includes a contemporary understanding of New Social Movements. This has been done so as to situate the DPM within notable fields of inquiry that provide a foundation upon which the research is based. Defining the organisation of social movement activity, exploring the significance of resistance-based practices, and considering the inclusion of young people within activism are necessary in order to detail the challenges encountered by young disabled people when participating in the DPM. Without such exploration, this research would not be in a position to discuss how the Movement may address the challenges highlighted by the respondents in their responses to the questions posed. The next chapter outlines the methodological approach taken, one that is rooted in emancipatory disability research.

4. Methodology

4.1 Introduction

This chapter outlines the development of the research and details the steps taken to justify the selected methodological approach. It also demonstrates the ways in which the views of respondents are analysed and other factors were addressed as the research design evolved. This provides clarity with regard to the decision-making process and illustrates how the research is situated in relation to both past and current discussions regarding research methodologies into topics concerning disabled people. To achieve this, the chapter begins by outlining how the research was conducted, taking account of disabled people's access requirements, ethical considerations, and the use of semi-structured interviews. Seventeen respondents were selected through a purposive and snowballing sampling method; they took part in semi-structured interviews, *via* face-to-face meetings and audio calls. The chapter details data analysis, how the data were encoded, and the significance of thematic categories. The chapter argues that EDR provided the most suitable framework within which to conduct an investigation of the research questions. The decision to structure the chapter in this way was also inspired by Dodd's (2014) doctoral research, which explored challenges facing the DPM. This is to provide clarity and to ensure the reader is provided with a comprehensive account of the research approach. The decision to structure the chapter in this way was also inspired by Dodd's (2014) doctoral research, which explored challenges facing the DPM.

The chapter addresses the issue of reflexivity, exploring how my role – as researcher – influences the process of collecting and interpreting the data. In the wider sense, this requires reflection on how the social world is interpreted. The chapter outlines the justification to use a critical realist stance. The relationship between epistemology, methodology, and methods is unpacked throughout the chapter, and highlights how I perceive the conditions and boundaries of human knowledge. This is imperative in order to establish whether the social phenomena investigated can be adequately examined within the parameters of the specified research design (Wodak and Meyer 2016).

4.2 Methodological Approach Taken

The research process involves formulating a design that acknowledges the epistemological and ontological positions, a foundational theory that emphasises the direction of analysis and method to gather the data at the operational phase. All aspects are interrelated, requiring consideration to ensure that the research objectives, through to analysis and interpretation, provide credible findings that contribute to the body of knowledge and provide meaningful conclusions, and thus further opportunities, to those interested in the social research topic. To begin with, it is necessary to consider the approach towards recruiting respondents and determine how this aligns with the emancipatory disability research approach.

4.2.1 *Sample Recruitment*

An EDR approach necessitates that discussions of disabled people's experiences, including their narratives and perceptions of disabling barriers, be rooted within the political, cultural and economic structures (Barnes 2001). This is to achieve clarity regarding how the process of disablement is produced and reinforced, as well as determining the consequences such outcomes have for challenging the widespread marginalisation endured by disabled people. In order for this research to produce meaningful outcomes, which are – equally – transformative for the DPM and, it is hoped, empowering for activists, requires two respondent groups: young disabled people and "established figures" within the UK DPM. The definition of "young person" is a contentious issue[5]. Taking this into consideration, the research defined a young person as an individual aged 18-30 (LSE 2013). For the group consisting of established members, they were required to consider themselves – or to be considered by others – as an influential/established member of the UK DPM.

Respondents were selected *via* the purposive and snowballing sampling (Bryman 2015). Initially, the intention was to locate and identify respondents through national and regional networks established and managed by disabled people and their organisations. This was justified on the grounds that DPOs are an important source for securing and promoting the

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[5] In the UK, organisations and government policy have a tendency to frame youth between the ages 18-25, whilst in Europe, various research institutions and social affairs committees have widened the age range from 18-35.

collective identity of the DPM (Roulstone and Morgan 2008). Whereas it may imply a preconceived notion of the authenticity and reliability of disabled activists, i.e., only those connected to organisations are deemed valuable to the investigative process, the research process remained flexible by offering respondents the chance to recommend activists not linked to established organisations and networks.

It became apparent that contact with DPOs and networks would not provide anticipated outcomes. Repeated attempts were made to contact gatekeepers and administrators by telephone, email, and social media communication, yet dialogue was infrequent or non-existent; furthermore, the majority of organisations failed to share the information sheet provided (*see* Appendix One) with potential respondents. Despite extensively mapping potential organisations in the UK and utilising various contact methods, it is assumed that the current funding implications for third sector organisations (Jones *et al.* 2015) had an impact on their receptiveness and capacity to assist with my request. Furthermore, gatekeepers and potential respondents may have been disinclined to engage because of historical exploitation and poor engagement by researchers and research institutions (Tang and Sinclair 2001). I was uncomfortable with persevering with organisations that had not responded, as disrupting their work programmes or appearing intimidating seemed counter-productive. It was decided that the scope of organisations and networks would be widened to include those that do not meet the criteria for self-organisation: these are host networks managed and controlled by disabled people. Literature is replete with reference to the role of gatekeepers within social research; May (2011) argues that researchers perceive the role of gatekeepers as facilitators who grant access to respondents and endorses the research objectives, yet Saunders (2006) highlights the significance of power relations between gatekeepers and the researcher. A further review of the process of gaining access through gatekeepers is provided by Crowhurst (2013). Within this research, the approach was to recognise gatekeepers as social actors who participated and influenced the dynamic process of gaining access to respondents.

This approach to widen the recruitment approach produced a greater frequency of replies and offers to disseminate the information sheet. Nevertheless, engagement was limited and interest remained low. Further speculation would be unhelpful, despite reflecting the issues and concerns highlighted by those who provide a critique of traditional disability research (Oliver

1992; Traustadóttir 2016). There is a need to consider the social relations between academics and marginalised, disempowered individuals. This led to a consideration as to whether the language and concerns outlined in the information sheet and advertising pack (*see* Appendix Two) were irrelevant or inaccessible to disabled people (Oliver 2009). Through a process of redrafting the information and advertising documentation, as well as continuous engagement with organisations, contact with gatekeepers and coordinators who were receptive to the research aims was indeed established. A list was created, documenting those who had declared an interest in helping to recruit respondents; waiting for potential respondents to initiate contact followed. Seven gatekeepers informed me of specific names of disabled people who had declared an interest in engaging, and others made contact who had no existing links to the organisations. Through discussion with respondents found *via* organisations and networks, snowball sampling occurred as the respondents put me in contact with their friends and fellow activists and campaigners. This form of sampling was most closely applicable to this research, as it employed respondents who utilised their own social networks in order to provide access for the researcher to specific populations (Browne 2003).

The receptive organisations and networks differed for the two selected respondent groups, young disabled people and “established figures”. The gatekeepers for young disabled people were:

a) the UK section of a user-led European Disabled Youth Network;

b) a national organisation providing guidance and support to families with disabled members

c) a national charity producing government policy through its work with a youth network;

d) a national user-led charity providing guidance to disabled people and local/national government;

e) a national – politically-orientated – user-led group campaigning on disability rights;

f) a North-West UK user-led organisation campaigning on disability rights, and

g) a North-West UK user-led organisation associated with disability arts.

The "established members" were sought *via* the List of Influential Figures on Disability Issues (Pring 2016) and the call for involvement disseminated through their respected organisations or networks[6].

Defining activism and disability is an essential part of the research process, thus the aim was to provide open- rather than closed-ended criteria in order to maximise the number of disabled people interested in the research question and aims and who could be included. My subsequent discussions with respondents were an opportunity to gain an understanding of the individuals who volunteered to be included. It was necessary to confirm that they considered themselves disabled and involved or interested in the activism and campaigning of the DPM. Nevertheless, it was a useful exercise as two promising respondents were outside of the age range stipulated; a further five individuals either had not been born or did not reside within the UK. The decision to omit respondents who were not born in the UK was made in accordance with the ethics committee.

Of particular note was in the case of two individuals who did not define themselves as disabled, but argued that they were prominent disabled activists.[7] Their values, ideas, and experiences are undeniably important, yet it was decided to decline their offer of an interview through the requirement that I wished to prioritise the experiences and opinions only of those who identify as a disabled person. This raises interesting points for the recognition of allies within the DPM: they may not self-identify or declare that they have health conditions or impairments, or otherwise challenge neurotypical labels. Such an issue is not a restrictive criterion in the recruitment of respondents; rather, it was necessary to and appropriate for the investigation.

Once it was confirmed that a respondent would indeed be interviewed, an email or telephone call followed to confirm interest and arrange a suitable time, date, and location. A consent form (*see* Appendix Three), a copy of the information sheet, and a request for information regarding access requirements were sent to respondents. I remained in regular contact with the individuals

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[6] The list is hosted by the Disability New Service and is compiled according to discussions amongst a panel of prominent disabled activists and campaigners committed to addressing social injustice issues experienced by disabled people.

[7] One was a sibling of a disabled person; the other worked as a personal assistant to a disabled activist.

during the data collection and analysis phase of the research. During write-up, respondents were provided with a list of their quotes used in the thesis and asked to approve their inclusion in the chapters. I offered to explain in what context the quotes would be used, but none of the participants took up the offer.

4.2.2 *Respondent Demographics*

Seventeen individuals were interviewed between May and September 2016. Respondents were not required to articulate the precise nature of their impairment, health condition or non-neurotypicality; all identified as a disabled person. During the introductory part of the interviews, respondents were invited to highlight any self-defined, relevant, and interesting aspects of their lives for me to become aware of their background. Also, such details gave an indication of their perspectives on their situations. The data recorded below are deliberately vague in order to protect the identities of those who engaged. The information was captured from the interviews:

Category	*Pseudonym*	*Gender*	*Age*	*Location*	*Ethnicity*	*Mode*
Young Person	Regina	Female	Mid-Twenties	Northern England	White British	Audio Call
Young Person	Richard	Non-binary	Mid-Twenties	South-East England	White British	Audio Call
Young Person	Margaret	Female	Early Twenties	Lives Across UK	White British	Audio Call
Young Person	Chloe	Female	Mid-Twenties	South-West England	White British	Audio Call
Young Person	Jeremy	Male	Early Twenties	London Area	White British	Audio Call
Young Person	David	Male	Late Teens	North-East England	White British	Audio Call

Young Person	Mari	Female	Mid-Twenties	London Area	British Indian	Audio Call
Young Person	Rose	Female	Early Thirties	North-West England	White British	In Person
Young Person	Kate	Female	Early Thirties	Northern England	White British	Audio Call
Young Person	Mike	Male	Mid-Twenties	North-West England	White British	Audio Call
Young Person	Hillary	Female	Early Thirties	Scotland Area	White British	Audio Call
Established Member	Marley	Male	-[8]	Midlands Area	Black British	Audio Call
Established Member	Rachael	Female	-	London Area	White British	Audio Call
Established Member	Christopher	Male	-	South-West England	White British	Audio Call
Established Member	Jukie	Female	-	North-West England	British Irish	Audio Call
Established Member	Janet	Female	-	London Area	Black British	Audio Call
Established Member	Robert	Male	-	Midlands Area	White British	In Person

Table One. Summary of Respondent Demographics

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[8] Respondents from the established members group were not required to provide their age.

4.2.3 *Reflecting on the Sample*

The research question relied on the inclusion of disabled people with a diverse range of impairments, health conditions or non-neurotypicality; people were not selected because of their conditions or labels, as this would imply that the findings are restricted to focusing on issues specifically associated to individuals of particular groupings (Barnes 2014). As the research identifies key thematic concerns affecting all disabled people, it was decided to frame disability as a form of social oppression and acknowledge this is a pan-impairment, health condition, and non-neurotypicality issue. Respondents were not required to articulate the nature of their impairments and labels.

By not taking into consideration the type of impairment, health condition or neurotypical labels there is a risk of excluding individuals who are less widely represented in the make-up and hierarchy of social movements (Barnes and Cotterell 2012). Similarly, the decision to direct attention to individuals associated with DPOs and self-led networks could merely reflect the author's own pre-existing beliefs and values around disabled people's self-organisation, rather than concerns regarding diversity from within the DPM. This reinforces the perspective of leading scholars and activists who have raised concern about the demographics within the hierarchy of the Movement (Morris 1991; Priestley 1995; Campbell and Oliver 1996). Although the nature of impairment, health condition and neurotypical labels were not considered as part of the selection criteria, respondents were not discouraged from exploring aspects of their health, impairments, and labels during the interviews – particularly if such aspects were related to their activism (Soldatic and Meekosha 2014). On numerous occasions, respondents discussed their health and how this affected their understanding of disabled people's emancipation. For example, Jukie documented her experiences of mental health conditions, and Jeremy explained the impact of identifying as an autistic person and a member of the neuro-diverse community. At this point, it is worth considering the discourse and language surrounding neuro-diversity, madness, and distress (McWade, Milton and Beresford 2015). There is substantial literature, academic and grey, that rejects the medical pathologisation of such conditions and labels. Activists and academics involved in this area attempt to critique the diagnosis, actions, and policy initiatives that reinforce normalisation and propose normative ways of functioning (Kapp *et al.* 2013). This contributes to the need for politicising people’s experiences, as well as advocating for disabled people to have control over the processes that reinforce neurotypical activity.

In this research, ten of seventeen individuals identified as female. Three were from black and minority ethnic backgrounds. The majority of respondents were based in England; there was significant underrepresentation of people from Wales and Northern Ireland. For reasons of confidentiality, it was deemed appropriate not to provide specific locations for each respondent. Young disabled people were asked to provide their ages, to ensure they met the selection criteria; nevertheless, irrespective of their ages, there was commonality among the significant challenges encountered when engaging in activism and protest. Whilst respondents from the established members group were not required to provide their ages, it became evident that each had over twenty years’ experience of engaging in the DPM. All were typically involved with DPOs and it was predicted that there was a shared history and identity as regards disability activism.

It could be argued that the sample was narrow in some respects. One person identified as learning disabled; eleven of the seventeen were wheelchair users. However, ensuring a diverse group of activists may have led to difficulty in interpreting the data, resulting in fragmented and, potentially, contradictory findings. This is recognition that the research never intended to provide a representative group – the focus came from highlighting the need to debate what is required in order to address the challenges experienced by young disabled people when engaging in activism. Respondents were selected on the basis that they grant access to a range of perspectives on the phenomena under investigation. Thus, they represent a perspective, rather than a population. The sample size is related to the inductive logic of the chosen methodology and will come under scrutiny regarding the applicability of the findings; it is important to recognise that the research is reporting in detail about the view from within a “particular frame”, yet does not claim to map its findings across all of those who match the inclusion criteria. Although it is anticipated that the sample has relevance to the understanding and operations of the DPM, no claim is made that the group seeks to be definitively representative of the social movements associated with disablement and disabled people – nor of part or the whole of the disabled community. Through the research, the attempt was to focus on the transferability of the findings; the intention was to establish further links between the analysis of findings from the study, additional experience, and the claims in wider literature. A reduced sample size allows the process to provide a rich and transparent, as well as contextualised, analysis of the accounts of the respondents recruited. This should support subsequent researchers and reviewers in evaluating the transferability of the research to persons in other contexts.

Furthermore, taking the above approach and reasoning into account, a higher number of respondents would not indicate an improved piece of work. Rather, it is an acknowledgement that the analysis requires time, reflection, and dialogue – which larger datasets will inhibit, especially as the selection criteria necessitate consideration of the limitations and access requirements of the disabled respondents, as well as those of a disabled researcher who has a severe physical impairment.

The decision to utilise the selection criteria outlined was further influenced by the initial investigation of existing literature, as I wanted better to understand current debates surrounding how disability is understood and the key issues affecting the development and sustainability of the DPM. In addition to age, interest or experience of activism and self-identification as disabled person, the areas to explore are:

- What constitutes young disabled people's position in the DPM?
- How are people included and what is required to ensure participation within the DPM?
- What is the overall organisation of the DPM, including a commitment to specific values or ideas?
- What do people want to highlight and what requires addressing in order both to increase participation within the DPM and to ensure young people can influence the overall direction and agenda?

Although this influenced the selection criteria, and ultimately affected who took part, it is nonsensical for a researcher to predict whether any potential respondent would be able to answer such questions sufficiently or appropriately for the purposes of the research. The criteria were used to guide the methodological process and were not operationalised in practice. For example, it is not possible to conclude with any reliability as to whether somebody “understands” the organisation of a social movement. Thus, it is inappropriate to impose a prescribed answer or definition, in the case of disability, that must be met by respondents in order to validate their experiences, opinions, and ideas. Any attempt to impose a restrictive definition or answer would reinforce the unethical power relations that have plagued and continue to plague disability research (Stone and Priestley 1996; Symeonidou and Beauchamp-Pryor 2013). The significance of self-definition, as well as giving due respect and value to people's contributions during the research process, are essential to mitigating the marginalisation, exploitation, and discrimination experienced by disabled people.

4.2.4 *Ethical Issues*

Ethical issues must be considered throughout the research process, from the design stage to data collection and analysis. Acknowledging the historical and contemporary actions taken by researchers and academic institutions that have led to the exploitation of disabled people, the research took ethical considerations seriously. The process abided by the Statement of Ethical Practice, outlined by the British Sociological Association (2017), and ethical approval was granted by Liverpool John Moores University. To adhere to the principles of emancipatory research, it is devoid of covert, non-consensual data collection – with intentions made transparent from the initial recruitment phase. As respondents identified as having impairments, health conditions or experiencing disablement, they are classified as “vulnerable” (British Sociological Association 2017). However, such classification has come under criticism and the term is troublesome for contingents and representatives within the DPM (Morris 2015). In this context, attention was paid to ensuring a satisfactory level of protection for the respondents. Guidelines and reports were reviewed (Barnes 2008; National Disability Authority 2009; Office for Disability Issues 2011) to ensure that the safety and protection of all respondents remained paramount. The research was based on six key principles:

- Promoting the inclusion and participation of disabled people in research and research dissemination
- Ensuring that during the research attempts were made to meet the individual’s access requirements
- Avoiding harm to research participants
- Ensuring voluntary and informed consent from each respondent before participation in research

- Understanding and fulfilling relevant legal responsibilities, and
- Maintaining the highest professional research standards and competencies.

Guidance by the National Disability Authority (2009) provided a detailed breakdown of all of the issues raised above, with suggestions and clear examples as to how to conduct research among disabled people. To ensure the on-going assent or consent status, respondents were reminded of and supported in considering their right to withdraw from the study at any point throughout their engagement, and their awareness of the research. All were contacted throughout the various phases of research production, and were provided with updates and opportunities to seek clarification or to provide comments and suggestions. Respondents acknowledged their right to review how they were represented in transcripts/field notes, providing edits and further input to elaborate upon or to reinforce their original statements. A pilot interview was conducted and I requested feedback on the strategies applied and performance as an interviewer. At the end of each interview, respondents were asked if they wanted to receive a summary of the thesis and key findings; fifteen out of seventeen agreed, indicating their preference for receiving the thesis in an electronic format or for an informal discussion outlining the key findings.

To be explicitly clear about the benefits to taking part, the study was explained in terms of exposing disabling barriers (Finkelstein 1998) and that it aspired to have an impact on the "individual self-assertion and experiences of feeling powerful" (Lather 1991, p. 3). Respondents were provided with no financial payment or voucher reward for engaging with the study; although this may appear exploitative, it is a decision based on the limited resources attached to the research project.

As outlined above, it is imperative to respect the dignity and autonomy of all respondents as well as to provide them with an inclusive and accessible experience. Therefore, respondents were encouraged to provide me with details of access requirements that needed attention and consideration prior to their involvement in the semi-structured interviews. This information provided a brief for me to identify suitable support mechanisms with the intention of facilitating the individuals' understanding of the documents and of identifying a safe, accessible venue in which to conduct the interviews. Although it was requested that respondents proposed a public venue that met access requirements, an alternative offer to conduct the interview over a secure audio call was offered if environmental barriers prevented the interview from occurring in a specific location. There is extensive research comparing the advantages and implications of conducting research through in-person and audio call methods (Iacono, Symonds and Brown 2016). Whilst these two methods will provide different concerns, such as social desirability and avidity biases, the decision to select a method should be based on the practicalities of the research design and the preferences of the respondents (Szolnoki and Hoffman 2013). Individuals were also encouraged to include needs-related or refreshment breaks during the interview process and to incorporate any of their existing support mechanisms in order best to support their inclusion. All respondents were informed that if they experienced levels of distress that could not be addressed by doctoral supervisors or gatekeepers associated with particular organisations, they could be directed towards alternative groups and support sites.

It is worth noting that I could have attempted to include disabled people in the production of the research, especially at the initial stages of development. Not only would this have benefited the research process, it could demonstrate the importance of involving disabled people as collaborators seeking to realise emancipation. Justification for choosing not to include disabled people at this stage was based on limits on time and resources; the aim was to collect advice, reflections, and suggestions specifically through an engagement forum. As I am an activist, involved in the various organisations and agendas referenced during the interviews, this process should not create distance between fellow campaigners and myself. Furthermore, the difficulty in attempting to interview disabled people was initially underestimated. The process of collecting their politicised experiences and the challenges encountered, and desperately trying both to balance my own theorisation of their contributions and to provide originality, was difficult to achieve, especially whilst not misrepresenting or diluting their valued contributions. A phase of reflection necessarily considered the theoretical framework underpinning the research questions, weighing this against the personal preconceptions of the research topic. Any attempt to balance the contributions depended upon the research design and the method through which the findings were analysed (Richards and Schwartz 2002).

4.2.5 *The Decision to Offer Confidentiality*

One original intention of the research was to leave decisions on their respective level of confidentiality to each individual respondent. Of particular interest was the outcome that the majority of young disabled people interviewed did not want to be identified in the completed thesis, whilst all established members were content with being known. Without prompting, all established members stated they would defend their opinions if challenged; however, the young disabled people who opted for confidentiality explained they were concerned it would prevent access to particular organisations, would lead to their being ostracised by specific activists, and would damage their progression and future career. At this juncture, I could not justify providing confidentiality for a select group of respondents yet leaving others named. Concern was raised as to whether this would undermine the protection of all respondents; it was decided that all respondents would have their names and any identifying features removed from the completed thesis. Pseudonyms were used in place of real names; these were selected by randomly choosing the first name of authors and film directors on the nearest bookshelf. Only I know which adopted name represents each respondent.

4.2.6 *Using the Semi-Structured Interview*

As is the case with semi-structured interviews, the acknowledgement of the hermeneutic process is necessary to understanding how the research is accepted such that it produces meaningful relations between various individuals. The hermeneutic cycle refers to the meaning that is accessed during an investigation; however, to construct an interpretation requires that a comprehensive account be given of the wider issue, including initially hidden and obscured structures, if it is to be understood at all. The difficulty emerges when it becomes evident that meaning is accessible only of the parts – in this case, interviews – captured. Hermeneutics is also relevant to the relationships established during the process of research production. According to Gadamerian hermeneutics (Gadamer 2004), central to the environment of semi-structured interviews is the necessity to consider the complexity, the dynamic, contextual, and historical factors, associated with constructing and sustaining relationships. The interview is an opportunity not only to generate data, but also to echo the topic of interest between the individuals involved in the dialogue – in this instance, interviewer and respondent. What is produced is a "self-awareness of the individual [...] flickering in the closed circuit of historical life" (Gadamer 2004, p. 278); therefore, the hermeneutic process exposes that which is perceived to be lost, forgotten or hidden from the existence of the interviewer and respondent.

It was decided that a qualitative method utilising interviews was best placed for this level of enquiry, especially considering how “quantitative research and analysis has failed to capture the full extent and complexity of the oppression encountered by disabled people” (Barnes 2003, p. 10). Furthermore, it was feared that the prescribed, closed nature of surveys and questionnaires would not illustrate the radical change required to realise disabled people’s emancipation. Morris (1991), too, argues that the decision to use qualitative methods, particularly *via* interviews, is essential for the exploration of social movements. The use of semi-structured interviews provides an opportunity to conduct the research with individuals rather than toward them (French and Swain 2004). Such an approach is recommended for those committed to EDR, as it reduces the potential for omitting integral areas of discussion with respondents.

Semi-structured interviews challenge the hierarchical division of power, control, and elitist perceptions within research production (Cohn and Lyons 2003; Alshenqeeti 2014). Respondents were invited to discuss the topic outlined by a researcher; also, they were supported in expressing opinions, thoughts, and ideas – ultimately elaborating upon and diverging from the prescribed set of questions throughout the periods of dialogue. It is important to note that the chosen methodology refers to the overall research strategy implemented rather than to a sole prescribed method. Utilising semi-structured interviews with disabled people highlights three distinctive principles to consider. One of these is the requirement of a safe space within which to establish dialogue and thus encourage interaction as a precondition for engagement. Establishing a safe space reflects the necessity to create domination-free communicative spaces. Such a condition effectively calls upon both researcher and respondent to deliberate over the boundaries of their respective participation. Secondly, it requires thought regarding any control over each interview, the exploration of concerns and worries, and how to address emotional, intimate, and institutional issues that may arise throughout the research (Wicks and Reason 2009; Bergold and Thomas 2012) – certainly beyond the data collection phase of the process. Thirdly, there remains, nevertheless, a necessity to consider how disabled people's marginalisation and exclusion from society – and aspects of daily life – may limit or restrict their participation in the interview.

A decision was taken to complete formal data collection after the seventeenth interview. As outlined above, there was difficulty in securing interviews with disabled people; a substantial amount of time was dedicated to establishing dialogue with gatekeepers and organisations willing to disseminate the research information. Furthermore, once respondents were selected, it took considerable time to ensure access requirements were met – including the support required for a disabled researcher to conduct the interview. As the thesis required completion according to a specific schedule, there was a valid concern that further attempts to secure interviews would impact on the analysis and write-up phases. Similarly, the decision to limit the number of interviews to the seventeen accomplished was influenced by reaching "saturation point" (Saunders *et al.* 2018). There was indeed significant variation in the ideas, experiences, and views articulated during the interviews, yet repeated themes and categories for analysis began to be discovered and noted. Strauss and Corbin (1998) argue that saturation is achieved when the continuation of the research would be counter-productive, implying that new themes would not in fact further contribute to the overall analysis thus that further coding was no longer feasible (Guest, Bunce, and Johnson 2006). Even though all seventeen interviews provided rich data and were satisfactory for the data analysis, these were complemented by the extensive "grey" literature, written by disabled activists, readily available through a variety of sources – as discussed in Chapter Two.

Interviews are compartmentalised to a specific phase of the research process. It is paramount that clear parameters be determined, delineating how the respondents may influence the direction and overall design of the research, particularly during the interviews; this phase indicates who is ultimately in control. Engagement within interviews also has three additional prerequisites: the use of material resources; the opportunity for reflection on the relationship between interviewer and interviewee, and the respondent's relationship to the research process and its contribution to the body of knowledge. By observing respondents as knowledgeable individuals who may benefit from an attempt to construct emancipatory research practice, there is a requirement to consider support to engage (McCartan, Schubotz and Murphy 2012). Alternative methods for interview, including the use of technology and physical spaces, offers of personal assistance, and remuneration, should all be considered resources (Goeke and Kubanski 2012); nevertheless, provision of support depends upon the funding frameworks and established research programmes that permit research production in the first instance. Failure to address the issue severely affects the implementation of an emancipatory approach. I was unable to provide paid support initiatives or remuneration for engagement; this factor had an impact upon the opportunity to abide by all of the principles of EDR.

Reflexivity is discussed later in this chapter, and is highlighted in Chapter One. Reflection is integral to the implementation of a hermeneutic research strategy. In the context of this research, the position of a disabled researcher who also meets the criteria of the respondents interviewed led to the challenging of the false assumption that a binary relationship exists between researcher and respondent. The relationship between the interviewer and interviewee meant a reflection of the desire to analyse the findings *via* the politicisation of disability, and a mutual understanding of one another's aims and aspirations through taking part in the research process. To achieve this, I contributed personal reflections and ideas during the course of the interviews. I was open in my comments regarding how the process of disablement was a consequence of the political, economic, and cultural structures within society. An opportunity to address this came from ensuring that the DPM be an effective social movement that aims to politicise disabled people's everyday experiences. Furthermore, each respondent was informed that their interpretations of the research topic remained paramount and essential to the production of research.

4.2.7 *Process of Data Analysis*

A thematic analysis procedure was employed, with particular emphasis placed on the latent themes identified through the data collection (Boyatzis 1998). This required extending beyond the semantic content of the data and engaging with the underlying ideas, opinions, and values that informed the respective respondent's position and answer to the questions posed. As outlined by Braun and Clarke (2006), the development of themes acquired under this particular thematic analysis approach requires the researcher to interpret the data and position it alongside the theoretical positions outlined within their research. The thematic analysis employed here is, arguably, clustered closely to thematic discourse analysis as proposed by Taylor and Ussher (2001). This is primarily based on how the data was analysed to understand "broader assumptions, structures and meanings [that are] theorised as underpinning what is actually articulated in the data" (Braun and Clarke 2006, p. 85).

It is imperative to acknowledge that a prescriptive approach to analysing data is non-existent; thematic analysis requires flexibility in order to accommodate the research questions and the types of dataset available (Patton 1990). The approach taken here was to adopt a recursive process, wherein I was required to manoeuvre back-and-forth throughout the thematic analysis phases. Building on the extensive literature surrounding steps taken to conduct thematic analysis (*see* Roulston 2001; Bird 2005), I employed the following five stages during the analysis phase of the research, which are then expanded with further insight below:

- Initial engagement with the data (transcription of interviews; completion and reflection of field report)
- Locating early codes (employ systematic approach through entire dataset to ascertain potential codes)
- Identifying potential themes (consider repeated patterns of codes and construct list of themes)
- Reviewing potential themes (determine whether list of themes can be collapsed into fewer themes and review data to consider the prevalence of the themes)
- Locking themes (reflect on data and literature to decide on set number of themes as basis for subsequent discussion).

An interview guide was developed, consisting of initial themes drawn from the existing literature. The guide also took into account key ethical issues, such as accountability, confidentiality, consent, and transparency. Two interview schedules were created, one for each respondent cohort (*see* Appendix Four). The questions were formulated using the social model of disability as a foundational device for describing disability as a form of social oppression. Also, it followed a similar line of questioning by utilising the "tool for analysis of social movements" developed by Carling-Jenkins (2014, p. 73). This identifies seven key features that require further investigation: vision, voices, events, context, and individual, group, and public consciousness.

For the interviews with young disabled people, the questions covered the following themes: understanding disability, the journey into involvement in disability issues, current involvement, the organisation of the DPM, reflection on its current direction and workings of the Movement, and aspirations and expectations for the future. The interviews with "established figures" adopted the same themes, although the questions were constructed slightly differently to add further emphasis on recording the latter's analysis of the DPM over time.

All interviews were recorded and transcribed *verbatim*, with the use of a Dictaphone. A pilot analysis was performed after the first interview was conducted. This allowed for the acknowledgement of additional points of interest, which in turn resulted in the emergence of concepts and categories that formed the basis for further interview questions, themes, and areas of analysis (Corbin and Strauss 1990).

The transcripts were organised according to descriptive and analytic codes; following Cope and Elwood's (2009) discussion on coding, the data were examined to provide commentary on themes and patterns produced by the respondents, as well as by the researcher, *via* the explanations and accounts raised during the interviews. After every interview, a field report was completed, detailing four sections of notes (Bailey 2007): observational – what happened, such as reference to specific authors and activists; theoretical – attempts to derive meaning; methodological – a critique of the process and proposed changes, and analytical – a progress review.

The field reports and initial coding provided emerging analytical themes of significant interest. Using the initial objectives of the research, focus was placed on the identification of core categories derived from the themes apparent in the interview transcriptions, literature review, and the intended direction of EDR. Throughout the development of the epistemological, methodological, and data handling phases, a constant comparative method was employed in order to ensure that I reflected upon the connections and contrasts between the datasets (Glaser 1965; Denscombe 2007). This required fracturing the data to determine their impact on the thematic categories. From this, I was able to determine how often respondents referred to the central themes identified through the course of the interviews. A breakdown of the themes identified is provided below and frame the subsequent analysis chapters:

DPM Membership	Conceptualising Youth
	Perception of Authority
	Trajectories of Membership
DPM Organisation	Interlinking Social Movements
	Social Model of Disability Significance
	Political Ideology Significance
DPM Future Considerations	Archiving Activism
	Local and Online Mobilisation
	Caring about the DPM

Table Two. Themes Developed Through Analysis Phase of Research

Not all of the central themes were highlighted by all respondents, yet it was adjudged that even if a small number of respondents made reference to any of them then this element was deemed significant. Similarly, during data analysis, it was recognised that not all respondents would explicitly refer to key themes. Rather, their arguments implied an understanding or awareness of the issue. For example, interviewed respondents would articulate principles underpinning the social model of disability; some, though, would not use the term "social model of disability" until prompted, even though they were aware of the key principles and the relevance of this one within disability activism. Arguably, it is the responsibility of the researcher to unravel the complexity of individual accounts, and to unpack the language and terminology used in order to theorise on the basis of the data obtained (Dodd 2014).

In analysing the data I have sought to understand how respondents' stories, views, and ideas allude to the fluctuating level of challenges experienced when participating within the DPM, as well as to structural forces that have hindered personal progression into activism and campaigning. To achieve this requires awareness of the sociological themes, concepts, and power relations referenced or implied within the respondents' accounts. This is why it is necessary to follow a process of developing themes from the data, to become aware of the implicit topics that are organised around a group of repeating codes, and to determine a common point of reference that will produce ideas regarding the subject of inquiry (Ryan and Benard 2003; Bradley, Curry, and Devers 2007).

Prior to the analysis chapters of the thesis (Chapters Five to Seven), attention now turns to the significance of the broader methodological paradigm chosen – EDR.

4.3 Establishing a Research Design

The process for determining an appropriate design, which takes into account the aims, objectives, and intended outcomes of the research, is extremely complex. An exploration of possible methodologies and analytic frameworks requires the author to examine the opportunities and limitations of various designs that are perceived to complement, validate, and reinforce the overall purpose of the research. Essentially, framing and articulating the research design is not merely to offer a blueprint for research practice and to ensure ethical procedures are adhered to; rather, it encourages advocacy for particular research paradigms.

4.3.1 *Basing the Research within Disability Studies*

A starting point is briefly to outline facets of the ontological, epistemological, and methodological roots of Disability Studies. Doing so is applicable for two reasons: firstly it acts as a framework against which to conceptualise the basis of this research and, secondly, it reflects one aspect investigated during the collection, analysis, and interpretation of the data – the relationships among disabled activists, the DPM, and Disability Studies.

As outlined in Chapter Two, the social model of disability – which may be understood as a heuristic device that generated a socially oppressive perspective of disablement – is integral to researchers, academics, and campaigners who frame their work through a traditional materialist and radical structuralism lens (Goodley 2016). The interdisciplinary nature of Disability Studies has ensured the production of contrasting, contradictory, and complementary stances that reinforce or deconstruct – with the possible effect of weakening – the position of the social model of disability within the political, cultural and economic spheres of the self and society. Goodley provides a comprehensive account of the sociological theories that underpin the inception and continuous development of Disability Studies; nevertheless, for the purpose of the present chapter, it is necessary to acknowledge the influence of the way in which sociological Disability Studies shifted the debate from medical discourse to emancipatory research paradigms. The Structural-Functionalist perspective, which sought to label disabled people as dysfunctional and problematic for the creation of a regulated society (Parsons 1964; Barnes 2012), has been challenged extensively and been replaced with the desire for emancipatory research that contextualises the individual's subjective views and experiences. To this extent, the sociology of Radical Structuralism influenced this research.

Burrell and Morgan (1979, p. 22) argue that a sociology of radical change comprises radical humanism (subjective) and radical structuralism (objective), whilst the sociology of regulation contains an interpretive paradigm (subjective) and functionalism (objective). A critical realist approach is used as an epistemological basis for understanding disability and disablement. This is justified on the basis of capturing respondents' representations of the social world, whilst acknowledging that such representations are affected by context (Porpora 2015). I do not seek to validate their accounts of the social world; rather, I interpret their understanding by contextualising it within my approach to comprehending disablement. With the social theories that focus on the nature of how people function within society and make sense of their position in a regulated and ordered system, radical change describes society to be in a potential state of conflict and may be explained through the observations of social structures (Hassard 1991) as one that articulates the social world as a product of social process and structural development. To accomplish this, the shared understandings born out of interviews must be captured – as must also how these influence my interpretation of the topic under study and the data, with the emancipatory agendas that address the material conditions and ideological productions entrenched in contemporary society.

To add further justification for a research design associated with the sociological framework outlined above, it must first be acknowledged that the social world is characterised by how human beings become aware of and respond to objects that – subsequently – alter their behaviour and interactions (Thomas 1966). Through the recognition of social structures and the potential for radical change, individuals will perceive and articulate their experiences through the discourse associated with the particular structures under observation – irrespective of whether they are embraced or not. Moreover, this focus does not have to be reduced to the everyday interactions and occurrences between human beings; rather, it translates into policies and practices decided, implemented, and reinforced by those with power. A review of the historical development within social research into marginalised and socially oppressed groups demonstrates the failure by researchers and institutions to ensure such groups have full and effective engagement in the process and production of social research (Bergold and Thomas 2012). This highlights issues pertaining to how disability research is conducted, by whom, and for what purpose. Kitchin (2000) provides an extensive account of the need to provide inclusive research strategies, ones that address how disabled people are marginalised during the research process. Whilst it is paramount that such debate remains ever present, there is a need to recognise the distinction between research *into* disability, not underpinned by the characteristics and aspirations of Disability Studies, on the one hand, and research produced *by* or *alongside* disabled people, which aims to improve the living conditions for disabled people. Research has effectively failed disabled people in three domains (Oliver 1992; 2002). Firstly, it has not adequately captured and reflected the experience of disablement from the individual perspective of those defined or identified as disabled. Secondly, it has not provided recommendations and accounts that are advantageous to the policy-making processes such that these improve the material conditions affecting disabled people. Finally, it fails, because disability has not been politicised, to recognise the struggles of disabled people.

Emancipatory research posits the importance of disabled people controlling the research production, ensuring respondents or participants work alongside the researcher (Zarb 1992; Bury 1996). However, my research cannot thoroughly adhere to such a principle, given the limitations imposed by the research programme. Although respondents' access needs were taken into account and their interviews formed the basis of the findings, their discussions were restricted by the researcher's initially establishing the aims and objectives of the research. To justify the claim that the research encompasses an EDR approach, it attempts to embed Stone and Priestley's six core principles – albeit with some restrictions or limitations:

- Research is founded within the social model of disability
- There is a political commitment to achieving the self-emancipation of individuals with impairments by rejecting claims to objectivity
- The outcome of the research must benefit and empower individuals with impairments [and/or health conditions]
- Research is produced under the control of disabled people and their user-led organisations
- Respondents' voices are to be politicised
- Access needs of respondents should be taken into account and accommodated through the provision of various research methods.

(Stone and Priestley 1996, p. 709)

Whilst this approach was developed for the analysis of barriers that disable within social structures, it is utilised here to identify challenges and significant issues pertaining to participation within the DPM. This is justified on the basis that the research recognises the significance of the social model of disability and is producing outcomes that will benefit disabled people's social position within society. For the DPM to be an effective, sustainable, and inclusive social movement, research is required to acknowledge challenges to participation and provide dialogue that will establish ways forward.

The principle surrounding the rejection of objectivity has been discussed extensively within Disability Studies; however, Barnes (2008) suggests further deliberation is required in order to identify various methodological approaches within emancipatory disability research. The arguments put forth by Barnes and Sheldon (2007 p. 244), which suggests it is "difficult to support the notion that those involved in disability research should put aside any claims to objectivity", are not disputed here. Rather, the present research remains committed to engaging in the political struggles affecting disabled people and recognising the existence of oppressive structures that perpetuate the process of disablement. To achieve this, it draws upon Touraine's (1981) stance that identification with a social movement is necessary in order to gain an understanding of it.

A requirement of this research is also to reflect upon Oliver's suggested failings of research, and to address these through the implementation of an EDR design. This echoes the argument outlined by Morris (1992) that seeks to frame the personal concerns as representations of political issues. Aspects of Mills' "Sociological Imagination" (1959) can be found in the arguments put forth by Morris and Oliver; Mills argues that the focus on the individual's biography should be contextualised within the confines of the historical and political. Doing so provides an opportunity to explore the structures embedded within society and to question the mechanisms of human behaviour to recognise a sense of the self. The notion that the experiences of living/life contribute to the development of a society, as if it grows and develops organically, implies that social research must account for the biographical, historical, and intersectional nature of how such frames meet within the totality of what is referred to as society (Mills 1959). As a consequence, and to continue with the development of the research design, it is paramount to consider the epistemological position of the research as well as to identify the conditions and limitations of human perception.

4.3.2 *Ontology and Epistemology*

In social research, epistemology justifies and evaluates the conceptualisation of knowledge and modifies the methodological approach taken (Carter and Little 2007). To draw upon a context for explaining the epistemological process, the existence of the subject, the object, and the relationship between the two must be acknowledged. A comprehensive explanation for the purpose of knowledge also requires an exploration of its theoretical and empirical bases. A sophisticated theory of social oppression is untenably weak if it cannot be reinforced with sufficient empirical evidence, and *vice versa*. Moreover, this should not detract from the additional point of an acceptance or rejection of the premise of truth. The argument that the researcher/investigator is detached from the ontological and epistemological basis of the subject-object encountered, so as to appear objective in their interpretation and discussions, is unconvincing (Ghee, Glenn, and Atkinson 2007). It reinforces imperialistic, elitist perspectives of research production and supports the functionalist theoretical map for society – which my research aims to avoid. Essentially, the following questions must be considered: how do you know what exists, why do you believe it to be true, and why do I interpret it as such?

There is a risk of reducing the understanding of epistemology to distinctive, compartmentalised blocks required to explore the divisions between the identified subject, the object known, and the abstract notion of truth from the positions of the I and the Other. The truth is more complex than outlined above; a further descriptive analysis of epistemology within social sciences may be located in the work of Dillon and Wals (2006) and Onwuegbuzie and Leech (2005). For the purpose of this chapter, the position of the ontological and epistemological bases for this research must be prioritised and consideration given to identifying the schemes incorporated to validate the selected research paradigm.

The scheme outlined by Burrell and Morgan (1979) provides a foundation to justify the approach taken. As alluded to above, the analytical framework adopted, based on my ontological position, is a sociology of radical change that explores forms of resistance achieved through the exercise of power (as defined in Chapter One), modes of thought and production, and emancipatory practices (Skrtic 1995). As a result, the lens of the research reflects a critical realist stance, supporting the claim that knowledge exists through a combination of explaining and interpreting artefacts, social structures, persons, and the effects of human action and interaction (Rutzou 2016); however, this is achieved only once the analyst is in a position to review the nature of causation critically: the complexity of the various processes and structures that cause and affect the regularities and events within the social world must first be understood (Little 2016). It is imperative at this point not to become trapped in the irresolvable debates surrounding methodological pluralism offered by critical realists. Rather, there is a need to articulate disability as a basis for the oppressive relations for those with impairments and health conditions, and who are neuro-diverse. Here, critical realism is taken to understand what *could* be achieved by considering the social status of disabled people’s lives. Such consideration provides an opportunity for respondents to offer a perspective on how they are affected by the process of disablement and on the possibilities for realising disabled people’s emancipation. Furthermore, the significance of underpinning this research with an acceptance of disability as a political and social category is certainly not denied. As a result, critical realism and the social model are deemed compatible (Dodd 2014). This is because the manifestation of disablement may, by disabled people, be recognised as one of many experiences; whilst critical realism may offer a multi-faceted approach to understanding disability, the primary focus in the present discussion is on the social production of oppression. The notion of open systems is recognised and employed (Collier 1994) and is referred to as “susceptible to external influences and internal, qualitative change and emergence" (Patomäki and Wight 2000, p 232). The opportunity to explain the social world incorporates pre-existing structures as generative mechanisms that interact with other objects that possess power (Archer 2003).

Irrespective of the parameters associated with realism, the research has no intention of becoming lost in attempts to query a sense of reality. The research accepts that reality is understood in a binary sense: by researcher and respondent. This opinion, articulated by Ingstad and Whyte (1995), could be expanded as the reader – supervisor, assessor, student, activist, whoever – also becomes recognised as part of the discourse towards the nature of social reality. De Gialdino (2009) provides a comprehensive account of some of the ontological and epistemological characteristics mentioned throughout this chapter.

The ontological lens subsequently adopted affects the process of selecting the epistemological position. Data collection, analysis, and macro- to micro-sociological theories all depend upon and are influenced by the epistemological position adopted. It is a precarious status, though, as the disputes over flawed, limited assumptions for an explanation of knowledge, reality, and interaction are contested under the various research paradigms (Kivunja and Kuyini 2017). The research nevertheless adheres to Frazer and Lacey's argument that "even if one is a realist at the ontological level, one could be an epistemological interpretivist […] our knowledge of the real world is inevitably interpretive and provisional rather than straightforwardly representational" (1993, p. 182).

If, by attempting to adhere as closely as possible to the principles of emancipatory research, I seek to establish dialogue with individuals in order to discover the practical, political, and cultural needs of a socially oppressed group then a paradigm based upon reciprocity, gain, and empowerment is selected (Oliver 1992). This requires both respondent and researcher to self-reflect, to decide how the research topic is situated within the wider context of oppression, and how it will be beneficial to all involved. A personal relation with the research cannot be separated: my position of researcher is, to an extent, similar to those engaged for the purpose of the research objectives; the research adopts an interpretivist epistemological basis, yet it is positioned upon a trajectory towards an emancipatory paradigm. It acts as a device through which to explore the meaning of disablement *by* disabled people *for* disabled people (interpretivism) while it directs its focus on disability as a social issue, one of political struggle and significance (emancipatory). The research therefore adopts an inductive reasoning approach. From the data gathered, a broader set of patterns emerge through the use of coding; once identified, there is an opportunity to create general conclusions that offer insight into addressing the challenges and issues raised by the respondents.

The position of researcher is explored next, drawing attention to the enlightenment model (Weiss 1979) and illustrating the need to question the purpose of research at the foundational level of establishing a research design.

4.3.3 *Researcher Position*

As outlined in Chapter One, I became involved in disability activism at fourteen years old, when exploring the relevance of the social model of disability to articulate the personal experiences of marginalisation, discrimination, and isolation. My personal, professional, and academic trajectories have continuously led me to recognise the importance of the DPM, Disability Studies, and DPOs. This has resulted in my taking an insider position within the research because of the knowledge, access to people and information of which I am already aware or am able easily to obtain through existing networks and relationships. Arguably, this provides an advantage when addressing the complexity of the research topic and goes some way towards understanding, unravelling, and comprehending the tension between researcher, topic, and respondent group (Tedlock 2000). There is, though, a need to emphasise the sensitivity required when undertaking research that will include or make reference to individuals, organisations, and knowledge sources already known to the researcher (Costley, Elliott and Gibbs 2010). Undertaking the current research meant clarifying my role to respondents who had pre-existing knowledge about me, framing my position as one who aspires to support the inclusiveness, effectiveness, and sustainability of the DPM, a Movement with which I have been affiliated since my early teenage years.

Of course, a further need exists: to consider the ethics of insider research (Floyd and Arthur 2012). It is my belief that I have benefited from being in this position because it has allowed for a stronger rapport with and smoother access to a shared reference point with the respondents. By outlining immediately my ontological and epistemological stance to potential respondents, I believe the premise of my possibly contaminating data through inhabiting an insider role – as claimed in the works of scholars such as Hockey (1993) and Griffith (1998) – may be reduced. The significance of disabled people's involvement within the research process cannot be understated.

It is here essential to account for the power relations within the research process and to acknowledge my position as a prominent member of the DPM, known by name to the majority of the respondents in the study. This particular issue, considered alongside the important point that I ultimately controlled the research production, requires further reflection. According to Tregaskis (2004), disabled researchers are required both to explore the complexity surrounding personal investment in the research process and to acknowledge how research is affected by conducting it with people who also identify as disabled. To mitigate concerns that my known presence within disability activism would limit respondent's contributions during the interviews, I initiated all interviews by stating the importance of giving space to understand and acknowledge the personal experience of disability. This reinforces the arguments by Morris (1991), Thomas (1999), and Reeve (2002), who suggest that the personal experience of disability – while expressed as a personal issue – has a clear political dimension. As a researcher, it became my role to make sense of each respondent's contributions and ascertain how their ideas, opinions, and commentary, would improve disabled people's position within activism and social movements. However, to achieve this, I had to start by returning to the mantra "the personal is political" and support all respondents in elaborating on how oppression and marginalisation affected their individual lives, even if this challenged dominant narratives espoused by the DPM.

Doing so meant taking into consideration the public comments and statements I have made about disability issues, which may be known to the respondents – and may, indeed, be at odds with their comments. Strategies were implemented to reduce the power and authoritative position adopted by a researcher. I remained open to the possibility of clarifying my position and statements about particular aspects of disabled people's emancipation, if prompted to do so by a respondent. In three of the interviews respondents made direct reference to my position as an activist, in relation to the following topics: current DPM campaigns and demands, whether the DPM is inclusive of young disabled people's experiences, and further learning on DPM debates. On a particular occasion, Rose - a young activist - was asked where she would go to learn about key debates surrounding disabled people's emancipation. Immediately, Rose stated I would be the first person she would speak to. Similarly, during the interview with Janet (an established member of the DPM), she referred to comments I had made publicly about the hierarchal nature within the DPM. In agreement with my statement, Janet used my comments as an introduction to the points she made.

Whilst accounting for the influential position I hold within this research and disability activism more widely, my assessment of Rose's and Janet's comments has led to the opinion that – as a researcher and activist – I am approachable; familiarity with my work and activism led to an open, engaging discussion. Respondents are willing to engage with me on the basis of familiarity and because they recognise my commitment and enthusiasm for disabled people's emancipation. Nevertheless, I am in agreement with Stone and Priestley (1996), who suggest disabled researchers are not excluded from conducting oppressive research. In designing this research it was essential to reduce any, often inadvertent, abuses of power and consider the impact that my position might have upon the findings. Even if I am perceived as being approachable, respondents may feel uncomfortable sharing details of their personal experiences of disability or their opinions on the organisation and development of the DPM. They may acknowledge a potential to resist entering into a discussion wherein they will identify individuals and organisations associated with my activism and campaigning. Taking into account the arguments made by Finch (1993), who suggests respondents may come to regret sharing information so openly because of their familiarisation with the researcher, I utilised a number of suggestions proposed by Tregaskis (2004) in an attempt to overcome the concerns raised over my position within the research.

Respondents were offered the interview transcriptions in order to edit them, as well as to retain them for their personal archives; furthermore, all respondents approved the specific quotes used within the analysis and write-up – with the option to veto the inclusion of their data in the final, published thesis. All respondents were offered subsequent meetings, after the interviews, to provide an accessible space to reflect on how the research has affected their thinking on disability and activism. This latter point emphasises the need to consider reciprocity between respondent and researcher during the production of the research (Oliver 1992). The impact of power relations in the research process is well documented (Allen 2010). Nevertheless, it was essential that I clarified my position in the research and adopted the safeguards outlined above in an attempt to acknowledge the mutual, respected positions occupied by researcher and each respondent.

Building on the methodological considerations offered by Sheldon (2017), my position in this research has afforded an opportunity to use the interviews with respondents and the considerable time spent in exploring Disability Studies literature to challenge and question my personal understanding of disability, and my experience as a disabled activist. Although not the primary focus of the research produced here, the insight I have gained through the experience of interviewing disabled people has led me to reshape my own perspective on the nature and workings of the DPM. Prior to and during a substantial part of developing this research, I adopted a cautious position in my writing and deliberations on disability activism for fear of offending my existing contacts, comrades, and allies within the DPM. This was indeed challenged as I interrogated the purpose of my data collection and overall research aims. In order to improve young disabled people's participation within the DPM, I have needed to destabilise and to re-examine my existing ideas about and relationships within disability activism. This entails acknowledging the complexity surrounding my identity as a disabled academic activist and constantly reviewing the ever-changing perspective I acquire by studying disability. Ramussen (2006) suggests researchers must deconstruct their own identities, as an attempt to understand the position they take within the research. I have learned that this is essential, not in an attempt to assume an insider perspective, but rather to understand the context in which my research has developed and the conclusions that have emerged.

Such deliberation over my position within the research also led to a reflection on the decision to adopt an EDR design. Although this research does not strictly abide by the entirety of the principles associated with EDR, I assert that it is not possible to do so with any form of research. Rather than become trapped in an irresolvable debate as to whether EDR can be completely embraced, the researcher's primary focus should be on aligning their research design as closely as possible to the principles of EDR. Furthermore, the researcher must account for and be transparent in their assessment of the EDR principles that challenge or implicate the existing research design.

With regard to researcher position and EDR, it is necessary to reflect on two specific points. Firstly, it must be acknowledged I am afforded a level of privilege on the basis of my identity characteristics. Tregaskis (2004) highlighted that Disability Studies has historically been dominated by white men. As a white, Western-educated, physically impaired male from a middle-class background, my privileged position has afforded me opportunities to occupy positions of influence within disability activism and research. It could be problematic that I represent an identity that is scrutinised within commentary about the hierarchal nature of the DPM (Campbell and Oliver 1996); however, it is my intention to use the privilege afforded to me by means of conducting research that will bring about change within the organisation and membership of the DPM. Such change has the potential to disrupt the hierarchal nature and dismantle the historical privilege that has beset the sustainability and effectiveness of the DPM. The second point is in reference to the research agenda employed during the design of this study. Whilst I have attempted to capture disabled people's ideas and perspectives, it is imperative to recognise that the idea, development, and publication of the findings are credited to me. Although not, therefore, disputing the authorship or direction of this particular study, I have attempted to mitigate the concerns raised by scholars over agenda setting within research (such as Oliver 1992; Stone and Priestley 1996) by reflecting on my position within the research, as outlined above. I have offered a transparent account of the problems surrounding reflexivity and my attempt to access an insider perspective. No justification exists to dismiss EDR on the basis of the concerns raised here; instead, the process has included accounting for the opportunities and difficulties inherent in clustering the research design as closely as possible to the principles of EDR.

The development of EDR took inspiration from commentary within Critical Race Studies (Delgado and Stefancic 2012) and writings on Feminism (Gouin, Cocq and McGavin 2011), questioning the exploitative actions of the intelligentsia and embracing the researcher's position as being fluid rather than static (Eppley 2006). The notion of reflexivity is integral to the process of generating knowledge through qualitative research (Hammersley and Atkinson 2007; Gerstl-Pepin and Patrizion 2009). However, there is a lack of contemporary literature exploring this from the perspective of disabled researchers (Sheldon 2017). Accounts of the various positions that require recognition are extensive and draw attention to gender, race, age, and linguistic traditions; simultaneously, they fail to incorporate the experience of disablement and impairment. Personal characteristics, ideological stances, and emotional responses affect the extent of collaborative dialogue between researcher and researched (De Tona 2006), illustrate power dynamics (Declercq and Ayala 2017), and have an impact upon the construction of the research questions, data gathering, and overall conclusions (Kacen and Chaitin 2006). The basis of exploring reflexivity is, in this context, to go beyond the credibility of the findings. Buckner (2005) denotes this process as being integral to securing trustworthiness, while I posit going considerably further to acknowledge academia's role in "colonising" the production and dissemination of knowledge. This, undoubtedly, highlights the academic-activist relationship, the significance of accountability, and the limitations of the researcher through the production of barriers imposed upon the self.

The social exclusion of disabled people from mainstream society, segregation into traditional institutions, and the continued practice of medical and professional rehabilitators has formulated a narrative illustrating "absence of consideration within […] disability […] and citizenship (Beckett 2006b, p. 2). This questions the underlying motives and expectations outlined by the researcher, echoing Oliver:

> [D]o researchers wish to join with disabled people and use their expertise and skills in their struggles against oppression or do they wish to continue to use these skills and expertise in ways in which disabled people find oppressive? (Oliver 1992, p. 102)

As a result, it is necessary to acknowledge how the research identifies and interacts with societal structures in the social world. An exploration of young disabled people's views and experiences of social movements, including the organisation, ideological demands and practices will reveal various sides: established members, newcomers, allies, the State, advocates, and critics of social model thinking – all of which adopt different positions that require personal, political, and academic empathy. Essentially, and paraphrasing Becker (1967), the focus should not be on establishing a platform upon which to debate whether researchers can be impartial during the collection and dissemination of the findings. As Barnes

(1996, p. 110) argues, researchers are "either with the oppressors or with the oppressed". The transformation from social theory to action is difficult to predict during the production of the research, particularly leading up to the initial dissemination into the social world. However, the determination to ensure the researcher is positioned on the side of marginalised groups should not be rejected. Critics of emancipatory research and the notion of praxis as an essential part of disability research, most notably Shakespeare (2006), question the necessity to formalise a connection between Disability Studies and the DPM.

The DPM has been scrutinised to the extent that it is claimed no longer to represent the disabled population as a whole (Shakespeare and Watson 2002; Shakespeare 2006) – assuming it had such responsibility in the first instance. The research nevertheless aspires to have a meaningful impact on the development and existence of the Movement, the policies that affect its strategic position, and the continuous struggle for its members to participate within a more equitable and just society. To achieve such aims, it is imperative to acknowledge the concerns over methodological individualism and investigatory foundationalism, as outlined by Hodgson (2007). The research should attempt to avoid developing abstract terms that consequently remain inaccessible to the social actors affected by the research. It is my responsibility to ensure the conclusions of the research are available and accessible to those who wish to or may benefit from the research. This will be achieved by working alongside DPOs and interested parties to disseminate the findings and discuss the future possibilities of the research – an integral property of emancipatory research.

As a final point, it is worthwhile noting the journey that I have embarked upon throughout the research. Initially, the intention was to explore aspects of leadership within the DPM and ascertain existing and potential opportunities for young disabled people to be future leaders within the Movement. The focus changed once existing literature was reviewed, as I noted significant gaps highlighting the barriers encountered by young disabled people as they engage in activism. My research portfolio (Todd *et al.* 2012; Griffiths 2012; Griffiths 2016; Griffiths 2017) illustrates commitment to a social model of disability approach to describe the marginalisation of disabled people, and I have tended to advocate for a Radical Structuralist approach to address the social structures that perpetuate various forms of marginalisation. With this research, I was interested in understanding the organisation of the DPM and how individuals, as well as collective groups, affect young disabled people's participation. Whilst social, political, and economic structures should remain a focal point for the demands and activities of the DPM, it is necessary to consider how the existing membership can, inadvertently, restrict the participation of newcomers. However, I did not want to reject their understanding of disability; I have sought to combine respondent accounts with the existing literature, in order to determine how the DPM can address the challenges encountered by young disabled people. Beckett's and Campbell's (2015) idea of the social model as an opposition device, as well as their understanding of power, remained an integral part of my research. Although their work was published after I started the PhD, I have shifted in my theoretical position and no longer ground myself in historical materialism. The progression that is taking place within materialist thinking has led to the possibility of straddling various theoretical positions in order to create research that contributes to the emancipation of marginalised groups. The research produced here captures the experiences and ideas of existing DPM members and of those who want to contribute towards disabled people's emancipation.

4.4 Conclusion

The chapter highlights the importance of an emancipatory disability research approach. This is because of the commonality that exists between the aims of this approach and the research questions under investigation, insofar as narratives and perceptions of disabling barriers should be rooted within social structures (Barnes 2001). In order to comprehend the challenges faced by young disabled people when participating within activism and social movements, as well as to produce meaningful outcomes for the DPM in facilitating the inclusion of young members, the research identified two selected respondent groups. Semi-structured interviews took place with young disabled people aged between 18 and 30, who self-identified as disabled persons and were either interested in or participated within the DPM; interviews also took place with "established figures" who played an influential or prominent role in disability activism. The interview guide that was developed consisted of initial themes drawn from existing literature associated with disability, activism, and the development of social movements. Respondents provided stories, views, and ideas alluding to the fluctuating level of challenges experienced when interacting with the DPM, as well as to the structural forces that hinder personal progression into activism in campaigning. Once this was captured, it was my responsibility to utilise sociological themes, concepts, and power relations – rooted within Disability Studies and influenced by radical change – to determine a common point of reference that would produce ideas related to the subject of initial inquiry. This ensured a comprehensive approach towards identifying descriptive and analytic codes within the transcripts, which in turn led to the emergence of the thematic categories that formed the basis of the subsequent analysis chapters.

It was appropriate to base the research within Disability Studies and to adopt a methodology that was intrinsically linked to the social model of disability. As a result, it was necessary to capture the shared understandings of social processes and structural development – between the respondent and myself – and align these with the emancipatory agendas that address the material conditions and ideological productions entrenched in contemporary society. This led to my taking an EDR approach, especially as key scholars suggest that research has effectively failed to capture and reflect the experience of disablement, to recognise the politicisation of disability or to provide analysis that improves the material conditions affecting disabled people (Oliver 2002). To achieve an advantageous outcome, the research has aspired to the six core principles outlined by Stone and Priestley (1996). The ontological and epistemological bases for research reflects a critical realist stance, given that it is essential to understand the complexity of the various processes and structures that may both cause and affect the regularities and events within the social world (Little 2016).

With the methodological approach established, attention now turns to the subsequent findings as identified through the analysis of the data obtained by interview.

5. Young Disabled People’s Relationship to the Movement

5.1 Introduction

This chapter uses the analysis of interviews with young disabled people, and with established members of the DPM, to identify three significant aspects that affect young disabled people's relationship to the movement. The chapter argues that the current, dominant conceptualisation of youth, found within the DPM and wider social world, represents young people as passive, dependent upon the ideas of older, established figures. It has two particular purposes: firstly, to learn from existing figures, with the expectation of continuing their work and legacy, and secondly, to become involved only in discussions and activities pertaining to youth-related issues and agendas. This creates frustration amongst young people, as they thus experience a sense of marginalisation by certain members and organisations within the DPM, who suggest they are as yet naive to the various discourses surrounding disability politics. The research argues this concept of youth is reinforced through the micro-level interactions between individuals, as well as at the macro level through the provision of services and policy direction; nevertheless, it is evidenced – through the interviews – that a reluctance by young disabled people to adopt and promote social model thinking is a root cause of the restrictions placed upon them to participate in and interact with the DPM. The findings suggest how the process of becoming a member of the Movement necessitates opportunities to assess and explore the principles underlying the social model of disability. Whereas none of the young respondents rejected the social model, they did want the resources and support to take control of their own process of learning and growing awareness. To address this, the research promotes the use of safe and open spaces – as suggested by respondents – which would offer young people the mechanism to explore such themes. It is important to note these areas intersect and interact with one another and are produced from the perspective that the world is not a fixed, stable entity. Rather, it is one that is in constant flux.

The analysis given of the respondents’ data will act as a foundation for a subsequent discussion chapter that will critique the existing literature and posit original contributions to the body of knowledge. Although the research will contradict, challenge, and support specific ideas and arguments presented by the respondents, the research findings reflect the existing body of literature as well as the emancipatory disability research methodology, which requires the conclusions to support the politicisation of disability and provide suggestions for improvements to the lives of disabled people.

The first area identified is the conceptualisation of youth and its implications for young people's participation, as explained by the respondents. Initially, this chapter explores how young disabled people relate to and are affected by the terminology surrounding youth and activism; this is positioned alongside the perspectives of established members and their articulation of the purpose and importance of young people's engaging in the DPM. The second aspect centres on the notion of authority and command, with specific attention drawn to how young disabled people suggest how their position and status within the DPM is dependent upon the actions, behaviours, and ideas of the established, most notably older, members. Finally, the trajectories of membership – including how the definition of "member" affects participation in a social movement – are discussed. Attention is paid to how the purpose of a social movement is recognised and the consequences of the DPM's operating from a soft leadership approach.

5.2 Conceptualising Youth

The definition of "youth" affords an extensive range of explanations, depending upon the ontological approach taken to conceptualise young people's existence, capacity, and actions within the social world. According to Jenks (2005), realist approaches have sought to view children and young people as passive future-beings, capable of absorbing the diverse messages provided by established individuals and infrastructures – such as parents, educators, and the mechanisms of consumerist culture. This is reinforced in the extensive work carried out by Slater (2013), who concluded that conceptualisations of young people in contemporary Western society tend to promote young people as incomplete adults. This articulation of youth was reflected in the interviews:

> I think some groups or organisations are particularly uninviting and unwelcoming to young people. I think more to do with lack of experience then age - but of course the two come hand in hand. But then again, young people who have a lot of experience may feel they have the same experiences as I have.

During the interview referenced above, Regina – a young respondent – reinforces Alldred's and David's (2007) explanation that young people, as individuals within the wider social world, are perceived as compliant recipients of social forces and as responsible people-in-waiting. Regina expands her point by using a recent example:

> I went to an event back in the summer with three disabled friends. All four of us were under 24 at the time. And I felt like we stuck out. Everyone was much older than us, we were the youngest there by far. A few individuals did make the effort to speak to us, but I did feel like we were very much outsiders.

As a result, the research asserts two particular points: firstly, as young disabled people rely upon government policy and practice to navigate and access daily living, their perception of themselves and wider understanding of young people's position and status within society becomes carved into particular, intrinsic aspects reflective of dominant narratives associated with the service provision and objectification of the body by professionals. Secondly, the findings indicate that young disabled people are typically involved in discussions and activities that focus or require a view on their future as adults. To address this, the DPM ought to consider how young people's engagement is positioned within the existing demands, agendas and overall narratives of the Movement; at present, it would appear that there is sporadic attention to and action on this matter (Todd *et al.* 2012, 2018; ENIL 2018).

Jukie, one of the established members interviewed, explained how the emergence and influence of neoliberal capitalist ideals and promotion of consumerism and leisure consumption has affected young disabled people's explanation for the causes of disabling barriers within society. She argued that their broad, ever-changing relationship with the economy – in which they can be supported to access mainstream services and receive support from the State – results in a reluctance to challenge or focus on the economic events that have led to this point in time. I argue here that the premise of reluctance is interpreted as a negative portrayal of an apathetic youth generation, which – as Slater (2013) suggests – legitimises the need for an “adult” generation to take control and “show the light”. The research proposes that the DPM must acknowledge that, currently, young people's involvement in activism and social movements is for young people to offer individualised narratives of the future, and therefore must challenge how the perceptions of the future are colonised by economic events, corporate agendas and consumerist ideals (Facer 2011). To take such an initiative would not only benefit the movement but would also challenge expectations of youth by the social world. In turn, this would contribute to the critiquing and repositioning of young disabled people’s status and participation within the DPM – an aim of this research. As Jukie suggests:

> I think it's created a massive schism right now, between those people who were raised on a kind of capitalist ethos if you like, so they would be the ones that achieve much more, much further, long before the rest of us who are raised with the more socialist background. We had a very different education and a lot of the younger people in the movement who have bought into the kind of celebrity culture that is pumped through our TV screens, pumped through magazines and digitally at every aspect, is all saying, yeah, you do it for yourself.

At this point, there is merit for drawing upon the materialist approach by Alldred and Fox (2017), which conceptualises young people as "becomings" who continuously change within a series of relations based on time, space and location. Not only does this question how the notion of youth affects young people, it also highlights wider social consequences for how social movements incorporate the views of young people. As Jukie continues:

> There's a sense of this, I'm all right, Jack, pull up the ladder. There's very little, so you bring somebody on, so actually this is about connection, this is about don't stand and shout over the sun. You turn round and make sure the sun shines on those beside you.

To challenge the assumption that young people are members of the DPM, existing to promote individualised accounts of daily experiences, young respondents expressed a desire to take part in the discussions surrounding collective futures. This was perceived as young people's attempt to engage in the political and social struggles, as a way of demonstrating their interest and the potential to collaborate and discuss at a level beyond the personal, potentially anecdotal, narrative. As Hicks (2002) suggests, young people should be presented with opportunities to suggest alternative visions of the future and be part of a simultaneous critique of the present whilst envisaging a future that is possible, probable, and preferable.

Although the research does not dispute this point, it is asserted that young disabled people should be supported and encouraged to explore the political aspects of their interactions and relations with others. This provides a method and platform on which to assess the fluctuating levels of power, choice and control – within different areas – on a daily basis. As a result, I would argue, the importance of the lived experience remains paramount yet is utilised in such a way as to challenge the existing relations throughout the social world that produce aspects of marginalisation and inequity. To achieve the challenge depends upon whether or not the DPM actively encourages young people to be part of the agendas scheduled and action taken to plan for the future. Further, the DPM needs to dedicate time, resources, and activities to challenging assumptions that young disabled people constitute a risk to the existing plans and agendas of established members. As Jeremy – a young respondent – expresses, it cannot be taken for granted that young people are embedded within the cultural and political debates emanating from the established members; similarly, much depends on whether the members encourage youth participation:

> I am not familiar as such with the culture or the politics or the people and I am kind of alienated from that movement as well because I do feel a lot of it is kind of older people, with particular influence, that aren't looking to be too inclusive to [*sic*] our particular generation, they are more focused on seeking change for themselves in the immediate way.

Here, Jeremy refers to established members' "seeking change for themselves in the immediate way"; it is important to note that throughout the interviews with young respondents, it was interpreted that established members would position the DPM predominately as a challenge against the actions of the State, with particular reference to welfare, education, and employment. For young respondents, this is necessary due to the importance of the politicisation of disability; however, it was presumed that such agendas and focal points were selected irrespective of the involvement of younger social movement members.

The relations between the individual and the State are an ever-changing system that is different from the agendas and demands of the DPM. For example, discussions on the State/citizen relationship (Beckett 2006b), which effectively drifts into competing discourses associated with citizens of the State and customers of the market, are problematic. If young disabled people mention choice and control in response to this aspect, their reactions may be interpreted as a substantial challenge to the established members of the Movement – as outlined in Jukie's comment. Here, established members are focusing on the political subjectivity of disabled people and/or on revolutionary ideals associated with the destruction of capitalism. Effectively, the Movement perceives young disabled people as active but misguided, passive, in need of being taught or even disposable when matters "without a youth aspect" take precedence.

This point needs to be unpacked further. The research argues that young disabled people involved in the DPM are perceived by the Movement as being in competition with established members and long-standing figures. Similarly, the involvement of young people is, by influential members, interpreted as potentially leading to the dilution of the principles of the DPM or to a change in the direction of strategy.

Arguably, the point raised by Regina is a consequence of the continual cascade of events comprising the neoliberal expectations placed upon young people. It is useful to return to literature, at this point, to reinforce the arguments presented by the research and respondents. The literature review explores the premise of "ableism", inasmuch as the neoliberal lens advocates for valuing certain bodies over others and, as a result, relegates the supposedly useless and nonconforming bodies as a disruption and hindrance. To further this understanding, Campbell (2012) highlights how disability can be a form of collateral damage, incurred through actions that promote ableist ideals. The interpretation of Regina's stance follows a similar line of analysis, whereby those with considerable power view the body as a site of investment.

The assumption is that members of a social movement battle over the competing agendas and perspectives, as Margaret – a young respondent – highlights. However, it is not the ideas for emancipation that cause the friction; it is how young disabled people are perceived as integral members:

> I mean my personal experience of it is that you're not always going in the same […] every member of the movement isn't always going in the same direction with one particular goal. I think it goes back to this point that different people have different strengths and different knowledge bases and you have an area, you know.

Whilst there is extensive literature to explore the stigmatisation experienced by those exposed to disablement, it was noted that the premise of oppression – as outlined by Gleeson (1996) – affected how young disabled people perceive themselves. There were diverse reactions when respondents were asked how it felt to be referred to as a young disabled person. The majority acknowledged then rejected the process of internalising the negative and devalued experiences associated with disability. As Regina expressed it:

> When I say I'm disabled, what I'm effectively doing is holding a mirror up to someone and saying this is you, this isn't me, this is you, or this is society. I'm pretty sure most of the time that's not how they see it, but that's how I see it. It's a bit of a fuck you - I'm going to call myself disabled but I'm not talking about me, I'm talking about you. Like I say, I don't think the majority of people understand that's what I'm doing, but to me it's really empowering. They may think that it's me saying there is something wrong with me, but that's not what

> it means at all. I see my medical conditions and disability as completely separate things. And also I sometimes enjoy using identity first language because it makes people feel uncomfortable, and there's a beautiful irony in that.

Here, Regina shifts perception towards the principles underlying the social model of disability. Separating medical condition from disability is the process of differentiating between the functional limitations of the individual's body, on the one hand, and on the other as the product of discrimination and marginalisation experienced through disablement. The affirmative model (Swain and French 2000) offers a rejection of theorising disability through a lens of personal tragedy, yet there is a clear desire to acknowledge the option of using the experience and labelling of disability as a process through which normative practices and expectations may be challenged. Regina's quote is significant insofar as it questions the relation between membership of the DPM and an individual's perception of themselves: although the Movement is committed to addressing a range of social justice issues, predominantly influenced by crisis-driven agendas (Sheldon 2006), it continues to battle for a contemporary understanding of disability. For those interviewed, their identity would repeatedly be stigmatised by the wider communities with which they associate. However, they attempted to concentrate on challenging societal perceptions of disabled people – which led to involvement with and interest in the DPM.

The purpose of this chapter is to analyse respondents' interpretations of their identity as young disabled people attempting to navigate their inclusion within the DPM. As noted by Corker (1998), in order to understand disability culture and identity, it requires a process that formulates clear definitions. Within social movements, language is continuously debated and challenged, because it offers a specific framework within which to demonstrate how a specific group aspires to be perceived within the wider social world. To achieve a perception acceptable to young disabled people, there is a need to increase participation by young disabled people within political activities. This is done in order to disrupt the ableist rhetoric surrounding disability and to reposition how disabled people are valued. Nevertheless, recruiting and including new individuals necessitates re-evaluation of the existing criticisms inherent within the DPM – such as the evident hierarchy of impairment (Deal 2003). This was highlighted by David, a young respondent, who emphasised the importance of recruitment and commitment by members of a social movement:

> It’s probably impractical to think that that should be a priority because as we’ve established, there’s so much fragmentation, there’s so much kind of […] the idea that people – a hierarchy and various other things exist. My first thing is we need to unify, then we need to encourage more disabled people to join us, but the only way you’ll do that is excessive persuasion and then you need to try and create change for everyone else.

The sense of solidarity amongst young people, created by recognising similarities in their experiences and perceptions as young disabled people, drew parallels with Price’s (2011) work, which promotes the importance of consciousness raising and collective empowerment. It is evident from those interviewed that they perceive the DPM as a tool for facilitating dialogue and raising awareness of the common concerns experienced by disabled people. The Movement has been established for a considerable amount of time, yet this form of consciousness raising was essential in that it ensured young disabled people had opportunities to express concerns, articulate common barriers, and to question the social systems and structures that affect their human rights. Such contributions resulted in a form of collective empowerment, as the protesting and campaigning by those involved encouraged their friends to participate. The young respondents’ initial reasoning for accessing the Movement was not necessarily to address equity issues or access to material needs associated with daily living, but to direct their efforts towards asserting themselves as politicised individuals experiencing disablement. As Rose, a young respondent, explains:

> But I realise that’s quite complex, because the disabled people’s movement was started and it is predominantly occupied by people who would readily identify as disabled. But I also don’t think that every disabled person is also right for the disabled people’s movement because not every disabled person is politicised in the way that I might be, or you might be, or, you know, somebody else within that movement might be.

Here, Rose reflects the views of Price (2011) by articulating the specific realisations required prior to or during involvement in political activism. Through an acknowledgement of the internalised oppression experienced by disabled people, those involved in the DPM may start to challenge their individual negative experiences and feelings through gaining support from others involved in the social movement. Support from such a context aims to articulate how the social world reproduces this experience of disability, ultimately redefining the term by grounding it in the politics of disability and facilitating the emergence of disability pride (Martin 2012). However, Rose suggests this process of politicisation means not all disabled people would consider the DPM valuable:

> There's a certain kind of politics and certain realisations you have to come to before you can be involved in political activism and the disabled people's movement. I suppose what I'm saying [is], it's not for everybody.

Longmore (1985) notes that the second phase of the DPM is associated with the pursuit of a collective disability culture and identity. The desire for a positive identity, part of the pursuit of empowerment, stimulates the need to determine whether young disabled people are seeking standard identities that challenge the negative impact of being perceived as abnormal and different. It highlights the need to develop a positive disability identity by challenging the traditional values and expectations that assume the presence of a normative category. There was a growing recognition amongst participants that the DPM provides a space within which to develop the basis of a positive identity, rooted in pride, solidarity, confidence and a desire for self-determination. Although scholars have argued over how the notion of citizenship is affected by the micro-political aspects of interactions between individuals (Carens 2000; Andrews, Cowell, and Downe 2011), young respondents such as Richard believe it is paramount that young disabled people be presented with information pertaining to disabled people's history and pride:

> The ways that we talk about, disability, accessibility etc. need to be accessible to people that have no understanding of what those things are. We need to, especially when you're trying fight for your rights and you're trying to say, "Fuck you! No! We need this legislation now!"

By analysing respondents' views, a key issue has emerged pertaining to the role and expectations of young disabled people involved in the DPM. Similarly, young respondents highlighted how the concept of youth has impacted on their participation to mobilise activity and address the premise of disablement. Richard continues this point by suggesting people will not engage with activism if they are not supported to understand what disability means in the contemporary and historical context:

> Like, if that person has no understanding what it is like to be a disabled person or the barriers you experience then they're not gonna listen to you – you need a way of sharing stories, history and information with someone that has no understanding of what disability is.

Through this analysis, the research argues that youth is a product of the relations one has with other beings within a specific period of time or event, and is influenced by the relationship between institutional practices and academic literature. This is demonstrated by how the young respondents explained their identity, which ultimately depends on whether they meet the social, cultural, and political expectations associated with adulthood – as outlined by the neoliberal lens applied. Whilst the DPM should strive to provide an inclusive environment for young disabled people within which they may challenge this perception of youth, there is a substantial risk that existing influential members and organisations may act upon the current, dominant narratives associated with youth and adulthood and thus reinforce the neoliberal perspective. To challenge this, the Movement, as well as individual members, need to reflect on their practices and suggest methods and strategies both to disrupt this notion of youth, and to use such disruption as an opportunity to challenge wider ableist ideas.

This section of the chapter provides the introduction to how the concept of youth affects young disabled people's engagement with the DPM, as well as how established members articulate and define the purpose of young disabled people's involvement within the Movement. The research argues that the DPM must critique and challenge the current, neoliberal, ableist perspective of youth; to achieve this, however, very much depends on how young disabled people drive this need for change. Irrefutably, young disabled members of the Movement must be in control of raising and facilitating this debate, as well as of strategising and implementing the necessary actions. Attention is necessarily drawn to the existing framework of authority amongst members, as powerful contingents within the Movement may be a catalyst for or hindrance to this opportunity. The present chapter on youth membership will now review the second area to be discovered: that of authority.

5.3 Perception of Authority

The first key area was an opportunity to explore how the notion of youth has tended to fall within a dualism that promotes young people either as a problem, because they are incomplete adults, or celebrated because they possess a unique perspective that may supplement the dialogue and perspectives offered by established, older individuals. Although it should be argued that the notion of youth emerges by analysing the social relations between individuals and the various institutions that exist for the purpose of young, the focus is now on the emergence of power and of resistance. Here, I build upon the social movement literature associated with power and resistance to describe the respondents' views on the prominence of authority within the DPM – ultimately, to highlight the network of forces that affect young disabled people's position and status within the Movement.

The notion of authority became a key area of investigation, as respondents explained the power dynamics materialising at the very local level of actions and events. Rather than adopting a perspective that reinforced traditional explanations of power emerging through a top-down approach, the young people interviewed tended to frame authority as a phenomenon experienced through the interaction with DPM members at the grassroots level, for example, at local conferences, rallies, protest events, and repeatedly on social media platforms.

To understand this further, it is essential to explore the element of power and authority beyond the realms of the DPM; doing so requires recognition of the politics occurring within the daily actions and encounters between individuals and social structures. As identified in the first key area, the formation of an individual's identity is not established only through the forces and intensities associated with a specific social movement. That is to say, the DPM does not simply provide a space for the individual to understand their identity irrespective of the entire social world within which they exist; rather, the aspects of nature, culture, biology, psychology, and the social element produce an ever-changing world (Fox and Aldred 2016). Such spaces offer the potential to perceive and scrutinise power, demonstrating the continuities and fluxes within the relationships striving to exert control. All respondents referenced how their interactions with friends, family, employment and educational environments, media – and other settings – impacted upon their perception of power and opportunity to resist authoritarian practices. Kate, a young respondent, drew attention to this:

> My family was, is, very conservative […] and they are very much like, get on with it, chip away yourself, change things that you can but don’t be sort of out there with a chip on your shoulder […] that’s what my mum would see it as […] so I think it’s a big push for me to be quite vocal about rights, like at work they took some lockers away, and it took a lot for me to say “look this is ridiculous, you’ve got to do something. You can’t just leave me in this situation”. They wanted like security to help me with my stuff and I was like “you can’t disable me more than I already am just because it doesn’t quite fit your idea of where things should be.”

This focus on interaction with individuals and practices offers a reassessment of how young disabled people are currently positioned within the DPM. Whilst, through the social view on youth, it is perceived that young or new members are to be moulded by the ideas and actions of authoritative figures – typically, by established members – it became evident that respondents were conscious of their ability to affect one another's position within the Movement, to open up opportunities to encourage resistance, and to challenge the notion of power as residing within particular figures. As Kate suggests:

> I didn’t like the idea that people saw me as a bit of a troublemaker, making a fuss about nothing, wanting something special because of my disability, even though it is actually not something special, it is inequality. Erm, and I think that’s the same image that I’m worried about on social media. Erm, people who push their rights are often also heavily criticised by people who are obviously disablist or racist or against women or whatever, erm, yeah I just, I’m wary of that.

It became apparent during interviews with established members that, during their experiences of activism, some were dismissed because, as young members in the 1960s, ’70s and ’80s, they clashed with authoritative figures when trying to raise intersectional issues associated with disablement. As the Movement hierarchy of the time aimed to ground the DPM's objectives into a “Radical Structuralist narrative” (Goodley 2016), discussions of skin colour, gender or sexuality (to name but a few topic areas) would not be reflected in the dialogue. Marley – an established member interviewed – recalled:

> But, for me, the debate has been going on for over 20-odd years that I can remember around the understanding of disability and reminds me about when I was doing some studying around the […] the Union of the Physically Impaired Against Segregation. And this was the first time I came across Paul Hunt and some of the big ideas of disability movement and when I came across the like of Finklestein and Mike Oliver but, it has issues for me from […] because disability was seen as using the social model and not encompassing for me at the time, about my other identities that you know, of being black and disabled, or being a woman and being disabled, or being you know, gay and being disabled - it’s not as easy to see disability in those (*sic*) silo-type thinking.

Through the emergence of identity politics (Mollow 2004; Siebers 2013), the DPM does demonstrate the organic development of a social movement’s fluctuating and reacting to emergent issues by incorporating intersectional aspects highlighted through Feminism (Garland-Thomson 2005; Erevelles 2011), “Crip” Theory (McRuer 2006; Kafer 2013) and Race Studies (Asch 2001; Campbell 2008). The research argues that the frustration and rejection experienced by established members represented a change in the DPM's aims, objectives, and strategies, which became apparent in subsequent years. The intersectional aspects associated with the critique of internalised oppression led to a manoeuvre away from traditional Marxist interpretations of disability – from within the Movement – and ensured recognition of the difficulties associated with compartmentalising various forms of discrimination and marginalisation.

Currently, what is being produced and reproduced, from the perspective of young disabled people, is a level of authority that is reinforced by the acceptance and adoption of the social model of disability. The authoritative basis of the movement is, furthermore, affected by a hierarchal structure. Respondents from both groups acknowledged that members perceived as possessing power and influence benefited as a result of impairment-specific issues, social class. and family resources. Janet, an established member, explained:

> Young people are very much dependent on the resources of their parents and that's where the Disabled People's Movement needs to think a lot more about, unless a young person's parents have resources it will impact on what they can do or opportunities available to them. For those that have limited access to resources means they are less likely to attend meetings / events. A meeting was hosted in East London for disabled people. The event attracted a lot of young disabled black and Asian people and it was really good to see. I think the reason for this was because the meeting was brought to the people it was local and affordable to attend. One of the comments that came out of it was 'They liked that meeting because everyone shared the same interest'.

This demonstrates, though, the ease with which certain individuals are able to influence the decisions of others in ways that favour the will, interest, and values of those identified as powerful (Castells 2009). Such an assessment argues for power within social movements to be perceived as a relationship, dependent upon various aspects that produce the social world; on this basis, authority does not materialise through manipulation or conventional conceptions of human agency. Rather, it should be contextualised within the wider political, economic, and cultural networks that permit individuals to be perceived as authoritative. To change the current level of authoritarianism within the DPM requires a network of connections that challenge and disrupt the norms, personal and cultural contexts apparent at all levels within society. Reflecting on the example outlined, Janet states that young disabled black people were able to relate to one another and explore their shared experiences:

> They said it wasn't snobbery. Everyone could relate to one another. We came from similar backgrounds. We shared family experiences. But as we are talking about young people and when we think about the UK DPM it has very few

> young members and if we are to be honest it is disconnected from young people’s experiences. The world has moved on. There is a need for the DPM to start reflecting disabled people’s different lived experiences. Its worrying what the DPM future will be because if it is to continue then there is a need to create a space for young people. We have to move on [...] It’s not the ’50s or the ’60s or the ’70s! We need to see different faces and not a tick-box exercise, what tends to happen.

Disrupting the sense of normality, as a mechanism through which to stimulate discussions on power, authority and resistance within the Movement, also requires a review of the Movement's organisation and ideological stance towards challenging disablement: issues addressed in the next chapter. Respondents also explored the notion of “safe spaces” as a way of navigating the micro-politics and overt forms of authority within the DPM.

The opportunity to construct settings, those not directly controlled or substantially affected by the dominant forces, within a social movement allows individuals to establish and document their resistance towards those who perceive their activities and discourse as a threat or hindrance to the Movement’s progress. This research asserts that a safe space is not, necessarily, a response to the hegemonic ideas or identities existent within a social movement. A safe space is a demonstration that individuals are able to establish their own power and also possess the capability to resist. Scholars suggest that the essential need for safe spaces is to develop associations with compatible people and groups, within various locations, in order to challenge and seek change on specific issues – such as the discourse surrounding identity (Poynter and Tubbs 2008; Hunter 2008). Nevertheless, it is important to note that the position taken by this research is to explain “safe” and “free/open” spaces as one and the same entity, insofar as doing so explains the outcome as the emergence of spaces that offer alternative, occasionally contradictory, perspectives on disablement. Young disabled people wanted opportunities to explore disability issues without being challenged or perceived as a threat by established members. Their discussions, which fluctuated between the principles associated with structuralism and humanism, were felt to be constantly at risk of criticism or were otherwise used as evidence to justify the marginalisation of specific young members of the DPM from future activities. As Hillary, a young respondent, outlined:

> I think one of the things that the disability movement is struggling with at the moment is how to create space for new ideas and new people and new generations in a context where the people that founded a lot of these organisations and lead the movement are still alive and invested in what’s happening.

This had a substantial impact on young disabled people's experiences and perceptions of the DPM. Although many of the young respondents argued that established members possessed power and authority within the Movement, the safe spaces were environments within which to create a culture of self-respect, skills, and cooperative virtues – a setting that could permit young members to discuss with dignity and freedom, and be creative in their visions for addressing social injustice. There was a sense that the creation of open spaces for young people reinforced an appreciation of what it means to exist within contemporary society. Also, it permits an exploration of the different forces that produce the social world, along with an understanding of history. Irrespective of whether the discussions – within the spaces – navigated aspects of materiality, biology, psychology, society or culture, their realisation demonstrates a form of resistance by young people to challenge power through framing themselves as a group that refuses simply and unquestioningly to adopt and follow the dominant aims, strategies, and ideology of the DPM. This is relevant for social movements that are influenced and occupied by the founding generation, which according to Hillary is the case for the DPM:

> Most other movements have existed long enough that the founding generation are [*sic*] literally dead and buried, which means that there is less of a challenge when people want to do something different or challenge the principles that underlie something, but because the disability movement is still relatively immature, in terms of its age, at the moment, those kind [*sic*] of challenges could be seen as a direct challenge to an individual, rather than a challenge to a movement.

Young disabled members of the DPM seek to create the space either through fear of a reaction by established members or because of actual experiences of exclusion and marginalisation by specific individuals and organisations. This research suggests that the emergence and existence of safe spaces within social movements provide a clear depiction of the power and resistance emanating from members, as various forces are constantly affected by the action and reaction of social movement members. Young disabled people need, as has been stated, to resist and establish power within authoritative spaces as they seek to challenge and expose the various dynamics of control operated by existing, dominant forces. Whilst such forces may reside outside the DPM, the Movement is best placed to provide capacity and support for young disabled people to create the spaces both within and external to the DPM. Substantial, significant consequences regarding the status and position of young people within a social movement may result if action is not taken.

To expand upon this point, established members were asked during the interviews how they felt about the notion of safe spaces for young disabled people. Whilst there were elements of trepidation from the young people, predominantly because the existence of such spaces could be perceived as a challenge against individual members of the DPM, the established members were extremely supportive of the idea. Janet, a prominent figure in the Movement, argued:

> It's not the Movement principles about advocating for equality that needs to change. It's the faces that need to change. We need to make way for young people and there is a need to connect with their interests and experiences. There's [*sic*] people who are in the Movement who are not in tune with young people's reality. We shouldn't have a Movement which is poorly represented of different experiences. They need the space to explore their interests and ideas.

Similarly, Christopher – another established member in the Movement – advocated for young disabled people's having support to establish a formalised, separate network with a specific mandate to address and highlight youth issues:

> It wouldn't be easy, because the young people would need to take the initiative and I suppose, and within the structures we've got here at the moment, it would need to be done with either and perhaps [radical, political networks]. I'm not sure that all young people identify and align themselves with those groups. I mean, alternatively, I can't see why young disabled people don't create their own thing and just get on with it and you know, sort of, partially link up with some of those groups, there would be political differences.

For the young respondents, there was a sense of *double* resistance occurring through the use of safe space. They were resisting, firstly, in terms of a refusal to accept the explanation of disablement and the direction required to address disabled people's emancipation, which were predominantly being offered through engagement with established members or by exploring various literature sources. The second aspect of resistance was to the normative discourses deriving from biomedical, psychological, cultural, and social theories of disability, which – the research contends – attempts to position the disabled individual as needing to be healed, fixed and become normalised. By using a range of forces, such as social media platforms, specific literature, and collective formations, those interviewed were able to resist the power of particular belief systems – from members of the DPM to the wider social world. As Kate, a young member, explains:

> I suspect a lot of it comes about from social media to start with and then maybe they join a group of some kind and then get into it more real life type thing, as I like to call it, separating real life and internet. I think, again the key is just accessibility- giving young people the opportunity to physically access these things.

Young respondents spoke about how the spaces affected aspects of trust; they were able to discuss the significance of engaging with traditional charities – which offered resources, accreditation and skills development – whilst recognising that these institutions are regularly criticised by substantial contingents of the movement. As Regina, a young person, stated:

> It upset me that they made so many assumptions about us despite never speaking to us, never knowing us. We were judged for our association with the [traditional] charity and I think that is wrong. I think if that was a group of older disabled people it would've been handled in a very different way. And that has really imprinted on my mind - some of these groups like [radically, politicised group] that are very fucking judgemental and not understanding.

Those highlighting this issue acknowledged the detrimental impact of these organisations upon disabled people's emancipation. However, they were also capable of assessing the micro- and macro-politics surrounding their existence and used their resources in order to become effective campaigners and activists. It was noted that the safe spaces offered young people the freedom to analyse and critique various disability concepts with a feeling of liberation; there was less pressure to identify and engage with specific discourse, to adopt particular terminologies or align with particular ideals proposed by influential figures. As Regina suggests:

> [B]ut [radically politicised groups] do not have the right to dictate which charities people can or can't work with. I don't think [traditional charities] are part of the Movement, but as a newcomer programmes like this are a million times more accessible than just jumping in and joining a [radically, politicised group]. It's very structured and, despite all my issues with [traditional charities], it was a good introduction to activism.

The research indicates how the exploration of safe spaces, and the effect this exploration has on a young person's membership of the DPM, provides an insight that challenges the need to focus on an individual's agency when they are navigating the complexity of power and resistance. From this, attention is directed to the political level within the Movement.

Returning to the feeling of liberation: ultimately, the emergence of safe spaces was suggested so as to protect against the notion of failing to embody or display a certain identity expected when becoming associated with the DPM. Respondents expressed how it appears the Movement comprises and welcomes a specific group of people with particular political values. Failure of members to align with this composition results in the implementation of aggressive tactics used to dismiss and ostracise individuals. This point is discussed in the final area to be analysed in this chapter.

5.4 Trajectories of Membership

The final area of this overall theme is an exploration of how young disabled people established and recognised their membership of the DPM. Of particular interest is Tarrow's (2010) proposal that social movements struggle in their coordination and organisation because they are partly autonomous and self-determine their ever changing agenda and strategies. This raises an issue regarding how individuals become aware of a situation that requires action. Bringing people together to understand and articulate a common interpretation of the issue is dependent upon individuals' becoming conscious, as Rogstad and Vestel (2011, p. 249) explain, "when personal experiences change from being subjectively perceived to be interpreted as patterned, i.e. fitting into a larger collective horizon".

The investigation, then, aims to uncover how young disabled people recognise and explain the purpose of their involvement within the DPM; it also generates a discussion pertaining to how, as individuals, people recognise who is disabled – which, consequently, influences the perception of who is a “legitimate” member. During the interviews, young people expressed how organised routes for developing skills and becoming an effective campaigner, typically provided through user-led organisations or traditional charities, resulted in expectations that young people should develop and utilise planned strategies to challenge disabled people's marginalisation. Echoing the bureaucratic phase of a social movement’s lifecycle, offered by Blumer (1969), there was a compelling desire to adopt a professionalised approach to activism and social justice. As David suggested:

> I think […] personally I think my confidence has increased by working in the Movement and I think I am at the point now where I can stand up for my own rights if I think I am being treated unfairly and I can fight for other people as well and I think I have also gained a lot of useful skills to be professional from being in the Movement such as communication and listening also being able to clearly put my view across and being able to debate with people in a calm manner and being able to appreciate their views at the same time as being able to express mine in a professional manner.

Oliver and Barnes (2012), amongst other scholars, have raised concerns over the DPM's apparently becoming a contingent of professional consultants and governmental strategists. These authors argue that it has subsequently led to the demise and ineffectiveness of the Movement. For the young respondents in the study, the majority aimed to professionalise any attempt to campaign or to become involved in activism, and that this factor created implications for those perceived as not following such an approach. For example, some young respondents discussed the importance of operating as a disability rights consultant or striving to engage in advisory work with government departmental structures; equally, those who supported the professionalisation of their campaign activities argued the importance of gaining accreditation, furthering education and pursuing career advancements. They believe that such efforts would be advantageous in shaping the influence of the Movement. Members who and groups that rejected the notion of becoming professional were seen as being unable effectively to negotiate and tackle the issues affecting disabled people's participation and inclusion within society. By remaining at a grassroots level, and mobilising to challenge the networks of power that operate with considerable resources, there would be fewer opportunities to advance the aims and strategies of the DPM. The overall view of young people interviewed was to establish a means of working within the current systems.

This way, a level of legitimacy in the arguments and narratives presented by young campaigners and activists would be achieved. In order to encourage young disabled people to express interest in participating within campaigning and political activism, which would facilitate the further mobilisation and inclusion of members, the young respondents wanted to achieve recognition of their being valued contributors to the debate surrounding disablement. The challenge was not to harness considerable numerical support; instead, it should articulate those demands and ideas that would foster interest from others (Dryzek 2001). Here, young disabled people wanted to focus on the legitimacy of their arguments in such a way as to ensure that disabled people, either involved with or non-aligned to the DPM, were able to recognise the links between specific, emancipatory issues and the wider patterns of their experiences. As Mike, a young respondent, explained:

> When I start working with a new [disability rights campaigning] group, I don't know if you've noticed this about me, but I kind of take a, I kind of sit back first and see how the group is run and how young people are being involved and their own personalities and professional experience. Then, after a while, that's when I start putting more into the group and sharing my ideas. So I always like, I don't know if that's a comfort for me, but I always like to sit back in any group I begin working with and kind of thinking about new ways of working and thinking with the people who I'm collaborating with. Show them how it relates to my life and make it real for them.

This creates tension between how young members understood the purpose of the DPM, on the one hand, and on the other, how that is articulated. Historical and contemporary accounts of disabled people's participation are littered with examples of restrictive practices that prevent disabled people firstly from accessing prominent social positions or in turn from creating progressive change. For many established members, their trajectory included repeated attempts to express their ideas and demands against exclusionary systems and structures. The mere opportunity to articulate common exclusionary experiences through accessible mechanisms – such as personal assistance, easy-read information and assistive technology – became paramount (Barnes and Mercer 2005). By understanding the considerable oppression experienced by disabled people from the 1960s onwards, which necessitated the desperate attempts to organise and sustain the challenge of authorities, a somewhat dangerous disparity could emerge. Members and groups who focus on expanding opportunities for disabled people to have their views included within the wider discourse surrounding disability, predominately at a grassroots level, encounter those who prioritise collective action by adopting tactics to articulate demands and ideas in such a way as to resonate with the pre-existing power holders that have a clear influence over disabled people's emancipation.

To understand this further, I return to a point previously made in this chapter. It was interpreted that young disabled people felt undermined, patronised, and perceived as naive when engaging with certain groups and individuals within the DPM. This was recognised, by the young people, as a reflection of their journey to become aware and conscious of the issues creating and reproducing forms of disablement. Whilst the approach taken by young disabled people was to focus on specific events and issues by relating these to their own experiences and framing them at the personal level, they saw their involvement as being in order for them to gain further knowledge thus become representative of matters lying beyond the constraints of being labelled a young person. Age appeared to be a factor in how somebody was treated as a valued member of the Movement; this can be explained by considering how the Movement is perceived as a possession, owned and controlled by specific figures and established, influential members. Respondents recalled that they felt like new flag bearers: being captured by established members and used to their own advantage or being remoulded. Equally, new members were always seen as not understanding of the politics within the politics and, therefore, being manipulated.

This is significant for two reasons; on one level, there is a willingness to support young disabled people to have prominent positions within the Movement and become the next generation to take over the demands, aims and strategies. However, this comes with specific conditions; Hillary notes that there is a desire to "remould" the young person to reflect the aspirations and ideals held by the current, powerful members. It is an important distinction, as a young person will be supported only if s/he continues the work and legacy of the individuals who support their inclusion and involvement. Similarly, it is assumed that new members are not aware of or cannot fully comprehend the issues surrounding the politics of impairment and disability (Oliver 2013). Respondents from the established members cohort believed it is unhelpful to raise such agenda points when the DPM is addressing the inequity reproduced by the State and its subsequent use of agents and apparatus, referred to by this research as "dismissing the politics within the politics of impairment". When new members explore debates associated with this perspective, their comments may be perceived as a hostile attempt to destabilise any activities by the DPM. The latter point was also reflected in an interview with Robert, an established member of the DPM, who believes it undermines the social model of disability and hinders progress by activists:

> They fail to understand the politics of the politics of disablement within society where the social model has to be the core that placed disablement purely within the social sphere external to the individuals' bodies, so that enabled the complete negation of the social model but I would absolutely agree with the fact that it fucked all of us long term by enabling those who seek to undermine the social model for their own purposes not necessarily consciously but just to continue to practice the way they had, that was its achievement, and that was a significant nail in our [the Movement's] coffins and a significant nail in the social model.

Respondents understood that participating within the DPM opened up additional spaces for encounters to focus on the various perspectives to understand disability and to address the barriers for disabled people. For young disabled people to navigate the aspects associated with recognising the purpose of their involvement and addressing issues that arise from this notion of possessiveness by established figures, there is a need to expand on the notion of subjectivity. Those interviewed believe DPM members and organisations fluctuate between offering utopian visions for an accessible social world, responding to short-term and crisis-driven agendas and advocating for radical politics; this is reinforced in the literature, as scholars have argued for analysis of how subjectivity is positioned within social movements and, thus, meaning is created (Escobar 2008; Flynn 2016).

It is argued, through this research, that the DPM is attempting to navigate various discourses whilst attempting to remain as close as possible to the underlying principles, and sociological perspective, suggested by substantial contingents of the founding members. With the emergence of identity politics, which sought to disrupt the reductionist approach of operating solely within a binary equation of the disabled and non-disabled categories, the Movement has become more open, facilitating the inclusion of individuals from diverse backgrounds. Nevertheless, the Marxist frameworks and specific political ideologies, proposed by initial members and carried forward by certain factions, attempt to remain contemporary as the Movement maintains an association with Radical Structuralist tendencies (Tomlinson 2014; Goodley 2016). Although attention may be drawn to the setting where such subjectivities are supposedly created, it is the relational aspects between members that are of particular interest. By analysing how member interaction affects one another's social position within the Movement, it is possible to uncover how young disabled people perceive their responsibilities and roles – and, subsequently, suggest whether relationships between members are "antagonistic or supportive" (Bishop 2004).

Understanding disablement is regularly contested, which illustrates the contrasting opinions of DPM members. A fundamental aspect of this issue is the prominence of social model thinking and the substantial level of acceptance and expectation placed upon its incorporation into the DPM's aims, strategies and overall objectives. Respondents discussed the relevance of the social model of disability, with all articulating support for its effect on their personal liberation to articulate the barriers they experienced. Furthermore, this model was recognised as a tool through which to assess then demand changes within the social world, emphasising the need to address the social factors that caused marginalisation. As evidenced through this research, respondents were critical of the social model's definition and implementation by certain activists and campaigners; as a result, a section of Chapter Eight is dedicated to exploring how the model may be utilised as an oppositional device (Beckett and Campbell 2015). It became apparent, though, that the model was linked to an individual's purpose within the Movement. Respondents, particularly younger people, felt that it became a condition of their inclusion and participation within the DPM. Their responsibility was to promote the social model, with the purpose of raising awareness in disabled and non-disabled peers; similarly, they recalled how it is insinuated that their participation requires them to apply a social model perspective to all aspects of their work and campaigning. As Mari, a young respondent, explains:

> I feel I would campaign more than I have been with the support that can be the social model. I would campaign for more support, because if you don't have support to get out, or support like how the social model says that you wanna be in your day, then there's no point in actually campaigning. Because I was gonna say, if you don't have support to, if you need support to go outside, and you don't get that support to go out and go to a club or bar, your campaigning for everything to be set free, it kind of defeats the purpose.

Here, subjectivity emerges as a source of conflict and creativity (Razsa 2015), as young disabled people either embrace the expectations placed upon them by the Movement's hierarchy or else challenge the contingent through a critique or rejection of the social model, both of which have consequences for the young person's involvement and recognition as a member of the DPM. Effectively, the young respondents are attempting to seize opportunities to control how they are produced as subjects of a social movement. For young people involved with the DPM, the politicisation of their identity, and acceptance to adopt the social model as a strategy for inclusion, manifests itself as an attempt to change how politics are conducted throughout the social world. This, inadvertently, establishes new ways of explaining the meaning and cause of disability, providing young disabled people with opportunities to analyse and question the direction taken by established members. It is argued that becoming a member of a social movement necessitates a process of exploration and critique of subjectivity, referred to as the "subjective turn" in social movement literature (O'Sullivan 2012). All respondents acknowledged they were part of a process for envisaging and realising a different social world. Interviews with young disabled people detailed how their level of participation within the Movement – predominantly in relation to decision-making practices – needed to be addressed. The research suggests that individuals who want to identify as members of the DPM require opportunities to engage in a variety of mechanisms and methods in order to demonstrate their participation and involvement within the Movement. As highlighted in Chapter Three, emphasis is typically placed on social movement members for them to acquire the necessary resources and abilities to occupy locations, control positions and gain access to the decision-making processes at various levels within the social world. For disabled people, the inaccessible environments and normative practices negate such opportunities. Therefore, the DPM must have inclusive and democratic procedures that ensure its members are able to promote, suggest, and develop practices that are both valued and perceived to contribute to the politicisation of disability and the removal of disablement. Rose, a young respondent, suggests:

> Those things that young people, their experience is just as valuable and important, because they're the ones that you know, are gonna have live with the consequences of the absences of support. That is what you need and we need and I need to make people aware of […] I also think it's quite a big thing to expect a lot of young people to make those realisations and to have the knowledge that I've just talked about.

This quote draws attention to a specific issue affecting young disabled people as they reflect on their subjective position: the premise of a comprehensive, accessible strategy for the Movement. During this part of the interview, young respondents explained that membership implied they were expected to develop a comprehensive plan to address structural barriers associated with disability and youth, effectively tasked with envisaging a utopian future and identifying the steps to realise it. Whilst this expectation was not explicitly articulated by established members within the DPM, it was assumed that participation within social movements was for this reason. As Richard, a young respondent, states:

> I think that people that I would consider part of the disabled people's movement have probably already done or have some work to their name that says "I changed this", and I think maybe in that sense the disabled people's movement can be quite gated.

Arguably, this demonstrates the significance of previous comments on becoming a flag bearer. It implies that young disabled people, becoming active within the DPM, encounter two trajectories. Either they will be active by offering creative, unique suggestions for tackling inequality or once involved are expected to become a passive recipient of instruction and learn from established members, ultimately taking responsibility to advance established members' ideas. This illustrates the dilemmas surrounding young disabled people's participation within activism. The findings also imply that the Movement is positioned to provide answers to problems already identified; however, as the interviews demonstrate, there is ambiguity surrounding that assumption. The intersubjective relations between members means it is necessary to question the emancipatory potential of the DPM. The findings and overall analysis suggest the need for Disability Studies to explore fundamental questions, such as who participates, how a member is identified, and defining their affiliation to the social model of disability. Through the interpretation of the data, it is suggested that young people are restricted in exploring their own subjectivity, which affects their personal sense of meaning, and are therefore left to question the validity of their membership. This is because their involvement is predominantly based on their understanding whether the "community" of members has a shared or unified understanding of disablement, all of which is occurring whilst the DPM is assumed already to have formulated the problems appropriately. As Richard continues:

> I would like to define myself as part of the disabled people's movement, but I think that my involvement has come from my passion and my ability to speak about disability issues [which is not enough]. What I think I'm trying to get to I don't think that other people would define me as part of the disabled people's movement. I dunno. I'm kind of questioning everything right now.

From this, it is not suggested the DPM is in need of establishing a harmonious environment that obviates any form of conflict or oppositional ideas. Rather, it questions what form of leadership is apparent within the DPM and how a social movement may develop a community that seeks to sustain and encourage relations of conflict, as an attempt to facilitate critical discussion on the key issues encountered by the disabled people's community. During the interviews, the perception that social movements – those that emerge and promote libertarian and egalitarian idealism, and organise to champion a collective identity – are leaderless was scrutinised. Reinforcing points made by Gerbaudo (2012), respondents discussed how specific members and organisations appeared reluctant to be associated with the terminology of "leader", yet were instrumental in contextualising disability issues, framing the collective action required and encouraging participation from across the DPM. By articulating this as a form of reluctance it is implied the DPM operates with a form of soft leadership. It positions key individuals to establish a space for activism, enacting spontaneous reactions to pressing issues whilst perpetuating the romanticised myth that contemporary social movements operate without a prominent leadership structure. However, it was suggested a form of stealth leadership (Western 2014) was also apparent, as young respondents explained that other members denied any presence of leaders, though continuously acting on and promoting the demands and ideas offered by certain groups and individuals. As Regina, a young respondent, explains:

> I mean if they were truly democratic, and I think that's a good thing, but in my experience they aren't truly democratic, there are leaders, they just pretend there isn't and I don't think that is helpful because it's misleading and confusing. But, if a group was truly democratic and every member was equal, then I think that would be a really positive thing.

Through the emergence of new social movement theory, the opportunity for the DPM to explore new avenues associated with identity-based issues remains ever present; this is combined with the Post-Structuralist debates taking precedence with Critical Disability Studies – a discipline with a substantial impact on the DPM. Nevertheless, this is in opposition with the dominant practice within the Movement, which is to continue along the route of expanding on political subjectivity and implement social model thinking across all aspects of tackling disablement. The influential members within the DPM are critical of the competing debates associated with bringing impairment back into the debate surrounding disability.

The significance here is to highlight how the presence of leadership – either soft or stealth – affects young disabled people's involvement and interaction with the DPM. To achieve this, it is essential to focus on the politics emerging from within the DPM and assess how these have an impact upon the expansive discourse surrounding the "politics of impairment". The data, thus far, are interpreted as showing the DPM struggling to promote an united front, an inclusive environment for members, and to provide a space for extensive debates pertaining to disabled people's emancipation. This is because it is perceived to align with the characteristics reflective of new social movements. Such a perception is problematic as its foundations reflect Structuralist issues; also, dominant contingents of the DPM operate from within a Marxist framework. The historical developments within disabled people's activism has formulated a specific political subjectivity, rooted predominantly in class-based issues, but does not necessarily reflect the aspirations of and demands by young disabled people when they become involved in the Movement.

To challenge this, Campbell's and Oliver's (1996) claim that there is a substantial problem over diversity in the Movement. Whilst it is an issue echoed in the interviews, particularly from those who spoke about the intersectional aspects of their marginalisation, it is a prominent issue for young disabled people who believe the direction taken by the leadership orbits an elitist vision of what it means to be a politically active disabled person: notably, white, British, of higher educational attainment, and with a desire to be in employment. This reinforces aspects of the DisHuman, which seeks to resist this idealised depiction of the self (Goodley and Runswick-Cole 2016). The marginalisation experienced by those underrepresented in the Movement demonstrates how the DPM may inadvertently become exclusionary. Whether this is a result of how the social world produces and frames the priorities encountered by disabled people or is a reflection of how the Movement is organised will now be explored.

5.5 Conclusion

To conclude, this chapter has explored young disabled people's perceptions and experiences of becoming a member of the DPM. Through reflective interviews, young respondents challenged how youth is conceptualised and attributed to their participation and activities, which has consequences for their position and status within the social movement. Overall, the impact of youth identity upon the desire to engage in activism and be accepted by other individuals involved in the DPM was a significant focal point for those interviewed.

Such conceptualisation was established through an analysis of the entities that produce and affect the social world, questioning the impact of the education system, government support services, and medical practice to reinforce a perception of youth that is fundamentally associated with being passive and requiring knowledge. This key issue was also recognised by established members, who spoke about the need to develop open spaces that would offer young people opportunities to explore a diverse range of matters that have an impact on disabled people's route to emancipation. They include topics that would run counter to the dominant aims, strategies and agendas currently adopted by the DPM. Here, the chapter has focused on the notion of authority and reviewed the perception of power between members. This was analysed on the basis of the relational aspects between individuals. However, young disabled people's resistance to certain elements of the Movement was noted. Finally, young respondents explored the purpose of their involvement and there was an initial critique of how the DPM addresses leadership and organisational issues.

As evidenced throughout the chapter, the research argues that contemporary explanations of youth are rooted within the dominant display of normative practices associated with a neoliberal lens on the social world. This understanding of youth posits that young people are naive beings that require the support, order, and a specific regime offered by those found in experience and maturity. It became apparent, during the interviews, that this notion of youth is perpetually reinforced through the interactions and relations of members within the DPM. It is argued that young members of the DPM are predominantly involved when the agendas necessitate a youth perspective, or when the point of social movement legacy and sustainability becomes apparent. The research does not suggest that the DPM caused or created this understanding. Rather, the material entities and relations within the social world support and promote this representation, which continues when young disabled people engage in political activism and social movement activity. To challenge this, the research asserts that young disabled members of the DPM should be supported to challenge the existing authority within the Movement and develop safe spaces to explore and critique the various strategies, agendas, and ideas found within the Movement's discourse. If achieved, it would positively disrupt the wider consequences associated with framing youth, as well as provide new and cohesive strategies to include younger members within the DPM.

The next chapter details the respondents' accounts pertaining to organisational aspects of the DPM.

6. Organisational Aspects of the Movement

6.1 Introduction

This chapter explores the challenges identified by young disabled people in the context of how the DPM is organised around specific ideas. The chapter argues that the emergence of interlinking movements reflects the concerns experienced by activists and scholars regarding the approach taken by the DPM to address disabled people's emancipation. This highlights the limited potential of a rights-based approach; further, it questions the effectiveness of the DPM, as contingents and members seek a professionalised role and collaboration within the current governmental infrastructure. With the social model of disability remaining at the core of the DPM, it is clear how this concept facilitates the collaboration of disabled people to unite; however, its influence as a vision for social change requires consideration. This is because young disabled people perceive it as a condition of their inclusion within the Movement and they are unable to question or critique its parameters, with such activity being regarded as an attempt to dilute or weaken the model's position. The present chapter initially explores the recognition of interlinking movements, which coexist and draw attention to the competing discourses associated with the overall purpose of the DPM. Secondly, it discusses the influence of social model thinking and application within the DPM's organisation, direction, and agendas. Finally, the chapter explores the significance of socialist ideology within the DPM and how this affects young disabled people's participation in and access to the Movement.

The analysis and discussion of this overall topic reveals the reactions from respondents when asked to critique how the DPM is produced and reproduced in the social world, and how the organisational entity of the Movement affects the various matters of power and resistance.

6.2 The Emergence of Interlinking Movements

When discussing the premise of a movement established by disabled people, one set up to campaign and advocate for disabled people's emancipation, the terms “Disabled People's Movement” and “Disability Rights Movement” were used interchangeably by respondents. Academic and “grey” literature is also replete with reference to both phrases (Winter 2003; Lawson and Gooding 2005; Iriarte, McConkey, and Gilligan 2016); however, there is a significant lack of research and analysis to determine whether there is a substantial, significant difference between the two. Furthermore, the current research found that respondents indicated several reasons as to why the Movement exists. The significance both of a rights-based approach and of a Movement that has sought to demonstrate commonality among a group of people disabled by the social world was highlighted, along with the importance of allies and developing a sense of pride, as well as the approaches taken to establish practices that would address marginalisation.

This should not be perceived as isolated social movements' attempting to dominate or eradicate the existence of other approaches. Rather, it is to recognise that there are differing positions taken within the Movement. Therefore, each respective position cannot be summarised in one specific approach or organisation, although commonality is found in the identification and articulation of disabling barriers. The recognition of oppression experienced by the individual or collective requires activists and campaigners to demand change, whether – for example – through the existence of support packages, access to an inclusive education system, gaining meaningful employment or the freedom to explore their sexuality and the forming of relationships. This goes some way towards illustrating the heterogeneity of the members, with their different histories and identities, and how the directions taken by members are not segregated; they do not operate in isolation. Some activists and campaigners will propose and implement resistance-based practices and others may call for radical change, arguably rooted in a specific political ideology, yet the actions and focus of the membership overlap to a greater or lesser extent. As a result, the Movement comprises interlinking movements, as shown below:

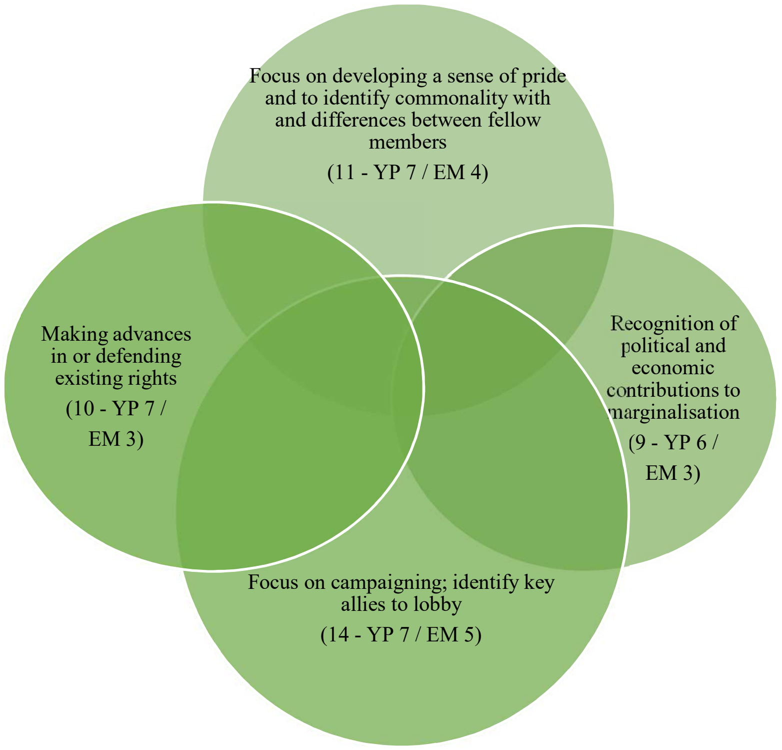

Figure One: Venn diagram illustrating direction taken by the Movement to address the premise and extent of disablement (Respondent Numbers – Young People / Established Members)

During the interviews, respondents were asked to provide their definition of the DPM. It transpired that two different terms are used interchangeably: a “people’s movement” and a “rights movement”. Whilst this aspect is explored in further detail below, the interviews were an opportunity to understand how it is perceived that the Movement focuses on specific issues in order to address disabled people’s marginalisation. Such issues formed the basis of the DPM’s integral role. Respondents were asked to articulate the overall direction taken by the Movement, as they saw it. Figure 1 (above) provides four key themes that emerged during the analysis of the interview data: rights, political and economic structures, identity and disability pride, and the importance of campaigning and building alliances.

The complexity surrounding how the DPM is perceived became clear. As opposed to understanding it as a homogenous entity, having a uniform commitment to understanding the problems surrounding disabled people’s social position and the action required to create positive change, the DPM is multifaceted. It is a reflection of disabled people’s shared experiences and awareness of the intersectional aspects associated with their existence and participation in the social world. The nature of interlinked social movements draws attention to the intersection between traditional class and social issues, alongside an acknowledgement of identity politics. Reinforcing points made in Chapter Three, Figure 1 illustrates that the DPM is unable to embrace a singular cause for the experience and reproduction of disablement. It is a social movement operating on a platform of various causes and rights-based issues, aspects that transcend the assumed divide between traditional class and identity issues. Although respondents noted the term “DRM”, the focus here is on understanding the organisation of the DPM. The four circles together produce what is referred to as the DPM, with each circle providing a direction for the Movement to follow in order to realise disabled people’s emancipation. Each circle also provides an insight into how individuals come together to form groups, networks, and potentially separate social movements, on specific issues. As identified during the interviews, activists and campaigners will join more than one circle. Respondents explained that the Movement and their connection to it meant that they focused on one or more of the directions outlined, depending on the topic under investigation. For example, the DPM would not be sustainable without a focus on establishing alliances and campaigning to raise awareness; yet, at the same time, there is a need to support disabled people to politicise their experiences and to develop in them a sense of pride to ensure the DPM was valued, respected, and pertinent to the lives of disabled people.

The position of the circles is significant, as the element within each circle was often scrutinised by the respondents. There is indeed overlapping among the different points, demonstrating the need to take multiple approaches to address disabled people’s experiences of social oppression. Parts of the circle, though, remain separate; their separation illustrates the frustration and discontent of some activists, who argue that the actions of the Movement are undermined if contrasting positions are adopted. A comparison between the issue of rights-based approaches, on the one hand, with the significance of overhauling the political and economic structures within society, on the other, is positioned in order to demonstrate that a small number of respondents recognised the importance of improving current legislation whilst, at the same time, illustrating how disability manifests within the current economic framework. For others, who identified within that circle, it was nonsensical to take a position of wanting radical change within political and economic structures; they would prefer to attempt to pursue change through existing legislation. Such dichotomy demonstrates diversity within the Movement, but it is also a realisation of the fragmented nature within the DPM – which comes as little surprise, considering the stages of collective action suggested by Blumer (1969).

Although the diagram complements the work of scholars who argue for social movements to be perceived as interlinked networks, such as Escobar (2003) and Castells (2015), there is a need to locate the diagram alongside the findings outlined in Chapters Five, Six, and Seven. Social movement scholars suggest how the interlinking capacity of social movement networks is sustainable on the basis of the network's accessibility to newcomers. The current research has, in contrast, identified that young disabled people feel excluded even when attempting to join and participate within the DPM. The findings presented in the diagram are a call for further discussion regarding why people feel excluded when attempting to join social movements and why established members may appear intolerant of newcomers. To achieve this understanding, there is a need to position such a discussion as part of an extensive approach to archiving key aspects of the DPM, to illustrating why such directions emerge, to identifying why there is frustration and intolerance amongst the membership, and – most importantly – to clarifying why disabled and non-disabled people should care about the Movement. This is explored further in Chapters Seven and Eight.

The interviews offered individuals an opportunity to explore their interpretations of the terms DRM and DPM, determining whether they are actually distinctive social movements. If so, the consequences this has on advancing or defending disabled people's rights. The literature of Social Movement Studies argues (Juris *et al.* 2012; Sciubba 2013; Fadaee 2015) that a rights-based approach is necessary to challenge the power imbalances between different groups. Doing so may take the form of local organising, collaborative working to establish alliances, and the expansion of networks to create different strategies. The DPM is viewed as an entity to re-energise the opposition to disabled people's marginalisation, drawing attention to the exclusion and – in some circumstances – brutality experienced by disabled people. As the data and expansive literature show in Chapters Two and Three, the Movement is centred on an overt platform of political activism. However, questions exist over a structured framework for participation, and raise concerns that substantial contingents of the Movement are unable to deliver their ideas and viewpoints. Instead, the ideas and narratives offered by influential figures persist, with little opportunity for them to be challenged.

The existence of interlinking movements was a discussion point throughout all interviews. It became apparent that competing discourses suggested that the Movement was grappling with both a focus on advancing disabled people's social position and the need to defend existing achievements gained through various national and international legislative frameworks. As a result of the disparity between those who perceive it from either the lobbyist's or the protectionist group's viewpoint, some respondents explained the DPM cannot have a singular description, given that it is based on the differing interpretations of its members. The DPM may be perceived as a campaigning group to advance or advocate for disabled people's rights; simultaneously, it operates as a support mechanism for promoting the aspects of pride, liberation, self-assertion, and self-confidence (Morris 1991; Corbett 1994). Hillary, a young respondent, outlined the intrinsic difference between a rights or people definition:

> I use the same interchangeably. If I was being very philosophical, I would potentially say the Disability Rights Movement can be inclusive of allies, just by virtue of how it's worded, whereas the Disabled People's Movement kind of implies that you have to identify as a disabled person in order to be part of it and actually very few people identify as a disabled person. So maybe 'disability rights' is a better term to use, because it opens up the Movement to more people, but I use them both interchangeably.

Here, Hillary argues that framing the collective membership as a DRM permits the inclusion of allies who would not define themselves as disabled people; this is in opposition to the DPM which, from Hillary's perspective, is a selective group of activists and campaigners brought together through their shared identity as disabled persons. Such a position proposes the DRM as a progressive force for raising the consciousnesses of disabled people and those who side with the oppressed. To draw upon the words of Biko (1978, p. 92), "The most potent weapon in the hands of the oppressor is the mind of the oppressed"; thus, the DRM organises a space in which to stimulate resistance-based practices (Prince 2016), with a focus on supporting disabled people to overcome the sense of inferiority and fear propagated by those with considerable power, including at the local, grassroots level. The "power" aspect is also considered in Chapter Three, which includes consideration of how new social movements focus on resistance. Here, it calls for the inclusion of allies directed towards improving disabled people's social position. By conceptualising the Movement as one that focuses on disability rights, rather than merely on a collection of people, it reinforces the notion that – to take inspiration from Biko's writing – disabled people are not appendages to the ableist society.

Seven of the eleven young disabled respondents shared thoughts similar to Hillary's. For those who did not articulate a similar perspective, the need they saw was to recognise the DPM as a politicisation process experienced by members for them to understand disability and to explain how disablement manifests within the current political structures. For example, Rose argues:

> I suppose the difference may be the politicisation of those involved to some degree, ’cos those that would identify as members of the disabled people’s movement, who’ve had a particular experience and they reflect on it in a very specific way, that makes them very political and stick to their principles and stick to their guns and say specific things.

It was important to acknowledge the existence of interlinking movements, as these provided different positions to access depending upon the individual’s sense of identity, their understanding of activism, and their aspirations for the future. The DPM is perceived as a sanctuary, a safe space for disabled people to reject the marginalisation and seek hope, guidance, and support to achieve emancipation (Swain and French 2001). This is problematic because of competing discourses offering different ideas and perceptions to explain the experience of disablement or to recognise the existence of impairments and health conditions.

Young respondents were not critical of the existence of interlinking movements that focused on a rights-based approach and a collective, political movement comprised of disabled people. For example, David suggests:

> For me, the main difference is they are coming from different points of view and opinions, but they are still trying to achieve the same aim.

David recognises that different approaches are taken to articulate the notion and experience of disability; he argues that they are directions seeking a common purpose, which is to address disabled people’s marginalisation. Whilst it may be possible to articulate the different focuses and strategies used, it also acts as an opportunity to further the inclusion of new members and advance emancipatory practices. This was so in the case of Margaret, another young respondent, who believed the Movement should be comprised of a community that supported one another:

> The movement is something that should become extremely kind of supportive and positive […] it’s a hub for those people to share ideas, to support one another, to rally and to campaign and to basically do whatever they can in order to embrace what it is to have a disability, but also push for the correct rights, responsibilities, recognition.

Margaret illustrates the various ways in which the social movement can generate change, whether through supporting its members to build solidarity or by establishing what is required to raise awareness of the issues faced by disabled people. She also recognises the need to articulate a rights-based approach, but, at the same time, suggests caution because legislative action can only be realised if there is a sustainable and effective desire to improve social conditions:

> [B]ut I believe that you know, you can have all the rights that you want in the world, but without the awareness and the recognition and the representation, really sometimes, the rights on a piece of paper mean very little.

This focus on rights, which underpinned much of the discourse pertaining to the existence of interlinking movements, was a point of concern for the established respondent group. Most notably, those who identified as materialist thinkers or Marxist followers challenged the prominence of a disability rights approach, as it weakened the demand to explain disablement through social structures; furthermore, a rights approach placed emphasis on the need to explore the intersectional aspects associated with identity, and potentially to celebrate rights, as a mechanism through which to address inequality. This is reflected in the Disability Studies scholarship, most notably from historical materialist perspectives, which argue that the demise and fragmentation of the DPM is a consequence of the over-reliance by disabled activists on addressing matters of social inclusion through utilising legislative frameworks (Oliver and Barnes 2006).

Robert, an established member, noted the criticism levelled towards the DPM, particularly as the organisation struggles to appear flexible, to accommodate criticism, and to organise resources to facilitate the emergence of new ideas. He starts by suggesting that the emergence of different directions taken by activists has resulted in a failure to create solidarity or to mobilise support throughout the social world:

> Our fault for what we did, through failing to mobilise the wider community of disabled people, but more fundamentally the non-disabled community; we failed to achieve any significant in-roads and until you could bring in significant numbers of the wider community you are doomed. We enabled them to escape any real engagement by allowing ourselves to undermine the social model, be that key individuals or whole atmospheres or academics or whatever; so we have to accept that it is our fault.

He argues that action taken by the Movement has ultimately led to a weakening of the social model, not necessarily by questioning its usefulness, but by failing to attract new members. Robert’s point regarding how individuals struggle to engage is reflected in the previous chapter. Young disabled people expressed how it was problematic to explore the possibilities and implications of social model thinking, ultimately leading to a struggle for them to participate in the DPM. From Robert's perspective, the failure to build engagement with the wider community is a consequence of the model’s proceeding through various debates while lacking an agreed position on its application to address a disablist society. This has resemblance with points made by Marley, another established figure, who believes the model has been, as it were, lost in translation and is embraced by the DPM in a tokenistic way:

> As a buzzword, the Movement embraces the social model. It’s when you speak to certain people in the Movement who say they belong to the Movement and how it’s interpreted and applied, then it gets lost in translation. And there’s not a consistent interpretation of the social model, for me.

Robert continues his perceptions by not discounting the oppression produced by social structures. However, he advocates for activists to take responsibility, to challenge the significance of and desire for “normality”. A sense of “normality”, which positions disabled people as deviant and a hindrance to the functioning of the social world, can be addressed only by producing radical change that critiques the actions and behaviours of beings within wider society. This reinforces points made by Regina (in the previous chapter), who calls for the social model to be utilised as a mirror to showcase disabling practices produced by everybody. Robert states:

> That doesn’t mean society isn’t doing it to us, but actually we played the key role, the key role in screwing ourselves […] Actually you can make really radical stuff because the powers above don’t watch it and they don’t care what you do, so do something interesting, do something radical, do something challenging because they don’t even know you exist, so why are you still kind of trying to parody and mimic normality, they don’t care.

He believes that creating political and economic pressure will establish different social conditions for creating a diverse and inclusive society. To achieve these conditions, he calls upon activists to use their ideas and skills to occupy the public space and demonstrate radical action. Robert believes that the space used by activists is an area of tension for the public. He questions why the DPM should seek to collaborate and build dialogue within existing power relations, as this ultimately leads to becoming incorporated within a system that undermines disabled people's striving for emancipation. The danger of this is understood by recognising how dominant ideologies outline and produce existing ableist notions of citizenship, democracy and humanity.

Although forms of resistance may be maintained by pursuing dialogue with those who have considerable power, Robert argues that attempting to navigate within a space comprising deliberation and radical activism will lead only to failure for the DPM – highlighted in the "doomed" comment. Radical activism necessitates moving beyond attempts to access an array of rights (Peled and Shafir 2005) and should question how society is organised. At this point, it is worthwhile noting that Margaret, a young respondent, raises concern over how the DPM articulates a call for change. She is concerned that aggressive, radical demands may lead to disabled young people and non-disabled people being reluctant to engage:

> It puts people off whose minds we're trying to change and that's really, really important. Because let's face it, there's a bloody much bigger percentage of people who aren't disabled than who are, and we need those people on our side. And I think that sometimes what we are in danger of doing, is frightening those people and putting them off, rather than encouraging them to join the cause. If we really want this movement to go anywhere and get shit done, we need to be treating it with care.

Robert, however, is persistent and highlights that the failure of the DPM, and the significance of a rights-based approach, is due to people's demanding a recognition of normality and value within existing systems, rather than critiquing existing structures:

> They end up being trapped into wanting to be normal as opposed to being valued and different. They want their share of the normalised cake of society and my argument would be they need to be aware that they're not going to be and they are not even if they think they are, they are just tokens in a kind of social gain of both normal people's minds, years of state and social practices […] no way is there any real degree of equality happening there.

The research argues that "State and social practices" refers to the emergence and infiltration of neoliberal and capitalist ideals of citizenship, adulthood, work capability, and responsibility, meaning these practices strip away the value of difference, dignity, and recognition. This raises concerns that a rights-based approach is meaningless. Instead, members of the DPM need to determine why non-disabled people drive for a sense of self-worth and value within the current neoliberal framework for understanding these ideals. Such an approach will reposition the status of disabled people and offer the potential to destabilise the structures of society.

The position taken by Robert is a focal point within scholarship; Springer (2016) argues that neoliberalism has considerably devastated our social world and continues to affect all aspects of daily living. Political mobilisation and social movements must not adopt a strategy that fails to acknowledge the impact of the dominant forces benefiting from neoliberal influence, as doing so would further obstruct any potential challenge or development of resistance (Graeber 2009). The validation of Robert's point may be found in the writings of Purcell (2016), who advocates for the need to turn away from current behaviours and actions established through neoliberal rule. Furthermore, Purcell suggests that anyone wishing to challenge the current structures should be supported to recognise the extent of its effect on the social world. Although the premise of economic and political frameworks are key to Robert's analysis of the DPM, Robert's words are interpreted as a call not only to challenge, but also to explain the fundamental basis of such frameworks. By challenging the interactions between social movement members, as well as the implementation of policy initiatives at a macro level, Robert argues the Movement is disintegrating because of the desire to position disabled people as wanting change within the confines of the existing system. This will lead to minute advancements yet will not address the issues affecting the majority of disabled people:

> The movement was basically destroyed by disabled people being complicit with a superstructure that was much more able to identify what it needed to do to negate any significant structural change in the way society works in relation to disabled people […] I would argue and I think what we have ended up with is kind of a minor incremental [change] that only really benefits an elite few which it tends to be more educated middle-class people, like me and you, whilst the rest are fucked.

This critique of a disability-rights approach was not shared by all established respondents; others suggested the emergence of a rights-based approach was intrinsically related to the rejection of a charity and medical model explanation of disablement (Haegele and Hodge 2016). Jukie, an established member of the DPM, recognised the disability rights approach as a natural progression; she argued that interlinking movements had emerged because of younger disabled people's articulating demands different from those of established, influential figures within the DPM. To understand this further, Jukie reflected on the history of the Movement and noted how established figures are concerned that young disabled people would not align their demands with historical agendas:

> I think there are some people mistrustful and they feel like you're letting the side down or something and like, the old guard are deeply suspicious of that kind of conversation […] I do think those conversations are beginning to be had but I think the old guard remain deeply suspicious. But I think bit by bit, you start to make changes because the discussions are happening, they're happening in people's living rooms.

Jukie alludes to the importance of members' connecting together and brokering dialogue within public and private spheres. Opening discussions within people's living rooms suggests members are building networks within the DPM, irrespective of the organisational aspects that may historically have kept such actors apart. This is significant: occupying such spaces, and ensuring established social movement figures prevent disconnect between members, certifies that new connections are made and networks remain established beyond the initial introduction. Although Jukie recognises that "the old guard remains deeply suspicious", this could be a reference to the expected development of subgroups that emerge within these private encounters. Initiating contact, and the provision of accessible environments that foster discussion regarding disabled people's life chances, ties members together through their common claims and familiarity with one another. This is reflected in the work of Krinsky (2010) and Krinsky and Minsche (2013), who investigated how social movement and non-movement actors connect to each other to articulate specific claims about social justice issues. The historical developments within the DPM illustrate how common aims and solidarity emerged between various groups with differing experiences of health conditions, impairments, and neurotypical labels. For Jukie, this is an opportunity to recognise how people engage with the Movement from different backgrounds:

> But it excites me and again, maybe this is just because of where I began in the movement, right at the schism between those of us who were, had acquired impairment and those who were born with impairment and the other splits in the movement between those with physical and sensory impairments and those of us who were lunatics and given psychiatric assessment, do you know what I mean?

Of further note, it may be assumed that discussions emerging from "people's living rooms" will be a reference to the inaccessibility of societal environments encountered by substantial numbers of disabled activists and campaigners. Discussions are confined to the somewhat accessible infrastructure of an individual's home. Nevertheless, as recognised in the previous chapter, young disabled people are concerned with how their views and ideas could be interpreted as criticism directed towards influential and established contingents within the Movement. It is suggested that the private space is occupied in order to satisfy Movement networks' demand for a level of secrecy as the specified network goes through a process of stabilising to become an effective entity (Crossley *et al.* 2012).

Jukie documents the collaborative actions of disabled people, including of individuals with hereditary impairments, of individuals who acquire notable health conditions, and of those who reclaim the language of "madness" in an attempt to challenge the professionalised development of services – a point reviewed extensively in contemporary literature (Beresford 2000; McWade, Milton, and Beresford 2015). The opportunity to bring marginalised people together, from the disability arts forums, mental health survivor networks, and DPM, was not only an attempt to address solidarity; also, it led to the development of definitions to explain disability beyond physical impairments. According to Jukie, social movements organised by individuals resisting mental health practices were not aware of the social model of disability and were reluctant to embrace the advancements that could be made by politicising their experiences:

> People who had been through the psychiatric system didn't quite have the same understanding of disability and it took them a while to actually get on board and go "oh yeah, absolutely, I get it." Disability, if we're thinking of it in a social model, we're totally disabled by these ridiculous psychiatric records […] but this allowed for all sorts of disability arts. They started to embrace each other's culture, embrace together in actions and various kinds of motions that were going on at the time. Working together made a much stronger movement and kind of feeding into each other's activities and cultural kind of movements just added texture and breadth to our own identities.

Throughout her activism, disability arts was a by-product of the different social movements, occupied and controlled by disabled people, exploring cultural elements associated with disability. Whilst this was an attempt to create solidarity, by exploring the intersectional aspects of identity, it also highlighted the emergence of interlinked social movements.

The historical account of interlinked, and somewhat fragmented, movements, and the suspicion amongst members, offered by Jukie was also reflected in contemporary examples by the young respondents. In discussion with Jeremy, a young respondent who self-defines as having autism, a significant part of the interview was dedicated to exploring the separation between the DPM and the “neuro-diverse movement” (Jaarsma and Welin 2012; Singer 2017). Whilst Jeremy acknowledged that issues surrounding neuro-diversity are embraced, to an extent, by the DPM, there is a significant community of prominent autistic people who are distanced from the DPM and do not associate with the strategies, demands, and aspirations of that social movement.

> I don’t think the autistic movements are as particularly as activist-driven or seeking of change as perhaps people with disabilities at large are - how they formed can differ quite dramatically.

When asked if he identified as a member of a social movement, Jeremy stated his desire to belong to the DPM, but that he was unsure whether he would be perceived as a valid member:

> I definitely identify myself as part of the disability rights movement, but whilst I would say in principle I would identify as a member of the DPM the reality is I don’t work with the [*anti-austerity groups*] or grassroots movements so it’s a lot harder for me to say that I am part of that Movement.

Jeremy’s comment reflects points made in the previous chapter, which alludes to the challenges faced by young disabled people as they attempt to engage with groups committed to political and economic changes. Here, Jeremy aligns himself with a rights-based approach yet aspires to identify with a Movement that recognises the commonality amongst disabled people. He realises that this aspiration is problematic because, from his perspective, he is not connected with prominent organisations or individuals occupying such agendas.

Jeremy moves on by offering a critical view of the current autistic people’s movement. He perceives it as one tending to be monopolised and controlled by parents who – to a large extent – focus on addressing discrimination through medicalised initiatives and demanding the involvement of professionalised practitioners and services which promote the vulnerability of everyday living:

> [A] lot of the autistic movement wasn’t actually formed by people with autism *per se* but their parents. A lot of the focus around autism is on growing up and how parents can adjust to that; I mean if you look at [*a national charity*] which is the largest autism-based organisation or charity, the activist element is more parents and sort of coming to terms of a child being or having autism and you know there is also those sort of movements set up looking at a cure to autism.

For Jeremy, the inclusion of autistic people within a Movement, and specifically one founded on the idea of disabled people's taking action and controlling agendas, requires one to identify as a disabled person; this is problematic, given that interactions with education and welfare services may result in an individual's not accessing support and, therefore, not being perceived as a disabled person:

> I think a lot of milder forms of autism are still, you know, not necessarily eligible for things like welfare benefits in the first place. Anyway, so people do end up finding jobs and being supported by the family or something like that.

Barnes and Mercer (2005) argued how the expansion of welfare provision, including its association with contemporary economic principles and concentrated power for professionals, has resulted in the eligibility criteria's providing a definitive answer as to whether somebody is disabled. Arguably, the DPM must challenge this: the policy for personalisation has reinforced an individualistic account of disablement (Sapey 2010), problematic for those unable to access services. No access can lead to the individual not identifying as a disabled person. Jeremy believes this has an impact on young disabled people's aspirations to join the DPM; they have a reluctance to participate because their own understanding of disability is influenced by practitioners and structures encountered throughout their life.

This issue is further complicated by suggestions made by all of the young respondents that the DPM is not inclusive, as was mentioned in the previous chapter. The majority of young respondents interviewed distinguished between the differing directions taken within disability activism. There was recognition of how social movements position themselves *vis-à-vis* the State, including how a focus on rights necessitates a lobbyist approach. Lobbying may lead to supporting the State in developing and implementing policy initiatives that are rooted in improving legislation and raising awareness of disabled people's existing rights. Nevertheless, the nature of interlinked movements meant that language to describe activity and direction differed; it left young disabled people "lost". As Mike, a young respondent, suggested:

> Sometimes it gets confusing to me because I've also heard of the self-advocacy movement and the disability movement and the disability rights movement, so it doesn't all roll into one, if that makes sense? It sometimes gets confusing, which terminology to use.

The DPM was described as, predominantly, being associated with protesting, aligned with trade unions and certain positions on the political spectrum. Whilst a People's Movement prioritised aspects of welfare reform and social security, a rights-based approach was acknowledged as progressive, appearing receptive and inclusive in supporting members. Taking account of the initial research question, the interviews focused on an exploration and critique of the DPM. It became apparent that respondents believed the Movement was founded on two fundamental pillars – the social model of disability, and a political ideology associated with the left of the political spectrum.

6.3 The Significance of a Legacy

Arguably, many of those recognised as current pioneers and established figures within the DPM were integral to its initial development and organisation. Therefore, the current leadership and direction of the Movement is still influenced by representatives of the founding generation; the agendas and strategies adopted are still dependent on specific individual association with certain topics. This is problematic for those who reject or criticise the political affiliation of the dominant figures within the DPM. According to Slorach (2011), the separation between impairment and disability, made explicit through the UPIAS (1975), was developed by committed socialists; furthermore, the initial development of the social model of disability and – to an extent – the wider analysis of disability and social oppression were inspired by Marxist theoretical frameworks.

The influence of socialism within the DPM is not without criticism. Most notably, campaigner Simon Stevens (2013; 2018) has indicated that control of the Movement predominantly rests with those claiming to be aligned with socialist ideals. In recent years, influential organisations such as Disabled People Against Cuts (2015) have appeared both to back and to gain support from political leaders associated with the resurgence of socialism in contemporary politics (Hattersley and Hickson 2013; Honneth 2016). According to Crowther (2016), however, this will not result in a progressive disability rights agenda because it will, ultimately, weaken the DPM. The arguments put forth by Crowther, Stevens, and others, are weak. They fail to recognise the complexity surrounding political representation within social movements. As evidenced by Barnes (2007) and Morris (2011), the DPM has championed an agenda of rights that includes practical solutions such that disabled people may take control of the support used on a daily basis.

Given that this research explores the challenges offered by disabled people's social movement members as they attempt to engage with and influence the DPM, it was deemed appropriate to discuss the significance of social model thinking and political ideology within the DPM. Notwithstanding the importance of the social model as a heuristic device to capture the demands of disabled people and direct attention on the material barriers, this research argues – through the interviews and supplementary literature – the Movement is founded on a politicisation process for the individual, as well as the collective. The perception is central to the organisation of the DPM, thus it requires examination to determine how the legacy of the social model and entrenchment of specific political ideals affects young disabled people's experiences.

6.3.1 *Social Model of Disability*

In the previous chapter, the significance of social model thinking was outlined; respondents indicated how the model could be exploited to exclude individuals who questioned its validity. Furthermore, established members within the DPM were concerned how the social model could be destabilised if substantial challenge manifested with minimal consideration for a contemporary "politics of impairment" (Soldatic and Meekosha 2014). Here, it is useful to start by focusing on what young disabled people thought about the significance of the social model of disability within the overall organisation of the DPM. According to Regina, a young respondent, who recognised the influence of the social model:

> I think the social model is the cornerstone of the Movement. Everything revolves around it and it's a massive part of the culture of the Movement. It is important to me as an individual, it's central to everything I do, my work, my volunteering, my activism, and my friendships with disabled people.

For Regina, the use of the word "cornerstone" is significant. Previously, it was identified that the model is recognised as a foundational idea, one that has generated action and demands that centre upon this shift towards those societal responses and recognition that create the experience of disablement. Regina nevertheless highlights its influence upon the creation and development of social networks, as it provides a common point upon which to build solidarity and support amongst disabled people committed to emancipation. When asked to consider whether people who do not support the social model would be included within the DPM, she argues:

> I imagine if there are medical model theorists in the Movement they'd be on the outskirts, but I've never come across any myself. These people seem to have been absolutely oblivious that the movement even exists. I mean I got involved before ever knowing that the term 'social model' existed, but I still embraced that culture of wanting to change others and not myself […] I think they would be quite excluded because they don't have the same definition of disability as the majority of the movement.

It may be argued that Regina does not suggest dismissing the significance of the social model, nor is she proposing that the DPM distance itself from such a perspective. However, she does indicate that people who focus on the biological limitations of the body are oblivious to the activities of the DPM; they would be excluded because of their reluctance to adopt the social model description of disability. Such a description, according to Regina, is supported by the majority of the DPM. This does not detract from the politicisation process of participating within the DPM, although there is concern as to whether it would lead to the collective's diluting the social model inadvertently. The present research argues that young people attempt to scrutinise the model, deconstruct the term, and explore the principles that link matter and meaning with the personal connection of everyday life, irrespective of whether this interaction between young people and the social model is occurring at a macro or micro level. For example, Mari suggests framing the model as a way to realising participation within the community and creating distance from a narrative of care, rehabilitation, and treatment:

> I think it's about meeting our social needs and where we wanna go out, where we want to interact, where we want to be involved in things. And it's about not [focusing] on our medical needs, exercise, it's not about personal care, it's about going out, doing something with our day.

The DPM will, as an attempt to react to oppressive forces within the social world, produce exclusionary practices by placing emphasis on the utility of the social model. This occurs as a result of concerns from established and influential figures regarding the criticisms levelled at the model. The various networks that traverse the political, economic, and cultural spaces produce a list of priorities experienced by individuals as they navigate daily aspects of marginalisation and inequity (DeVault 2008). Such priorities, generated by broad social and cultural formations, necessitate the need for disabled people to challenge and resist current practices and to demand alternatives. Nevertheless, there is substantial concern that without the described process of disablement offered by the social model, disabled people would be further excluded. This is because the Movement will experience further fragmentation: oppressive

State forces will use the narrative of a weakened social model of disability in an attempt to portray a redundant, detached, and disillusioned social movement. Rachael's interview reflected this when she was articulating the significance of the social model and its influence upon the DPM:

> Well, the social model isn't out of date, it's only a tool. Nothing changes, you know, e.g. we need to change society in order for disabled people to be full citizens and we need to continue to understand their various needs, to determine what needs to change for our full rights to be realised. Now what has changed? You know, those disabled people who say "oooh, the social model doesn't include my impairment, well, actually it includes everybody, because if everyone really understood it for what it was and used its basic construct, they would see it applies to every socially exuded individual."

Rachael continues by alluding to an integral question for the Movement as to whether the social model required updating. The field of Disability Studies has, for a considerable time, focused on this question. The expansive literature provides suggestions for alternative models (Tschanz and Staub 2017), a return to grassroots development (Finkelstein 2007), and the potentially disastrous implications if the model were to be abandoned (Oliver 2013). For Rachael, the discussions pertaining to updating the social model or finding an alternative are misguided, and are problematical for the DPM's direction and agendas:

> We are still excluded in many areas, we are still largely living in poverty […] and we are still living with non-disabled people's attitudes of what it's like to be a disabled person in society. I think we do read too much into the social model. The social model is very weighted towards constructs that says that in order for disabled people to be included in society we need to do and understand things differently.

This research argues that the social model should be recognised by activists as an oppositional device, as outlined by Beckett and Campbell (2015). Therefore, it is not a question of updating the social model, which risks cementing the divide between supporters and critics. In contradiction to the points made by Rachael, a young respondent, Kate, wants to see further opportunity to debate the social model. Her argument centres upon the necessity to understand why people want a discussion and their justification for a possible update or different approach:

> [T]hey're then sort of saying we can't talk about how we got here or why we're here, why we think these things should be changed. Yeah, that just confuses me […] It was built on this model, the original model. They actually say – we can't

> debate it, we can’t look at it, we can’t criticise or alter it. That doesn’t make sense. Doesn’t that negate the whole movement in itself?

It is at this point useful to consider young disabled people’s perspective on the application of the social model within the DPM, alongside its intrinsic relationship to the everyday experiences of acknowledging and addressing barriers that marginalise disabled people. Richard, a young respondent, identifies how the model is prominent when contextualised within campaigning and activism. However, there may be difficulty in recognising and acknowledging the value of explaining a disabled person’s overwhelming experiences of marginalisation and discrimination, within current economic and political frameworks, thus a discussion on limitations is required:

> There are limitations to the social model of disability – the social model of disability exists within a world that is very much constrained by aspects of capitalism, constrained by the lack of community and all of these other things. I don’t necessarily think that it’s a problem because it is so important to so many people, that this idea that it is others’ fault that we are discriminated against, but I think that I would really like to see or be or hear just more discussions that look at the limitations of the social model of disability.

Richard draws attention to the ableist narratives experienced by numerous young people as they transition between services. The incessant use of medicalised assessment procedures and systems, which determine whether young disabled people may access certain environments, emerges from a medical discourse that protects the opinions of professionals. Richard is concerned that the assessment procedures for young people dominate the professionals’ understanding of disability, which has as a result that the social model is not considered until the young people have reached a later age:

> Especially because of the way that our, if you’re a disabled child, the way you are treated is still so heavily dependent on making sure you can walk, making sure you can hear, making sure you can talk and various other things, so it feels as if there’s still a medical model constraint on children, whereas, I dunno, yeah, I think that once you get to a slightly older age and once you realise that the barriers that are created are created by society, it’s a bit different.

The perspective of and opinions from medical experts and welfare assessors result in young disabled people’s being unable to relate to the principles of the social model of disability. The research interprets Richard’s points as expressing a desire to create discussion surrounding how the social model has relevance beyond the paradigms of establishing campaigns and fuelling activism; he wants to question why young disabled people have neither encountered the social model nor perceived it as relevant to their lives. It would appear, from the statement above, that it is only when young people move beyond the border zones of youth (Lesko 2002, 2012) do the opportunities emerge to challenge ableist rhetoric and ideals.

Richard's point is significant because it highlights young disabled people's possible disjunction from the social model and its application. The current research argues that discussions on the limitations of the model require considerable attention and careful planning. The opportunity to demonstrate the relevance of the model, particularly with concern for the need to promote choice and control in everyday life, necessitates adopting an approach that illustrates examples of social model practice and vision. The Movement – and wider allies – are required to promote the pragmatic ways employed by representatives of the DPM to tackle aspects of disablement. Examples from academic and "grey" literature demonstrate how organisations managed and coordinated by disabled people have utilised a social model perspective, alongside an "independent living" philosophy (Heyer 2015). Included are the development of personal assistant schemes, the adoption of anti-discrimination legislation, and pressure to reverse substantial cuts to disabled people's support mechanisms (Evans 2011). Such examples denote how the DPM provides evidence of economic exclusion and social isolation, which is underpinned by a commitment to a social model of disability perspective.

The commitment by substantial figures within the DPM to illustrate how the model has generated a set of principles and practical solutions remains ever-present. Having opportunities to stimulate debate on the applicability of the social model should be welcomed, provided they are part of a discourse that opposes the current ableist ideals of the physical, biological, and expressive compositions of the human being. This should not be interpreted as being a commitment to the social model of disability in order to ensure that the Movement remains ideologically pure; such a lack of clarity is reminiscent of Crowther's (2007) statement surrounding the DPM's future legacy. In this, he suggests that the issues encountered by disabled people differ from those prior to the implementation of the Disability Discrimination Act 1995; a contributory factor to disabled people's extensive marginalisation is found in the DPM's failure to engage in partnership with other organisations. As Marley suggests in the interview, young people should be recognising the difference between disabled people's various emancipatory terms, on the one hand, and on the other, questioning their application:

> People talk about the buzzwords of like, civil rights, human rights, anti-discrimination legislation, but often they talk about all of these things as being the same. […] And what I think young people would be very good at is our everyday […] what is our everyday conversations about the difference between civil rights, human rights? Or do they or not matter? But, do we have these discussions in the Movement to get our understanding of what we mean?

Returning to Richard's and Kate's point, young disabled people should be part of the process to determine on which questions the Movement should focus on then to reflect on the answers produced. For those interested in exploring the social model of disability, there is a need to engage with the Movement's history and achievements – a point raised by Oliver and Barnes (2010). In addition to the issues raised by Richard, Regina, and Kate, another young respondent – Rose – recognises how the model is utilised to describe forms of oppression:

> Despite my ridiculous and occasionally slightly obsessive level of effort, there are still things my life lacks that I need it not to lack. I'm talking particularly in terms of financial stability, employment, all those kind of things, freedom of movement even. Even just basic like […] freedom to go where I want, go when I want to go, as and when.

Rose, during this part of the interview, articulated how essential it is for the DPM to demonstrate a commitment to the social model:

> A lot of people within the Disabled People's Movement have criticised the social model for ignoring the physical connotations, impacts, of impairment because there are those that feel that that's exactly what it does. But I think we need a way of explaining our oppressions.

The criticism levelled on the basis of failing to recognise the experience of impairment is well documented within academia (Owens 2015). However, Rose argues that embracing the social model is necessary to offering an explanation of oppression that reflects various daily experiences. Whilst her awareness of the model's perspective came from participating within activism and campaigning, it was her opinion that the Movement must remain founded on the model in order to understand oppression. This has relevance to the points made by Richard regarding the importance of young disabled people's exploring and understanding the social model, as it offers a way to mitigate against the introduction of a medical discourse that justifies or disguises discrimination. By appearing to question the validity of the social model, such apparent discrimination permits the continuation of deeply rooted concepts of disablement and fails to disrupt understanding of social injustice towards disabled people. For Rose, the legacy of the model ensures that individuals may gain a sense of self-worth and offer or demand practical solutions to the experience of multiple types of barrier.

By focusing on the macro- and micro-levels, the historical and contemporary influence of the model ensures that disabled people involved in the DPM have a responsibility to support one another – especially young disabled people who will participate in activism in subsequent years. Through a process of mapping the principles of the social model onto the daily life experiences of disabled people, there are opportunities to reflect and critique the sense of reality and disabled people's experiences of the social world. This also allows disabled people, unaware of the politicisation process or parameters to explain disability through this lens, to follow a journey of discovery and to question how the world functions.

Of particular interest to scholars is how the social model affects the sense of humanity and being (Albert 2004; Gill and Schlund-Vials 2014). By exploring the model, Rose – and the majority of young respondents – were able to witness how the Movement was able to share and explain the experience of discrimination and prejudice. This strengthened the DPM and its position in asserting a desperate need to create change; not only this, it demonstrated the positive factors of belonging to an identity that promotes the idea for an alternative way of being, existing, and participating within the social world. The development of a political aspect of a disabled person's identity is necessary.

All respondents highlighted the nature of political views and their impact upon the organisational development within the DPM. For young respondents, there were significant issues surrounding how young members aligned with established figures and contingents that demonstrated specific political values. This occurred not just in the context of personal development and integration within the campaigns and actions of the Movement; also, it could seek protection from becoming ostracised by established members if criticism or confrontation were directed towards individuals. Whilst it is common for social movement members to seek solidarity in order to comprehend and participate in the spectrum of political ideas and viewpoints (McCrea, Meade, and Shaw 2017), the collective enterprise of the DPM must reflect on how its members react to those who investigate the dominant political ideas associated with the Movement.

6.3.2 *Political Ideology*

In terms of development, the DPM may arguably be referred to as a young social movement – particularly when compared to other liberation movements that have provided inspiration and learning for the pioneers of the DPM. The issue of dismissing or excluding specific individuals on the basis of their respective political values could have a severe impact on the sustainability of the Movement. Demonstrating an unwillingness to collaborate with people who do not share the same or similar political platforms means new and interested members risk being abandoned if the nature of the DPM's organised political framework were indeed inflexible.

How the DPM is organised politically is comparable to other social movements that grow as if organically through the development of various networks that may collaborate or challenge one another over the course of their existence (Ray *et al.* 2003). This is a necessary aspect of social movement formation, as groups and contingents join together to build a vision or articulate a desperate need for change (Saunders 2007). For the DPM, this is reflected in the emergence of organisations such as Disabled People Against Cuts and campaign groups such as Black Triangle, entities that seek to galvanise support and oppose those political and policy agendas of the current government that, arguably, both infringe upon disabled people's civil liberties and disregard their human rights.

Hillary, a young respondent, recognises the effort of those within leadership positions to demonstrate flexibility – but that it is dependent upon newcomers challenging or conforming to the existing political values:

> How people react to the criticism that they get from the evolution of the Movement, and whether they conform, create or crash and burn is very much kind of key to whether they continue to be involved in it or not, and I think that one of the things that the disability movement has historically struggled with is the sense that there isn't that flexibility to create and challenge as a newcomer.

The problem emerges when challenging or creative suggestions are interpreted as, sometimes personal, criticism. Hillary indicates the importance of political allegiance amongst DPM members. Young people, in particular, feel obliged to frame their discussions and ideas within the conventional political spectrum. For newcomers, if there is disparity between their political position and the current leadership then this leads to separatist or exclusionary practices. For the leadership, their ability to operate effectively within their networks is judged by their commitment to articulating aspects of disablement within a certain ideological or theoretical framework. The reason why newcomers are perceived as a challenge to the political legacy within the DPM is a reflection of how the demands of the founding generation remain ever present:

> But I think that that's changing by the openness of the people that currently have leadership positions […] At some point, consciously or not, it starts to matter where you lie politically and who you're aligning yourself with. And therefore, the people that then become leaders within that definition are defined by whichever fragment you've chosen to tie your colours to.

Although the notion of leadership is discussed in the following chapter, it is relevant to an analysis of the political legacy within the Movement. The research argues that the crucial issue, here, is how the Movement navigates through this constant flux of political ideas emerging from the various networks and subgroups within the DPM. There have been declines in protest-based action within the DPM, as well as the decimation of many organisations, controlled by disabled people, that advocated for separatist recognition, arguing that non-disabled people represented forms of oppression. The situation has led to the prioritisation of disability as a rights-based issue. For some, this requires collaboration with political contingents, such as having disabled people represented on advisory boards within government, political parties, and local partnerships. The move has led to a focus on legislative frameworks and the implementation of existing government policy and strategy.

Many young respondents were not in fact critical of socialism, yet they did feel excluded if they articulated any narratives that sought to critique or challenge outright enthusiasm for the political ideology. Jeremy, a young respondent, questions the partisan nature of influential organisations and representatives of certain disabled people's networks:

> Specifically, they [*anti-austerity protest groups*] are against austerity measures and a lot of them are socialists or Marxists in nature […] I think political ideology is an important part of the movement but I feel like a lot of it is quite socialist or Marxist driven.

His concern is derived from how contingents of the DPM may take a separatist approach, in order to articulate political issues that are aligned with a specific ideology; doing so, ultimately, creates difficulty when engaging with the Movement:

> I personally don't really agree that the movement should be so politically partisan so to speak or supportive of one person over another. I think a lot of groundwork can be done working with the government […] I guess, so that's something I struggle to associate with, some of the more politically driven elements. I guess, being more liberal as I am, I am more a sort of a liberal centre person, so that's been a bit hard to get used to.

Jeremy highlights the initial inclusion of newcomers into the Movement is dependent upon how the Movement communicates with new members – and particularly young people – in the context of its commitment to certain political principles, ideas or frameworks. The absence of notable and extensive coverage of the DPM within media, education, and political discourse means that a substantial number of young people are unaware of the history, significance, and potential of the social movement. Jeremy focused, predominantly, on the isolation of people championing neuro-diversity within the DPM; also, he felt the majority of young disabled people across the political spectrum were not provided with the support they needed for them to engage. Jeremy questioned whether there would be considerable interest from young people in wanting to become involved in the direction of activism and current discourse surrounding the Movement.

This raises an important issue regarding such organisations and campaigns, one that appears in direct conflict and contrast with organisations and networks that lobby and collaborate with the State to improve disabled people's living conditions. The research interprets Jeremy's point as being a suggestion that pressure groups should complement those organisations aiming to work with whichever government is in power, focusing on providing information, and creating dialogue between policymakers and disabled people, including their representative organisations. For young people, this would offer flexibility: some may seek to protest or directly oppose current decision-making while others want to protect people's rights within the current political, economic, and cultural relations.

Respondents outlined the significance of interlinking movements, with different focuses as to how to bring about disabled people's emancipation, thus the analysis was able to identify how a commitment to the social model of disability enabled young disabled people to engage in the DPM. Furthermore, the influence of specific political ideologies also affected individuals' interactions with the social movement.

6.4 Conclusion

The chapter has explored challenges highlighted by young disabled people with regard to key organisational aspects associated with the DPM. The chapter argues that the DPM is recognised as part of several interlinking social movements, each with specific or intersecting directions and strategies to address disabled people's oppression. The essence of interlinking movements reflects the demands to focus on a rights-based approach, whilst also recognising there are contingents that call for further radical action. Such contingents aim to identify the variety of barriers within the materialities of everyday life, arguing that disabled people's emancipation cannot be achieved through legislative reform of human rights. This issue is further affected by the significance of socialist ideology, which – in some circumstances – is utilised as a basis upon which to realise disabled people's emancipation. This factor may have an impact on the participation of young disabled people, and newcomers, within the Movement, particularly if they do not align themselves with or adopt similar political ideas. Such an issue is further rendered problematic when considering the position of the social model.

The social model remains core to the overall direction and activities within the DPM. At the same time, it is essential to recognise that young people are unable to question or critique the model. This is because such attempts are perceived as opportunities to weaken the position and importance of the model rather than simply being in search of information and understanding. Following on from conclusions drawn in the previous analysis chapter, it is clear that young people require support to offer a vision for change and to be involved in the identification of, and subsequent methods to address, the conflicts within society that perpetuate disabled people's marginalisation. To achieve sufficient understanding, the research argues, the social model should be kept at the core of the DPM while members should also be encouraged and supported in utilising their investigation of social model as a form of opposition. Doing so will allow for the opportunity to provide counter-rationalities, not necessarily with the sole aim of proposing solutions within the existing political and economic frameworks, but to highlight the conditions of a socially unjust society.

The political, economic, and cultural forces that perpetuate such ideals of normality, irrespective of whether they exist at the macro or the micro level, will use the criticisms of the social model in an attempt to sustain their oppressive and violent acts. This research argues that should the DPM reject the social model, it will, inevitably, become powerless to challenge the hegemonic narratives offered by those who operate against disabled people's demands for emancipation. Debate surrounding the model is required, yet there is a risk that the DPM could enter a phase of continuous dialogue surrounding the limitations of the social model. Rather than providing inclusive solutions and practices for disabled people to exist within the social world, attention is distracted from the factors and social structures that perpetuate disabled people's experiences of isolation, exclusion, and violence. To remain committed to the social model, it must be positioned as "an oppositional device" (Beckett and Campbell 2015, p. 3).

To conclude: through interviews with young people and established figures, there was an exploration of perceived interlinking social movements that identified the competing discourses associated with the overall purpose of the DPM. It also discussed the influence of social model thinking and how this is embedded within the overall direction and purpose of the Movement. Finally, attention turned to the prominence of socialist ideas within the DPM and how their existence could have an impact upon young disabled people's inclusion within and aspiration to be part of the Movement.

The next chapter, which completes the analysis section of the thesis, details the respondents' accounts pertaining to those future issues that will influence the sustainability and effectiveness of the DPM.

7. Future Considerations of the Movement

7.1 Introduction

During the interviews, respondents were asked to identify and explore what challenges existed that are associated with the sustainability and effectiveness of the DPM, and which would affect their participation within the Movement. Three themes emerged: archiving, local and online mobilisation, and whether young disabled people care about the existence of a disabled people’s social movement. The chapter argues that without a clear and coherent strategy to support young disabled people's participation, which includes taking account of the issues raised here, the Movement will lose traction in resisting current, normative perceptions of disability. This highlights the importance of capturing disabled people’s experiences in order to support future generations in their understanding of the history of disability activism and the potential for emancipatory action. Without addressing aspects of elitism and academic imperialism within archival practices, young disabled people do not feel empowered by the opportunities available to learn about the DPM. The issue of a clear and coherent strategy also requires consideration of how the Movement operates at a local level, and whether it indeed facilitates the involvement of young disabled people. As identified through the respondents’ own words, if action to involve them is not taken then the premise of whether young disabled people care that a social movement exists will be of little value.

The chapter explores the significance of archiving activism, with reference to the process of the collection, interpretation, and publication of the DPM’s history, current issues, and debates. The chapter moves on to highlight the importance of local mobilisation of young people; also, there is the significance of grassroots activism, as a way for newcomers and young disabled people to feel engaged and able to participate. Finally, the chapter reviews whether young disabled people do now or will continue to care about a DPM, and the consequence of their opinion; most notably, questions are raised as to how young disabled people inherit leadership positions.

7.2 Archiving Activism

Here, "archive" is taken to mean the product of the DPM's attempt to document the historical and contemporary issues of the disabled people's community. It is a broad spectrum of grassroots political activities and the thematic analysis of oppression, marginalisation, and liberation that occurs within and outside the Movement. All of these contribute to the awareness, significance, and accessibility of the DPM.

The development of archives is well documented (Greene 2002; Flinn and Stevens 2009; Erde 2014) Whilst there is much debate surrounding the definition of archives, scholars and activists alike have highlighted the importance of facilitating participation and developing data collection strategies to address the volume of records produced by social movements (Bailey, Cammaerts and Carpentier 2008). There are notable concerns with regard to the protection of existing archives with the continued reduction in resources, staff, and funding. This has led to a desire by archivists to enter an experimental phase of Archives 2.0, reflecting the fundamental shift to utilise new technologies and promote open, flexible, transparent, and collaborative values to capture and protect shared histories (Theimer 2008). The new phase of archiving is significant to the DPM insofar as respondents scrutinised the values that underpin Archives 2.0.

Thus far, the thesis has presented key issues associated with young disabled people's involvement in the DPM and organisational aspects that have an impact upon the Movement's direction, strategies, and agendas. The focus here is to outline specific points raised by respondents as they begin to discuss their priorities for the DPM's future. Of particular note is the significance of how archiving ensures that the Movement remains sustainable and effective, as it improves disabled people's living conditions. To explore this, the section will focus on two groups instrumental to the archiving process: academia, and organisations/charities focused on disability issues. The role of the intelligentsia is important because, as discussed later, much of the information surrounding the DPM's history and current issues affecting its trajectory is accessed through university sources. Not discounting the important work produced by academic activists, respondents drew attention to the problems that emerge when academia has an integral role in the collection and dissemination of materials pertaining to disability activism, social movements, and disabled people's experiences: one example is inaccessible language, which prevented people from understanding the essence of the materials. All respondents were critical of how their process to find information led them to academic websites, articles or journal collections. This raised further discussion with regard to the role of academia within the DPM. A focus on organisations and charities highlighted other issues, such as the expectation placed on young disabled people to retain a certain level of specific areas of knowledge about disability activism.

These issues are explored throughout this section and with reference, specifically, to two archives as highlighted by respondents. Firstly, LDA was established by Professor Colin Barnes to provide disabled activists, scholars, and learners with an online collection of documents pertaining to the work of disabled people and their organisations. It is intended to provide access to the writings of activists, scholars, and allies whose work may no longer be readily available in the public domain. Those involved in its development hope the archive can inform current and future debates on disability. Secondly, NDACA promotes and celebrates disabled people's contributions to art, music, film, and culture as a way of furthering social justice and human rights. Although hosted by a higher educational institution, its existence alongside LDA provides insight into the importance surrounding disability arts. According to Sutherland (2014) the emergence of disability arts would not have occurred without the politicisation of disability; however, the DAM celebrated expression of individual experience and identity through various practices. With a focus on liberation, it drew upon the significance of intersectionality and challenged the rigid frameworks adopted by disabled people's groups such as UPIAS. Disability arts evolved to focus attention on human rights issues and provide space to explore how personal experiences portray the extent and impact of disability.

The significance of archiving activism should not be understated, especially as it provides opportunities to establish connections and demonstrate commonality among those reflected in the archives. Further to building solidarity and challenging the power relations that preserve the existing accounts of individualised and collective histories, social movements are needed to promote community-based, dynamic, and fluid projects that capture the narratives and identities by and for the activists affected. This last point is of particular relevance to the DPM, as it attempts to grapple with the notion of access and shared ownership; for the Movement, it is essential to utilise knowledge of its history and purpose in order to rethink current practice and to create or justify aspirations and a vision for disabled people's emancipation. As outlined by Moore and Pell (2010), the nature of archives is to assemble collections so that communities are able to reflect on the dominant narratives and create a safe space within which to represent and redefine their own lived experiences. For the DPM, the intent to secure long-term preservation of materials and activities is influenced by the accessibility and location of such archives.

7.2.1 *Impact of Academic Involvement*

A starting point is to consider the role of academia. This is necessary to building on the legacy of existing and previous influential figures, stimulating debate and mobilising new members. Rose, a young respondent, explains how archives are important for supporting young disabled people's initial participation within the DPM:

> I think it would give those who […] maybe it takes time to come into the Movement, the chance to read the material and know […] and see that other people were indeed in history and are saying these things and the things you felt […] they needn't be ashamed/scared, any of the things that they've felt, because other people have also been in similar positions, had similar experiences and felt them before and wrote about them before and lived to tell the tale, I suppose.

Rose takes the position that archives are beneficial for young disabled people because they provide narratives and themes that are potentially similar to the isolation and marginalisation experienced by disabled people. This can provide support and demonstrate commonality, as individuals are able to recognise that their personal experiences are reflected in the lives of historical activists. Whilst this may be achieved through disabled people's autobiographies, non-formal educational routes, and the shared history of disabled activism according to DPOs, Rose believes academia facilitates the discussions needed to ensure a social movement is able to articulate the problems within society:

> It's a place where they're supporting; my views aren't viewed as abhorrent or strange or not equal, or not important or any of those things […] But how do I know that I'm not doing something which is inhibiting someone else's ability to get access to the things they need, by the very fact of my behaviour or

> presence? [...] Without the education, you don’t form the social movement without a recognition that something is wrong.

It appears Rose is highlighting two particular aspects: firstly, the decision-making process to select and collate resources that reflect the history of disabled people's emancipation and the activities of the DPM. This also includes ensuring they are accessible to those who will use them. Secondly, it is important to consider how and when it is necessary to draw upon these resources. Whilst academia provides resources and opportunities to critique and inspire discourse surrounding disabling barriers, it can assist members to take note of what they are attempting to achieve and the potential consequences this has for others. Nevertheless, it is worth noting the difference between archives of primary material and academic accounts, on the one hand, and critiques of disability activism on the other. To understand this further, it is relevant to consider the political nature associated with archival practices (Brown 2013; Millar 2017; Procter 2017), which has led to discussions regarding the manifestation, purpose, and emerging relations during the process of creating archives.

When respondents were asked about their methodology for exploring information on the contemporary and historical workings of the DPM, many referenced the LDA. However, they also questioned the involvement of academic institutions in collecting, disseminating, and managing the history of disabled people's writings. This was done not necessarily to express an intent of disabled people to be involved in the archival process. Rather, the aim was to highlight the inaccessibility of academia and demonstrate the elitist values of higher education. For example, Richard, a young respondent, expressed a desire to understand the opportunities and limitations of the social model of disability:

> So much of it is based around academia, which can be so inaccessible. I mean you can always kind of find those primers on disability, but – I’m sorry, on the social model of disability. [For the microphone, Richard is googling “Limitations of the social model”.] Ah! There we go. Development & Critique of the social model of disability, Implementing the social model of disability, social model of disability, Outdated Ideology, that looks like an interesting one but won’t be easily understandable!

Richard's journey to learn was continuously directed towards interdisciplinary accounts, provided by academics typically using sociological frameworks to promote the originality of their work. For Richard, it resulted in confusion, frustration and, unsurprisingly, disengagement. The second example referred to the NDACA, a project to capture the heritage and history of the DAM. The respondents who highlighted this Archive described it as a resource made accessible to ensure disabled people realised their own heritage. Jukie, an established member of the DPM, noted the significance of Disability Studies' retaining much of the information and dialogue pertaining to disability activism. Nevertheless, she highlighted the importance of collective archives organised and controlled by disabled people albeit with concerns:

> Well, I'd go to the disability studies departments, I'd go to Leeds, I'd go to Goldsmiths. I'd also go digging because there's a hell of a lot of stuff online. You know, so you'd go to particular names, I'd go to Disability Arts Online Magazine. I would go to NDACA. NDACA have just got, what, three quarters of a million pounds through Heritage Lottery Funding to literally archive and collate and carefully document as much of the movement as they can. And what worries me is, they're a little bit late getting off the blocks there, because a lot of people have destroyed their work or got rid of the stuff.

Jukie is concerned that much of the DPMs history may become lost due to the death and illness of prominent disabled activists and campaigners. Furthermore, the lack of a coordinated action to retain the history has meant many organisations and prominent figures are unable to tell their stories and highlight key issues. Sporadic action by higher educational institutions and funding bodies take responsibility to tackle this, but contingents of the Movement are abandoned and prevented from being involved. A lack of funding and employment opportunities or restricted provision of resources has led to academia's capturing, and subsequently dominating, discourse surrounding activism (Martin 2009). For Janet, academic involvement in archiving has reinforced a process to document and retain the selective histories of activism:

> I remember when I first started researching disabled peoples experience in Britain. I was very disappointed to discover that the literature was heavily white-male dominated. Again I also found that the campaigners and advocates for disabled people's rights as being dominated by white men who appeared to come from middle- and upper-class backgrounds. I only came across information about a few prominent black disabled activists. I truly believe that

> we need to change the way information is depicted about us. Otherwise it will remain in the academic hands and on the academic shelves unless we make sure that all people can connect with it.

She references how the higher educational approach asserts a trajectory that privileges the rationality, reason, and actions of a certain type of being. Drawing from the work of Braidotti (2013), she argues that the human depicts an abstract ideal and symbol of classical humanity, rooted in European values. Within the context of this research, there is concern that attempts to archive disabled people's resistance and solidarity have inadvertently reinforced a specific vision for disabled people's activism. Academia has captured and portrayed a vision of the DPM that largely isolates individuals that fail to resemble “the typical activist” – a Eurocentric, white, middle-class individual with a physical impairment. This leaves certain cohorts within the Disabled People's community, and newcomers to the DPM, abandoned.

Not discounting the concerns over academic imperialism, Christopher recognised the significance of academics to grant the Movement a sense of respectability:

> I mean academia is academia and it is another world, another reality and that’s why I think there was a widespread movement of disability centres being set up all over Europe after Leeds set theirs up. And I’m not sure even where they’re at now, you can’t keep in touch with everything, but I know there’s the Academic Network of Experts in Disability and many of those are from universities like Leeds and similar places in other countries. So, I mean they’re playing a role specifically within the European dimension, doing what they’re doing, got the funding from Europe […] provided the access to people we needed to influence.

The pioneers of Disability Studies, such as Morris (1991) and Finkelstein (2007), were also integral to the development of the DPM. Their access and status granted by their role in academia provided opportunities to draw on historical and contemporary research to offer data and evidence in the hope of improving living conditions. The inclusion of academics could permit access to policymakers and parliamentarians; the role of academia could assist with cementing the position taken by activists and campaigners outside of the intelligentsia.

For Robert, an established member, the relationship between academia and the DPM is complicated and should be recognised as an area of concern. Notwithstanding its impact on how the Movement structures its agendas and overall direction, Robert argues that it came to rely on academia and this has prevented young people – and newcomers generally – from participating. Without a comprehensive review of the academic role and its effect on the DPM, it could ultimately lead to the demise of the Movement. As Robert states:

> It's not that it is exclusionary because you could argue that because it was very effective at bringing disabled people in, those who had been previously marginalised, and that is to its credit and vast proportion of the jobs within academia about disability are disabled people and a far greater proportion than probably any other social sphere, absolutely it's again not a criticism in itself, it's just that what it ended up doing, because they were almost exclusively "the movement" *per se*, it ended the movement.

Robert alludes to the Movement's becoming incorporated within a structure that is predominantly framed by academic discourse, data collection, and theoretical debate. In doing so, the DPM becomes dependent on the internal politics and developments of the higher educational institutions. He suggests this process ended the Movement, drawing to a close the revolutionary appeal of disability activism and the radical politics established by founding members. The effect of this was a further detachment from the daily experiences of activists and campaigners:

> [A]nd once you reach that level, which is what academia does, it does it to the black studies and feminism and queer studies probably, as well, although I don't know much about that, is that you become inhibited, you become obsessed that you are unworthy of doing what you want to do because academia has shown that perhaps it doesn't work. Or that it isn't very sensible or not very intelligent when in fact you just shouldn't give a fuck and you should do whatever the hell you want.

Here, Robert does not reject the involvement of academia outright, but queries at which point involvement transitions to interference. He argues that young people and newcomers to the Movement feel pressured to immerse themselves in the information, knowledge, and debates that capture the complexity and plethora of disability issues. Robert concludes by suggesting people are capable of forming their own conclusions without participating in the existing academic infrastructures, in the hope of learning a specific historical and contemporary analysis of disablement.

The concern is regarding how the notion of academia, within the development and sustainability of a social movement, affects the opportunities for members to participate and contribute to the overall functioning of a social movement (Cox 2015). It is imperative that when newcomers and young people engage with social movements, they feel a sense of liberation to explore their creativity and expand on their passion for social justice. Although this research does not take such a critical stance towards the role of academia, it does note the exclusionary aspects that can emerge as individuals attempt to engage with a – somewhat – inaccessible and elitist environment. The importance of interacting with texts, histories, and narratives is to stimulate the imagination and consider the radical change possible that will challenge marginalisation and inequity. The alternative is to witness a sense of overwhelming confusion and inadequacy, as individuals grapple with the inconsistencies and contradictions, leaving potential activists concerned as to whether their arguments and ideas will be valued and respected by fellow activists.

The low numbers of disabled academics working within higher educational settings are another factor. As highlighted by Brown and Leigh (2018), the changes to funding structures and the increased marketisation and bureaucracy befalling UK universities has led both to low morale amongst existing scholars and to ineffective strategies to support disabled people to access research positions. Whilst this raises a debate regarding ableism in academia, there is a significant connection to the research findings here; if disabled people experience immense barriers to establishing an academic identity, with many compromising their research to maintain their personal lives and relationships (Brown 2017), then it may be assumed that disabled people will continue to be underrepresented in research practice. There must be viable opportunities for disabled activists to enter the academic realm and take control of the discourse and projects that attempt to capture the shared history of disability activism and social movements.

Although this research does not suggest that academia is the only place in which to collect, archive, and disseminate this knowledge, it will continue to have a role. Disabled activists must be part of this process. Not all disabled academics will have a desire to build successful careers within Disability Studies. However, just as Stramondo (2016) argues for disabled people to pursue roles as bioethicists because of the opportunity to reshape the ontological basis of understanding disability, so too should disabled people occupy historian and archivist positions. This will go some way to address the concerns regarding the emerging distance between academia and disability activism (Goodley and Moore 2000), and reinforce Campbell's (2009) demand that action is required to enable disabled scholars to engage in Disability Studies.

7.2.2 *Role of Disability Organisations and Traditional Charities*

The problematic nature surrounding archives was not confined to academia; it was relevant when discussing how traditional disability organisations and ones controlled by disabled people were involved in the process. Hillary, a young respondent, raised two concerns with regard to archiving: firstly, she noted that certain organisations would actively pursue an agenda to eradicate parts of their history because of the criticism directed towards their activities:

> I’ve worked for several organisations where I have been essentially tasked with destroying what might be in [an] archive because the [author’s] name is no longer politically acceptable.

This is most applicable when referencing organisations that have appeared to be exclusionary of certain groups within the disabled people's community or have operated on platforms that are considered ineffective to advancing disabled people's rights. A notable issue is the provision of funding to larger, traditional charities and how this provides them with opportunities to destroy or dismiss aspects of their work that demonstrate how they may actually have been detrimental to the lives of disabled people. A notable example is the decision by Heritage Lottery to award Leonard Cheshire Disability, an organisation recognised by its extensive network of institutionalised settings, grant funding to research disabled people's history (Pring 2015). In discussion with Pring, Evans suggests such organisations exclude disabled people and do not have the authority or expertise to write about disability activism – and may lead to traditional, oppressive charities' claiming ownership of the successes achieved by the DPM. Furthermore, Paulley argues that such approaches prioritise the archiving of events that do not reflect negatively on the organisations that manage and coordinate the archiving process. This means dismissing direct action protests and campaigns carried out merely as being a response to the exploitative and marginalising charities that operate "prison-like regimes".

It is not surprising that traditional organisations would take such an approach to protect the legacy of their actions, even if it results in a failure to highlight key aspects of disabled people's struggle for emancipation. Following on from Hillary's point, the problem lies in the certain organisations' failure to recognise and accept that they have erased specific moments of their history deliberately – examples that demonstrate how they contributed to the prevalence of barriers encountered by disabled people. Moreover, it is the desire by the leadership within these organisations to recruit actively individuals to be part of the process of destroying the records of their actions and ideas. Darke (*in* Pring 2015) suggests organisations, traditional and user-led, should appoint activists that are historians, who take a politicised approach and draw attention to the broader history of disability since the Second World War. He believes doing so can achieve better outcomes by demonstrating a greater importance, impact, and social and political legacy of disabled people and the DPM – ultimately improving people's understanding of disability activism and the change that is required to improve disabled people's social position within society. Whilst a valid point, concerns remain over how organisations are actively destroying their history to protect their current credibility. There is a difference between an attempt to capture disabled people's history, and ones that work towards destroying or mitigating the historical actions and legacy of specific groups and organisations.

Hillary's statement reflects part of the concerns raised by Oliver (2017) in his assessment of "parasitic" charities and organisations that deliberately rewrite disabled people's shared history in order to suit their own interests and agendas. This creates extensive problems for the archiving process, as the focus is no longer on the exploration of activism, and the significance of social movements. Rather, it is to reposition certain organisations as champions of the DPM rather than opponents. For Oliver, this approach to archiving reflects the desperate need by organisations and individuals to further their own progression on behalf of disabled people experiencing marginalisation, which means ensuring disabled people continue to be dependent and tragic.

The second point made by Hillary relates to the expectations placed upon young people because of extensive archiving and the desire to capture the history of the movement and disseminate it amongst young people and potential newcomers to the DPM:

> I'm not sure there needs to be an archive, but there needs to be an acknowledgement that you don't walk in the door saying exactly the right things to the right people and although you might be saying the right things today, that doesn't mean that they'll be the right things tomorrow, and it doesn't mean that they were the right things yesterday. And I kind of guess that potentially, archiving can put young disabled people at a disadvantage because essentially, rather than this gradual realisation process that led to these organisations being formed in the first place, we're expected to already be at stage ten, before we can enter.

Here, there is a recognition that issues surrounding archives is considerably more complex than just discussing matters of ownership and accessibility.

7.2.3 *Significance of Archiving*

Drawing on Hillary's concerns, the nature of archives creates an expectation that young disabled people should have a certain amount of knowledge pertaining to the debates and key issues affecting the DPM prior to their participation within activism. This raises the question as to whether the presence of archives and commitment to capture disabled people's history reinforces elitist practices and behaviours within the Movement. The research argues there is a danger in that archives may no longer become a tool to support learning or raise awareness; rather, it takes the form of a benchmark that restricts participation and determines who is included within the DPM. Whilst this research argues that archiving social movements – particularly the DPM – is paramount for their continued existence and prominence within society, there is a need to understand and assess the existing relations between individuals who take responsibility to archive disabled people's shared history. If opportunities are not provided to ensure there are accessible descriptions of activism, ones that reflect the various identities of those who take part or want to participate, then the importance of archiving will be lost and left to be hijacked by those who may exploit the current situation experienced by the majority of disabled people.

Expanding on the points made by Janet earlier in the chapter, the purpose of archiving should not be only to describe the activities of disabled activists and their organisations. It is to highlight problems, gaps, and concerns that must be addressed to improve the effectiveness of the DPM. For example, whilst being necessary to celebrate the revolutionary thinking of UPIAS (1975), it is equally important to consider why their ideas and mobilisation were exclusionary to those who had no physical impairments. This is part of the history of the DPM; it requires space to address the problems this caused, and how to ensure improvements are made within the present to ensure the Movement remains sustainable.

To explain this further it is useful to consider what Jeremy, a young respondent, thought about the significance of archives:

> As for the movements themselves, thanks to the reality of the internet, although a lot of this stuff is being recorded and only will be preserved by the sort of self-proclaimed people with disabilities who are also doing active journalism or blogging or whatever. All that will sort of be kept hopefully long into the future so that will be remembered, I think, but whether points will be written about it, to explain or understand the consequences of people's actions […] that's much harder to say.

Jeremy highlights the importance of the Internet and online-based methods to capture the DPM's activities. It is clear that he does not discount the importance of archiving. Rather, he argues that opportunities for individuals to outline their views are available and that existing technology can ensure it remains recorded. His prominent concern regards how such activity is then analysed and open to critique; he is ambiguous as to whether the Movement can provide a space to consider the implications of the activities or question the motives of those involved. Both Hillary and Jeremy question the potential of archives. However, of notable interest to the research is the aspect of neutrality.

Whilst all respondents discussed the issue of accessibility and ownership, it is for present purposes understood that it forms part of a wider discourse pertaining to how the archival process – and those responsible for collecting and harvesting the information – reinforce a particular vision of the Movement. It is naive to assume that archivists, whether academic, overtly political or technical, approach their responsibility through a lens of neutrality. As Zinn (1977) argues, the archival process may become trapped into recording what already exists, alongside an interpretation that protects the political and economic *status quo*. The current research suggests that the archiving of disability activism is an attempt to question the actions of past activists and organisations, their strategies and behaviours within the extensive networks and interlinked movements that form what is referred to as the DPM. Considering that the notion of humanity is flawed, depicting elements of hierarchy, privilege, and certain values, so do the social movements under investigation. For young disabled people attempting to engage with the history of the DPM, exploring access to archives means returning to the potential of safe spaces and ensuring a movement acknowledges its own limitations and flaws in order to welcome new members. If action is not taken then young disabled people will continue to question the purpose and motivation of archives, highlighting a sense of detachment or substantial pressure to conform to the actions, behaviours, and ideas espoused through the historical materials.

The future of the DPM necessitates extensive discussion as to the practices to collect and save materials, to make accessible, and to question how these affect the contemporary actions of the Movement. Fair (2014), in her review of the conceptual basis of archives, suggests they are undermined because people assume they provide an objective account of the material collected. She calls for a reconfiguration of what archives provide, proposing they are an opportunity to help define our current position. With regard to the DPM, the aspiration should be to use the archive as a way of demonstrating the elements of history to which activists should be indebted. However, it is how the information and materials are used today that will subsequently define disabled people and the Movement.

In summary, although archiving activism was merely one of numerous considerations proposed by the respondents, it highlights a significant issue encountered by the DPM and other social movements: how to establish the role of archives in this context, and how they should affect individuals as they explore, reflect, and connect with the ideas and practices emanating from the space occupied by social movements. Moving forward, the chapter explores the concerns regarding how the DPM appears to operate specifically on a national basis with prominent figures, which causes problems for young disabled people’s access and engagement at a local level.

7.3 Local and Online Mobilisation

The significance of technology was highlighted by all respondents, as the use of online spaces mitigated the disabling barriers encountered in specific geographical spaces. Reinforcing the arguments outlined by Castells (2011), online technology provides a means for activists to become aware of and inspired by the presence of existing social movements. Similarly, various online platforms provide activists with an accessible infrastructure through which to articulate messages of opportunity against the extensive network of marginalisation. Not discounting the importance of national and international action in order to address issues of social injustice, it is essential to acknowledge that participation within a social movement must take into account activity at the local level. Della Porta and Caiani (2009) suggest how social movements operating at a national level gain access to mechanisms that can raise the profile and messages of the movement. Whilst it is important to raise demands to a national level and to create solidarity on a transnational platform, this should not be at the expense of how movements fail to resonate with individuals in a local area. The DPM has much to gain from establishing a narrative of disability as a form of oppression, which crosses borders and requires international support. If the Movement appears, though, to operate specifically on a national basis, this will restrict young disabled people's access and overall engagement with the Movement.

7.3.1 *Building Local Activity through Online Networks*

Richard, a young respondent, highlights the importance of mobilising at the grassroots level to raise awareness of the DPM:

> Imagine what it'd be if you had a disabled people's civil rights movement that actually encouraged involvement from everyone that define[s] themselves as disabled. That would be so huge and yet so many people think that they are powerless within their own communities, in wanting to create the change that they want to see because they don't have skills, they don't have the experience. If we found a way to encourage more and more people to campaign on their grassroots basis for their local issues then you would see people recognising that the Movement exists.

Here, Richard highlights how it is essential for the Movement to capture the interest of all disabled people and encourage involvement within a rights-based approach. Richard argues that through extensive campaigning, disabled people can mobilise within their localities to demonstrate the importance of civil rights, as well as illustrate the existence of specific social movements. This reflects Hajer's (1997) suggestion that social movements formulate discourse coalitions, which operate on multiple layers and produce various framed agendas pertinent to the geographical space and time of the activities. Rather than criticise the supposed national focus of the DPM, Richard takes a different perspective. His use of the term "civil rights" reflects his thinking that disabled people's emancipation will be achieved through the protection of civil liberties and legislative frameworks. Key to this is the local mobilisation of activists. The focus is on how to increase activity, stimulate an ultimately growing membership, and create an environment where activists come together to create networks and alliances by addressing local issues. Again, it is not suggested that Richard feels the current approach by the DPM – that national agendas are paramount to improving disabled people's living conditions – is misplaced. Richard is arguing for an emphasis on local action and thinking to make people aware of the Movement. As Appadurai (2002) writes, this allows for social movement members to remain connected to diverse local sites across vast spaces. Richard continues with the interview by saying:

> But then I think the person who doesn't have my level of involvement within the campaigns and within disability rights, you know, the disabled person next door to me won't know about the disability rights movement.

It is not suggested the DPM remain detached from local activity; for those unaware of the Movement, the question exists as to how localised solidarity networks can be established to generate knowledge about the DPM and ensure it remains a viable option for disabled people to contribute time, energy, and resources to the Movement. Primarily, this is about raising awareness of the Movement and, at the same time, ensuring the Movement appears receptive to the actions of local activists and groups. According to Nulman and Schlembach (2017), such a question is commonplace within contemporary understandings of social movements. To address this, there is a need to recognise how the search for a common identity amongst social movement members must not negate the importance of highlighting shared concerns within localised settings. By framing global grievances as local problems, and *vice versa*, local networks can contextualise the issues and potential solutions with necessary variations specific to the geographical setting. With reference to the DPM, a shared local understanding of the barriers that restrict disabled people's inclusion can build empathy and a sense of parity between separate individuals and groups. This leads to the sharing of knowledge pertaining to relevant, existing social movements, which provides newcomers and potential members with the power to question why marginalisation occurs and offer a counter-narrative as to why – and how – it must end.

All respondents discussed the importance of online technology, and particularly social media, in the pursuit of mobilising local activists and supporting young disabled people to interact with the DPM. Whilst concerns were raised, as mentioned by Kate further in this section, the young respondents believed online campaigning was a useful method to capture the interest of non-disabled people and those not familiar with disability activism. As Mike outlines:

> I think some of the public, when they see us doing that [online disability rights campaigns] may see us in a negative light, saying “why are they campaigning, for example, when we was campaigning against the ILF closure”. When, for example, when my PAs spoke to their friends and family outside of working with me, they had no idea of what it was. What the ILF was.

Mike alludes to the public’s not having sufficient information to understand the implications and detrimental consequences of policy decisions to remove vital support from disabled people. The research suggests Mike is targeting the public through his involvement in online campaigns, to generate public interest and attempt to change government policy. He uses the example of how the Independent Living Fund closure, which witnessed extensive local campaigns to highlight how disabled people – identified as having high support needs – would lead to their further marginalisation (Gradwell 2015). The campaign to evaluate its impact continued at a national level (Inclusion London 2016) before becoming a priority at the local level, with disabled activists and their organisations campaigning to demand that local councils ring-fence funding to ensure individuals keep their existing support package. This demonstrates the significance of local campaigns, which uses activists at the grassroots level to mobilise and situate the demands from the DPM into a local, community context. Mike, throughout this part of the interview, was frustrated that online campaigning had failed to capture the interest of the wider community:

> So when some people see us campaigning online, but don't know what we was campaigning for, so what I'm trying to say is if more of society knew why we was campaigning, why local issues affect us, why it is such a danger for us, if they had more of a positive outlook when on social media, I think they would understand it a little bit more,

The research argues that young disabled people should be supported through the DPM to explore various campaign strategies, which can help disseminate key messages pertaining to the existence and prevalence of disabling barriers at the local level. Mobilising young disabled people, at the grassroots level, is key to ensuring the DPM is sustainable and effective in the long-term. Kate, a young respondent, raised similar points to Mike's when she outlined the importance of using online social media accounts to raise awareness of local issues affecting disabled people. From her perspective, this also has limited impact, as it fails to generate anticipated discussions with fellow activists and interested parties:

> A lot of my friends don't even read what I post or the links but it's like "well I'll post it because then you've got no excuse" [...] But I think a lot of people are just sort of, in my head, they just roll their eyes and scroll down, because I don't get any conversation from it and also I don't attend protests and things. Part of that is because my mum's my main carer and she is not into protesting about anything!

Kate perceives online technology as a route to participating in activism, bypassing the extensive barriers that restrict access to off-line displays of campaigning, including protest. The reference to 'not having an excuse' would suggest she is able to utilise this approach with ease, raising the profile of activists and the DPM whilst drawing attention to local issues. Kate also references how her mother is primarily responsible for the provision of her support; as she is unwilling to engage in activism, Kate's opportunities to participate are restricted and she thus focuses her efforts on using online technology.

Although respondents highlighted using online networks to raise awareness of local issues and to generate support through the prominence of existing campaigns, others suggested that technology could provide innovative ways to support young people. In particular they could develop campaigning skills and establish partnerships with local activists and campaigners. As Mari suggests:

> We've got blogging or vlogging. Facebooking. But we need to be seen as mentors, because we're of that age where we've kind of experienced most of what can happen. So, when kids are getting to an age, give our names to social workers, put us on a database, you know. Put our names and details on a database if we would like to mentor people. I know if mentoring services get a bit like, ooh we're gonna tell people what to do, but no we just gonna be dead busy and show them, you don't need to be isolated.

Here, the emphasis is on using technological infrastructure and existing local services to produce effective methods for connecting young people to one another and other generations of activists, to build confidence and campaign on issues that will provide greater choice and control for disabled people. This reflects the ideas of Todd (2017), who calls for the ILM to encapsulate four key aspects. Firstly, to enable members to connect, share experiences, and offer positive examples of campaigning – as this illustrates the importance of grassroots mobilisation and the need to connect local experience to national, global demands. Secondly, to build capacity amongst the membership of the movement to ensure people and organisations are equipped with the necessary skills to campaign, protest, and influence. Thirdly, to maintain a prominent position in the articulation and dissemination of campaign messages. Finally, the membership must realise that championing disabled people's rights requires different mechanisms depending on the respective location, context, and audience.

These four areas can provide the framework to increase local activity and address Mari's concern regarding isolation. As highlighted in contemporary research (Williams *et al.* 2018), disabled people experience marginalisation because policies and legislation rarely translate into good practice. With disabling barriers reinforcing isolation, it is paramount that disabled people are recognised as having the agency to intervene and be provided with opportunities to offer new and innovative ways of participating within the local community. Although Olsen (2018) does not specifically reference the importance of online technology, his ethnographic analysis demonstrates how disabled people are affected by loneliness; they remain at a disadvantage when policy development attempts to address the prevalence of isolation. Mari's idea, and the wider discourse surrounding the presence and utility of online networks, can begin to unravel the complexities surrounding young disabled people's mobilisation and access to the DPM. This reinforces research by Gale and Bolzan (2016), who suggest young disabled people’s position new social media technologies as an integral part of their daily life activities, focusing on blurring the boundaries between online and off-line experiences. The online space does not, necessarily, lead to the withdrawal from locally geographical areas; rather, it can be utilised to signify the importance of disabled people challenging traditional power relations, offering alternative representations of disability and being at the forefront of realising disabled people's emancipation.

Access to technology is dependent on factors such as accessibility, wealth, and geographical location. However, as highlighted in the work of Castells (2015), new technologies allow for local, public issues to be incorporated within a wider, global network of social movements. For Kate this is not realised in practice, as she assumes people dismiss the information and do not react to the messages and campaigns – ultimately raising concerns as to how the information is received and what impact this has on the mobilisation of new social movement members. Within the context of disability activism, Trevisan (2017) considers the development of activists who disseminate personal life stories online through blog posts. There is also the need to review how the premise of disability activism online has provided new and visible methods of challenging government policy (Pearson and Trevisan 2015).

7.3.2 *Online Mobilisation – a Bridge to the DPM*

For the DPM, the use of online technologies may become viable as it becomes apparent they are the only accessible route to question social structures and offer critical accounts. Rather than using technology as one of many tools to improve ways of exercising the power of communication, disabled people find themselves relegated to the confines of social media as access to support systems are restricted and individuals are unable to participate in the community on their own terms.

As highlighted by Bott (2016), disabled people encounter barriers even when attempting to participate in the monitoring of and reporting on human rights infringements. She noted that activists are unable to attend public events because many individuals are unable to leave their homes, due to a lack of support. Furthermore, inaccessible public transport, precarious working conditions, and continuous compulsory treatment orders and health programmes that reinforce medical model narratives, all come together to position disabled people as isolated figures, dependent on the voluntary actions of relatives/carers. This has serious consequences for the participation of disabled activists in campaigns and social movements.

For Rachael, an established member of the DPM, the significance of online technology reflected young disabled people's desire to learn and share information without having to conform to rigid practices, such as attending conferences or group meetings. From her perspective, the DPM should focus on building a dialogue with young disabled people through existing social media networks:

> We can use social media as it is a very important tool to inform and get people galvanised. Like demonstrating the kind of social pressures which make young disabled people pursue some kind non-disabled normality. The consequences of which is, they avoid being seen with other disabled people because they don't want to get labelled. I felt that as a young person and I don't think that's entirely gone away.

It is evident that Rachael considers social media as a gateway towards tackling the stigmatisation that young disabled people encounter as they develop and explore their identity. With reference to Richard's comments in Chapter Six, young disabled people have limited opportunities to contextualise their experience of disability within a political and civil rights basis; thus, online technology could provide young disabled people with the information, contacts, and possible narratives to generate interest in mass mobilisation. This does not satisfactorily address the material issues that require attention and resources, in order to enable young people to access and engage in specific locations beyond the online network. However, for Rachael, the DPM must have a presence through social media channels so that young people can access information and discuss matters pertaining to politics, disability arts and activism:

> People don't read books these days, they watch YouTube, you know, it's a different world in terms of information sharing. It's got to speak to young people and the way you get young people to think and do things differently is to look through things like social media, through music, through coming together and having fun but also having a point to it like how to embrace disability arts more.

The DPM must also address a specific point raised during the interviews – young disabled people experiencing online hostility or isolation from established contingents within the movement. Margaret, a young respondent, felt that it was difficult for young disabled people to access information or participate in the DPM because it does not appear to welcome newcomers, nor does it strive to include those who have an initial interest in the Movement's activities:

> If you know the leaders of the movement in depth and you follow them on social media and you're aware of their movements I think it's quite easy to be aware of what's going on. If you're not involved, and this is part of the problem I think, if you are not part of the movement and you have a great interest in that movement and you want to find out more, I think it's really flipping hard because I think it's quite closed off as a movement and quite excluding. And I think that's part of the problem. It can be really hard to find other people to fight your battles for you if you don't let them in.

The use of online networks can enable young people to emphasise what is preventing them from participating in the local community: whether, for example, it is because of inaccessible public services or inadequate personal assistance schemes. Although not discounting the comments made by Kate – which reflected similar issues raised in other interviews – with regard to using online networks as an only means to participation, the online method allows the user to refocus the debate, draw attention to specific issues, and build momentum to turn discussion into practice. Effectively, the mobilisation of young people through online networks can reshape what is meaningful within social movement activity – particularly at the local level. In terms of prioritising what action can be taken to increase young disabled people's participation at the grassroots level, the DPM would be well placed to explore the significance of online networks.

7.4 Contested "Importance" of the Movement

This final section is somewhat shorter than the previous two, yet all respondents briefly commented on the topic of caring about the DPM. Returning to Beckett (2006a), there is notable challenge with regard to how the DPM is defined, questioning how the activities and organisation of the Movement do not constitute a political coalition or expansive protest event. To suggest the DPM is important requires a review of whether young disabled people care about it and why. As is highlighted in Chapter Three, there is a significant lack of research and literature with regard to young disabled people's caring about the DPM. There is a need to question why, *en masse*, young disabled people are uninterested or have a feeling of ambivalence towards the DPM. Shakespeare and Watson (2002) highlight how disabled people reject the notion of disability pride to secure an identity rooted in the ideals of normality. Here, the investigation took a direct approach; respondents were asked initially whether they care that the Movement exists, and the reasons why young disabled people not involved in activism and campaigning should care. Regina, a young respondent, argued that young disabled people will care about the DPM only if they develop a sense of pride that leads to a critique of why people experience oppression. When articulating pride, she refers to "coming out":

> Those who haven't come out may not even be aware of the Movement, and you can't care about something you don't know about. When you're out, you're more likely to be involved in the disability community, and that ties in with the Movement, so it's a bit of a knock-on effect – you're more likely to get involved as result of coming out.

Here, Regina references how the DPM is populated with members who construct and articulate a proud identity. Engagement within the disabled people's community, acknowledged here to mean politically active campaigners who identify as part of a social movement, occurs because individuals are passionate about their rights and want to question the actions that lead to further marginalisation. Arguably, young disabled people will care about the DPM only if they are able to resonate with the ideas, strategies, and demands that emerge. For Regina, this requires a sense of pride and also an appreciation of the social model of disability:

> So, there are two things I think mean you're likely to care – coming out and embracing the social model. Those two things come hand-in-hand a lot of the time too. People understandably don't like referring to their bodies as disabled, but the social model allows us to reclaim that word and it empowers us.

The social model of disability becomes a means to enable young disabled people to recognise the significance of the DPM and aspire to participate. Organisations have used the social model as part of their learning and development projects with young disabled people in order to increase their presence in and access to disability activism (VIPER 2012; Todd *et al.* 2012;

ENIL 2018). Regina thinks appreciation for the DPM comes from awareness of and identification with the social model. This reinforces the arguments made by Beckett and Campbell (2015), who call for keeping the model at the core of the DPM, whilst positioning it as an oppositional device to facilitate disabled people's resistance practices. All of the young respondents shared a similar position to that outlined by Regina, which also includes recognition that substantial amounts of disabled people are unaware of the DPM. As Margaret, a young respondent commented:

> I don't think all of them necessarily know [about the DPM] […] but I think they all care […] because the Movement is something that has allowed them to have the opportunities that they have right now. So that in a similar way, me saying, do I care about the Suffragettes movement. Well, it's not something I really think about in my day-to-day life, but of course without it I wouldn't be able to vote.

Margaret's point is important because it frames the significance of caring around the outcomes of the DPM, rather than predominantly on its existence. A commitment to the Movement depends on how the DPM articulates the importance of its actions and how it requires more disabled people to progress its ideas. Margaret uses the example of disability pride and the extensive experience of bullying; she argues that young disabled people will not care about the DPM unless it specifically acknowledges that young people do experience hostility and frustration, and perceive disability as the limitations of their own body and thought processes:

> It's much harder to be involved in a movement that teaches you to really grab that [disability pride] identity if you'd been constantly bullied or that disability is basically what is bringing you down […] they bloody hate it.

In order for people to recognise the importance of a social movement, Carling-Jenkins (2014) suggests it depends on how members gain personally from being involved as well as how social movements achieve their outcomes through the involvement of the membership. The interviews explored this aspect within the DPM by asking respondents to consider what constitutes the individual and collective benefit for contributing and having an active role. As David, a young respondent, suggests:

> I think it is important because they should get the motivation and the inspiration so [they] themselves can aspire to do something more and it's, on a simple level, nice to know that what you're doing is making a difference.

This statement was shared by all young respondents, while others went into further detail to reflect on why wider participation is, or should be, considered important:

> Well, what I want to see from the Movement is essentially just reflecting my ideas and ensuring that, you know, ideas are being pushed across and promoted, but ultimately I am more looking to work for people and not people work for me, so I think that defines a lot of my thinking.

Here, Jeremy is looking for guidance and support from established figures within the Movement. He specifies that he wants to work for other members within the Movement, not lead or have responsibility over groups. This includes the recognition that his ideas are discussed within the DPM and influence its overall direction and purpose, an issue that has continuously been highlighted throughout Chapters Six and Seven.

In order to challenge the current conditions that perpetuate the experience of disability, the DPM has organised around a set of ideas and strategies. However, Rose – a young respondent – suggests young disabled people inherit the ideas of the Movement whilst also attempting to create a new social movement that is more reflective of the demands and ideas of the younger generations of disabled people:

> You both inherit a way […] a theoretical body of thought and a way of thinking, but then you should also be given the freedom to create your own if you wish […] it's not always gonna be the case cos some people don't have the understanding philosophically or psychologically to do that, so they are gonna inhibit people without even realising that's what they're doing cos they won't ask the questions they need to ask in the first place.

This research is not proposing young people are attempting to establish a new, alternative social movement to the existing DPM. What is most interesting from Rose's statement is how young people position themselves alongside the established, adult members; she is suggesting young people should have space to create their own direction, although some may not at present be in a position to achieve this. This is because of limited opportunities to become aware of the politicisation of disability, as well as a lack of support to ensure that learning-disabled people are able to access the DPM. In Chapter Five, established figures suggested young people take control and create their own youth-led networks that can engage with the existing organisations and influential members of the DPM. This may be a sensible approach, but it should not replace the need for the DPM to connect with young people and directly invite engagement. As existing literature demonstrates (Meyer and Tarrow 1998; Elliot and Earl 2018), young people want to interact within the existing debates, campaigns, and activities. Doing so may be perceived by established figures as too much of a risk as the latter attempt to control their image and key demands. Such an argument was reflected in the interview with Kate, a young respondent:

> I think if you come with a perceived very little experience and knowledge and then try to alter things, people clamp down on that. They push against it cos they don't want their little world to be altered […] so yeah – probably not [able to interact the way you want]. I think you'd have to do it more subtly, you'd have to do it longer terms, get in to discussions and […] it'd be a slow process.

Returning to Hillary: she argues that there are opportunities for young people to drive forward new areas of discussion pertaining to disability rights although it encounters resistance from established figures. This creates tension between young people and the wider membership, which can lead to young disabled people's not caring about the DPM's activities:

> I do think that there is space for new priorities to emerge, that are driven by younger disabled people, but I think that it just, it creates layers of tension because of the fact that certain things are so wedded with certain individuals [...] [This means] they don't necessarily care about the disability movement… but I think there's no real indication or very rarely is there an indication that the disability movement gives a toss about them.

The leadership within the DPM must take account of the comments made in this section. Hillary continues her point by outlining the difficulty for young disabled people to create sustainable projects, those which do not require the influence or resources of older, established figures within the Movement:

> [Projects] are generally, at this point, driven by older people that see the need for it and there's nothing wrong with that. But they're the ones that find the money, that create the space then follow through on it. I haven't really seen much evidence of sustainable things that have been driven by young people without collaboration from an existing source.

Young respondents understood the difficulty in accessing resources and funding to create sustainable projects. As Hillary notes, it is against a background of unequal power relations that restrict young disabled people's access to viable options that do not necessitate the involvement of existing projects. It is paramount that the leadership within the DPM creates a dialogue to ascertain what position young disabled people want to achieve within the Movement, and how to facilitate their better representation and diversity amongst the membership. Much of the discourse surrounding young disabled people's participation within activism does not highlight the reasons why people should feel committed and passionate about social movements.

This short section has provided an initial consideration of young respondents' views over whether they feel valued and respected by the Movement, which also requires consideration as to what constitutes the collective benefit from being involved in campaigning and activism. The challenges highlighted throughout Chapters Five to Seven require further discussion by the DPM – otherwise, as evidenced here, questions will be raised as to whether young disabled people will want to gain access to and influence the DPM.

7.5 Conclusion

The chapter argues that the Movement must consider the implications of the issues raised. Were it to fail to do so, there is a substantial risk that young disabled people will struggle to participate within the DPM. This will lead to their further disengagement and the realisation that young disabled people are restricted from articulating their ideas and reflections on significant aspects, such as their reactions to historical accounts of disability activism or the application of the social model of disability. Furthermore, the Movement will lose ground because it will struggle to establish a legacy: dialogue and action that pertain to addressing issues within the social world will inevitably be replaced with a fixation on the internal politics of its own survival and lead to increased alienation. The purpose of the thesis is to highlight the challenges encountered by young disabled people as they attempt to participate within the DPM, and propose a way to improve their inclusion within the Movement. However, if the issues highlighted here are not prioritised by established figures and influential organisations, such a situation will undermine any attempt to ensure that young disabled people have an active, valued, and respected position within the DPM.

The chapter has explored three interrelated issues that have a substantial impact on the sustainability and effectiveness of the DPM: its underlying principles on archiving activism, the local and online mobilisation of young activists, and the notion of members' caring about a social movement. The essence of archiving requires consideration of academic imperialism, as there appears to be a trajectory of higher educational institutions directing the collection, interpretation, and dissemination of disabled people's shared history. This is not, necessarily, detrimental to young disabled people's access to the DPM, although it does raise questions with regard to accessibility and the overall purpose of archiving. The chapter challenges the naive assumption that archives provide an objective account; rather, they can act as a method of destroying, or of providing only selective, histories. Young disabled people are left isolated, partly through being required to retain certain amount of knowledge and history regarding disability activism as a way to justify their inclusion within activist networks. The DPM must play an active role in coordinating the archival process while, at the same time, it needs to ensure the archives highlight the intersectional aspects within the Movement and provide an incentive for young people to participate in disability activism.

The issue of a DPM legacy is further affected by the significance of local and online mobilisation, which – in some circumstances – is not prioritised as a way to support young disabled people's participation within the Movement. Thus, it struggles to be a foundation upon which to realise disabled people's emancipation. This factor may have an impact on the recruitment and inclusion of young disabled people within the Movement, particularly if they experience difficulties in establishing local networks, engaging with established members of the DPM or influencing people who do not associate themselves with disability rights. The importance of online networks is that they provide a viable method to increase participation and support young disabled people to experience activism and campaigning. For the DPM, there needs to be an active pursuit by the leadership to build capacity at a local level so that young people have the skills, resources, and confidence to mobilise effectively. Young respondents offered suggestions as to how this could be achieved. It requires commitment by the Movement to realise this. If no action is taken, this will lead to the further marginalisation of people who want to engage in disability activism, especially for those who are unable to access suitable support. This chapter argues that should the DPM ignore the issues raised, it will, inevitably, lose the support of young disabled people. As highlighted in the final section, there is concern as to whether young disabled people, *en masse*, actually do or are encouraged to care about the Movement. To remain committed to young people, the DPM must consider whether it appears flexible to new ideas and work towards ensuring there is a collaborative effort to value and support newcomers. Remaining committed to the social model is just as important as creating a succession plan, centred on the youth mobilisation and leadership, to protect the longevity of the DPM.

The next chapter builds on the analysis phase by exploring how the DPM may address the challenges highlighted by the respondents.

8. A Way Forward

8.1 Introduction

The research has highlighted a number of key themes affecting young disabled people's participation within the DPM in three areas: membership, the organisation of the Movement, and the issues that affect the future legacy of the Movement. The themes should be read as challenges and barriers serving to restrict young disabled people's access and overall inclusion within the Movement. I argue that young disabled people encounter challenges when attempting to engage in the DPM, particularly surrounding their involvement in the development and dissemination of key demands to realise disabled people's emancipation, as well as opportunities for them to critique the social model of disability. Engagement with young disabled people should not rest on the assumption that young people are involved to offer a youth perspective; instead, their involvement is to contribute towards a discussion and strategy to realise what must be resisted and how social structures need to be organised to create a fairer and just society for all. Doing so may be facilitated by providing safe spaces for young activists to consider what is possible and preferable in the future. Whilst the social model is contested, it would be disastrous for the Movement if it were abandoned. Reviewing the data from this research suggests young disabled people are committed to the social model yet want opportunities to explore its significance and relevance in their lives. For this reason, I argue that the social model should be understood as an oppositional device, as outlined by Beckett and Campbell (2015). This is offered as a way forward to facilitate change, and to reinforce how important it is to include young disabled people in the organisation, demands, and sustainability of the DPM. My argument should be read as a direct statement to the Movement for it to address the challenges, so that young disabled people have an active and valued role within the DPM. I return to some of the key ideas made in the existing literature to reinforce my argument.

At this point, it is useful to review briefly the challenges encountered by respondents. The review will frame the subsequent discussion, as I explore how the findings reinforce the argument for the DPM to understand the social model as an oppositional device.

8.1.1 *Summary of Challenges*

The interviews highlighted young respondents' frustration over their participation (rather, lack of it) in the DPM. The challenges are grouped into three key areas.

With regard to membership, young respondents were frustrated by a lack of opportunity to engage in wider discussions pertaining to disabled people's marginalisation. When they were involved, it typically relates to an expectation that they would learn about disability activism from existing figures and their organisations. This is to safeguard the legacy and work of current, established members within the DPM. When presented with opportunities to reflect on new and existing demands and campaign strategies, young respondents felt their participation was dependent on their providing contributions only on youth-related issues. It was suggested by young respondents that young members were perceived by established figures as naive to the complexity surrounding disability politics. Thus their attempts to reflect on the social model would lead to the weakening of its significance within the Movement. This led to respondents' discussing authority and command within the DPM, as young respondents stated that their membership and participation were dependent upon the actions, behaviours, and ideas of the established members. There was frustration that the DPM appears to operate from a soft leadership approach, with certain organisations and individuals having considerable influence over the direction and organisation of the Movement.

The organisation of the DPM was another area of comment. The emergence of interlinking social movements reflects the various approaches taken to address disabled people's marginalisation. Whilst the essence of interlinking movements does not *per se* constitute a challenge, young respondents highlighted the difficulty of participating within the DPM, as contingents demand a rights-based approach or further radical action. Young respondents suggested there is friction between members and their organisations, as discussions take place over the effectiveness of the DPM and the implications of the different approaches taken by activists. This friction is recognised when considering the position of the social model within the Movement. Although not dismissing its significance to individual members, young respondents highlighted how it becomes a condition of their inclusion within the DPM. Becoming a member of the DPM necessitated showing support for the social model of disability. However, young respondents were unable to assess and explore the principles underlying the model: any attempt on their part to do so was met with criticism and hostility by established figures. This was further complicated by the way in which established organisations within the DPM were aligned with socialism and Marxist thinking. Young respondents not aligned to such ideas felt marginalised within the DPM.

The final area related to challenges that require attention in order to ensure the DPM remains a sustainable and effective social movement – referred to as "future considerations". Young respondents raised concern over the use of archives to capture the shared history of disability activism. There are challenges with regard to the role of academic institutions in the collection and dissemination of the DPM's history, current issues, and debates. Nevertheless, the importance of archiving raised a problem for young respondents, as there was an expectation to learn and retain specific information in order for them to access opportunities to participate in the Movement. The majority of young respondents argued that while archives are important and helpful, they may also be used as a way to restrict participation and to protect the ideas and activities of certain established figures and their organisations. This raised an additional point regarding how to engage in the DPM's activities both at a local level and online. Where young respondents initiated action at the grassroots level or through online social networks, some encountered hostility from other members within the Movement. This would usually include references to the challenges identified above, leading to concerns as to whether young disabled people are indeed encouraged to care about the existence of a DPM.

8.2 Young People's Position

Young respondents' participation in the DPM was typically restricted to situations that necessitated a youth perspective. Established figures and influential organisations in the Movement should take responsibility to create more and wider opportunities for young members to participate. Improving young disabled people's position within the DPM, arguably by disrupting contemporary notions of youth, requires a concerted effort by all activists and their allies to participate in the process. This is essential because a structured leadership network is non-existent within the UK. Unlike the North American DRM, which takes a collective approach to identifying grassroots and State-wide leaders (Foster-Fishermen *et al.* 2007), the UK Movement is assumed to be heavily influenced by specific individuals from established organisations. According to respondents, the activities and demands of the DPM gravitate towards certain members even though it is simultaneously suggested that the Movement is leaderless. For this reason, it would be counter-productive to recommend that improving the participation of young disabled people relies upon the actions of specific members and groups. Instead, the entire network of activists and campaigners must utilise their resources, be it online, local or national, to begin forming strategies as to how young disabled people may be valued members who are indeed part of a social movement to establish a socially just and fair society.

It became evident that young disabled people encounter extensive challenges to their inclusion within the Movement; action must be taken to remedy this situation. Respondents raised notable concerns over how the DPM is currently organised and how, in the majority of circumstances, established members and groups nominally support the inclusion of newcomers. The research found that the DPM is divided amongst its membership; their statements, actions, and behaviour appear divisive and antagonistic when discussing potential strategies to address disabled people's marginalisation. Young disabled people are reluctant to engage in learning or debates surrounding disability activism, out of concern for weakening the arguments and ideas of established figures. Their concerns relate to the pressure to appear loyal to the historical demands and agendas outlined by prominent members within the DPM. This meant young members encountered hostility and claims that they were, inadvertently, weakening the overall position of the Movement and its ideas, among them the social model. Such claims appeared to the DPM to be justified, on the basis that young members are naive and have limited understanding of the key issues affecting disabled people. As a result, young disabled people were either dismissed by established figures and their organisations or are restricted to discussions pertaining to young people.

There is desire and passion by young disabled people to participate in social movements, but these concerns are not receiving sufficient attention from prominent activists and are therefore not prioritised by the DPM. There is parity between what the respondents raised and the work of researchers and activists reviewed in Chapters Two and Three (Barnes 2007; Kelly 2010). Whilst some respondents discussed the existence of separate networks of young disabled people, reinforced by contemporary examples (ENIL Youth; Young DaDaFest), others, such as Christopher, an established respondent, advocated for supporting young disabled people to establish formalised networks that have a specific mandate to address youth issues. I argue that attempting to address the challenges by focusing on the development of youth networks will not ameliorate the anger and frustration felt by social movement members, as they witness the fractious relationship between groups and individuals. Eventually, the divisions and antagonistic relations will be interpreted as vindictive actions; the Movement will further weaken and become consumed by internal defensive strategies to protect its current operations and activities, instead of growing and developing with the times.

Divisions and protectionist reactions may be expected within social movements, as outlined by Tarrow (2011) and Blumer (1969). Thus, the DPM is no different and is trapped within a dichotomy between holistic and fragmented, individualised approaches to addressing the oppression of disabled people. Ellis (2005) challenges disability activists and campaigners who appear to favour civil and human rights frameworks over social rights, rather than strategically mobilising to place extensive demands on public authorities and government infrastructure to meet their obligations. Similarly, Dodd's (2014) research identifies the struggles within the DPM to locate the problem of disablism as a singular issue, which has resulted in activists' adopting gradualist or radical positions through which to tackle economic and social injustice.

It is understandable that crisis-driven agendas take precedence because of the precarious situation disabled people encounter – recent examples of protests, demonstrations, and events (Not Dead Yet UK 2018; ROFA 2018; DPAC 2018) are typically reactive to the situation at play; they do not in fact formulate strategies that reverse the tide of oppression. As Sheldon (2006) argues, the systematic roots of all forms of oppression are downplayed among activists because the DPM, unsurprisingly, becomes concerned with process and policy application.

Here, this research draws attention to the ways in which young disabled people's participation in the Movement may be increased. Young disabled people desperately need access to the DPM to challenge the current marginalisation encountered by disabled people. Achieving this requires building upon the existing networks also to ensure the Movement is perceived as a valuable and effective mechanism for youth participation. The DPM must consider the implications of current activities and question whether there are opportunities to imagine, debate, and create practices that will address various struggles. Whilst it is important to establish effective ways of facilitating resistance, this should be to disrupt the present and visualise the future. It is achievable: by ensuring the Movement questions what constitutes young disabled people's position in the DPM and how young members can be supported to address the challenges raised by young respondents in this research.

8.2.1 *Significance of Activism*

The DPM will need to consider how young disabled people acquire knowledge of disability activism and ensure that the different techniques required for the facilitation of knowledge are accessible, transparent, and open to debate. It has already been identified, in Chapter Seven, that there are existing challenges obstructing newcomers from using archives while, paradoxically, their lack of knowledge of those archives is held against them. Hillary, a young respondent, discusses how there is an expectation placed upon young disabled people to retain specific historical aspects of DPM activity in order to gain favourable responses from established members in the Movement. The archives are essential both to represent the branch of the DPM associated with historical activism and to tell its story; also, they are necessary in order to lay the foundations for building possible futures for present-day activists to explore, critique, and realise. Archiving cannot, nor should it, attempt to mask this issue; rather, the DPM must call for participatory and creative approaches to the collection, dissemination, and interpretation of the materials. The significance of archiving, as highlighted in this research, would suggest that a knowledge of archive material is essential to participating in disability activism.

The DPM should commit to supporting young disabled people – and the entire membership – to consider how the social world should be organised to build an inclusive, fair, and just society for all. This will be achieved by establishing discussion platforms and creating campaigns to support people in their identifying what must be resisted, as well as what their alternatives could be. According to Dator (2008), it is nonsensical to discuss the future in terms of predictions. Rather, the future resembles alternative possibilities that are forecasted. The DPM could envision a preferred future; it could determine the appropriate tools with which to study and explore the future of disability activism and the removal of disabling barriers. This is why it is paramount for the Movement to address the challenges highlighted by young people, as activists will then improve their understanding, i.e., by systematically reflecting on the existing knowledge and formulating ideas from the intersection between historic trends and emerging events.

It is important to note that what is being argued here is not the same as "knowing" the future. Activism and social movements facilitate opportunities to perceive the social world differently, challenging the existing social structures and adherence to conformity to normative practices.

Miller (2011) suggests whilst people are unable know the future, this allows for creative opportunities to consider what may be possible. The DPM should perceive the present as being an abundant resource, encouraging disabled activists to create new forms of action that can provide examples of deviation from the current neoliberal lens of ability and normality. It can lead to the evaluation of existing assets at the local, national, and international levels that, once utilised, disrupt the current social structures and question the basis of their functioning. This builds on the argument made by Richard, a young respondent, when suggesting the DPM must operate at various levels to demonstrate to disabled people that there is a need to challenge the marginalisation they experience. Richard argues for disabled people to mobilise at a local level to capture the interest of others who can support the creation of new strategies through which to address disabling barriers. However, the DPM must take account of young disabled people's current participation and the Movement's failure to challenge its contemporary understanding, thus its apparent rejection, of the role of young members.

This research has identified how young disabled people were unable to question or critique the fundamental principles associated with social model thinking or political ideology for fear of challenge from established figures. The challenges result in young people's being perceived as naïvely weakening the application and position of the model or of the Movement's activities. Young respondents refute this by suggesting the label of youth has restricted their participation and opportunity to debate the "big ideas" within the DPM, as Hasler (1993) calls them. This is because established and influential contingents within the Movement appear to articulate a definitive path towards disabled people's emancipation. In turn, this results in overtly protecting the current trajectory and in the perception of young disabled people as newcomers who will reflect the ideas and aspirations of the existing membership. The established groups, perhaps inadvertently, reinforce a prescribed future based on the current actions, demands, and activities of the DPM. This is not to deny the significance of the underlying principles associated with the Movement, nor to dismiss the anger and frustration of existing members who are critical of specific individuals, organisations for disabled people, and government departments. Such perspectives, histories, and ideas should be available to newcomers, for them to understand the development of disability activism. It is imperative for young disabled people to be aware of how past activists and DPOs were betrayed, marginalised, and abandoned by traditional charities (Trevisan 2016). Nevertheless, it is a mistake for established groups and individuals to restrict or deny the participation of young disabled people who do not share the same history, or for these groups and individuals to refuse to accept who is and is not an ally.

Young disabled members of the DPM should be supported to develop their skills, knowledge, and interests – irrespective of their backgrounds and associations with DPOs, CILs, traditional charities, and unions. This reinforces a point made by Margaret, a young respondent, in which she suggests the Movement should be supportive of the members who have different strengths and knowledge bases. Young disabled people's participation is to provide contingency within the present rather than merely to repeat the preferred narratives among the established figures.

8.2.2 *Significance of Youth Participation*

As Giroux (2009) posits, young people are assumed to take personal responsibility for their development of skills and knowledge. For Giroux, this means young people are dismissed as a generation requiring investment and guidance. The relational character of the State and citizen, markets and public services, consumption and provision, leads young people desperately to preserve the economic productivity of their actions and ideas. By this, I mean that the actions and decisions taken to produce the able body and mind have generated the desire for the individual to demonstrate the economic viability of their demands. As an example, some young respondents explained that the purpose of participating within the DPM was to provide an argument for protecting or improving disabled people's rights on the basis that disabled people become productive contributors to the existing economic frameworks. Thus, providing personal assistance will ensure that the individual may attain and remain in employment – "give us rights and we will become happy workers"! To take this approach, however, implies a need to align the Movement with conforming to the ideals of a viable and productive body, which concludes with the body's being owned by the investors. The perception then becomes that the individual, alongside the pursuit for economic prosperity, should focus on doing good to those who are assumed to "deserve" it, albeit within a personal capacity (Barton 1993). This, the research argues, has an impact upon the promotion of political activity by newcomers to social movements – particularly young people – given that the societal expectation of youth is to "meet up to the ideal of an active, independent, neoliberal subject" and, ultimately, become politically docile (Slater 2015, p. 49).

Above, it is argued that the Movement is perceived, by some, as a way to facilitate disabled people's becoming productive citizens. However, this idea of productivity is rooted in contemporary economic structures and ideology, most notably neoliberalism. There could be concern over fears that young disabled people's vision of the future is one colonised by the values of neoliberalism, and therefore is at odds with other members in the DPM. I contest this argument, as this research shows – in Chapter Six – that the Movement comprises different directions to realise disabled people's emancipation. It is important to improve young disabled people's participation within the DPM and ensure there are opportunities for more members to engage in discussions regarding disabled people's emancipation. Hou (2010), Mahoney (2012), and Facer (2013) suggest that youth involvement within social movements offers the potential to shift the boundaries of what is possible within the existing frame of the present. The key is to become aware of how the social world is undergoing constant reconfiguration as part of the global, technological, and economic developments, which positions the individual at the centre of responsibility and agency (Popkewitz 2007).

Slater (2013; 2015) explored connecting youth and disability. In their research, Slater argues that the dominant understanding of youth is often framed within a narrative of adults-in-waiting, wherein questions rooted in ableist and normative connotations seek to determine how young people will be productive to the functioning of a neoliberal society. Although Slater's research explored aspects of activism, it was not specifically focusing on the UK DPM. I argue that the contemporary understanding of viewing youth as incomplete adults is reflected in the Movement's organisation and trajectories of membership. Returning to the data, Hillary, a young respondent, suggests the DPM struggles to offer young disabled people space to create new ideas because founding members of the Movement are still invested in its organisation. When young disabled people attempt to engage critically with the demands and campaigns, established members interpret these as constituting direct challenges to their actions and original ideas. In mitigation of their response, young members are perceived as naïve and in a process of learning, which results in restriction on their participation. Young disabled people involved in the DPM are under pressure to demonstrate how they will, without question, be compliant in and supportive of the direction proposed by established figures. The DPM can encourage and support young disabled people to think about societal and collective futures. This aspect is reinforced in the argument outlined by young respondents, such as Kate, who calls for young disabled people to frame their ideas and demands for change within a long-term plan. Kate suggests that ideas requiring immediate action will be shut down by established figures, because young members are perceived to have little experience and knowledge of disability activism.

It is not argued that established figures within the Movement are deliberately organising to reinforce this contemporary understanding of youth participation. Rather, the DPM's standpoint is a reflection of the social structures that perpetuate and reproduce this current notion. Lesko (2002; 2012) challenges the assumptions and distinctive characteristics that frame youth and adolescence by drawing attention to how States operate. By elevating the prestige of health sciences and implementing specific policies within education and welfare, governments are able to ensure that an accepted discourse pertaining to youth goes unquestioned. This has the effect of achieving social order and protecting the ideas of the ruling elites. In turn, it extends to creating an environment that determines what is and is not acceptable; thus, conforming to normality. There is similarity between what Lesko and others have described here, on the one hand, and the DPM's demands to address the oppression of disabled people on the other. Activists and campaigners have sought to question those actions of the State that continue to reduce disabled people's living standards (Hollomotz 2012); furthermore, academic activism – predominately led by materialist thinkers – have highlighted the socio-historical context surrounding the perception of disability. As a result, the DPM already employs strategies to question and disrupt contemporary understanding of labels and is best placed to scrutinise the politics of contemporary representations of youth.

Young respondents highlighted the impact of welfare and medical assessments on their understanding of disability, activism and youth. The assessments would reinforce the rhetoric of "deserving" and "undeserving" of support services, which resulted in young people's questioning whether they could identify as a disabled person if the State were to deny them access to essential support. This, inevitably, affected their desire and opportunity to participate in disability activism. By supporting young disabled people to participate in disability activism, the DPM can demonstrate the significance of resisting current practices that define, control, and marginalise specific groups within society. It will go some way towards addressing the inclusivity of the Movement, as newcomers are welcomed on the basis that they participate in the creation of preferable and possible futures, whilst building solidarity amongst the membership. This would address the current challenges, raised by respondents in this research, regarding the inclusion of young people in order for them to offer a particular perspective.

For inspiration as to how this may be realised, the DPM should consider the findings of Slater (2013). Slater's work includes employing a variety of creative methods to ascertain young disabled people's ideas of a future world, as well as a three-month ethnographic study with young members of the ILM in Iceland. The findings highlighted young disabled people's accounts of ableism and the restrictive impact of categorising individuals as "young" and "adult". This provides a useful foundation for the DPM to ascertain how young disabled people are supported to learn about and take part in disability activism. Similarly, activities organised by the youth contingent of ENIL have led to the development and dissemination of suggestions for improving young disabled people's participation. Examples include their collaboration with the Council of Europe to organise Study Sessions on Future Leaders of the Independent Living Movement (Todd *et al.* 2012), and Political Participation of Young Disabled People (ENIL 2018). However, if the DPM is committed to improving the participation of its members, it will need to consider the involvement of safe spaces.

8.2.3 *Safe Spaces*

Through this research, young disabled people are encountering numerous challenges that restrict their participation and may result in a reluctance to engage proactively in activism and campaigning. It is essential for activists and Disability Studies scholars to consider the significance of safe spaces within the Movement, when reflecting on the sustainability of the DPM and its recruitment of new members. As Lempert *et al*. (2012, p. 45) suggest, safe spaces are "central to meaningful expression of missing discourses [...] to reclaiming lost narratives"; thus, the proposal to support young disabled people to articulate activism and emancipation will be realised only if safe spaces are resourced and provided. Respondents highlighted the importance of local and online mobilisation, as well as young people's having opportunity to engage in national strategies to tackle disabled people's marginalisation, thus the idea of a safe space must go beyond geographical boundaries. A safe space for young disabled people is controlled and monitored by young disabled people, offering a space to relax, to express ideas and opinions without fear of hostile reactions. It is a space to debate as well as to facilitate environments in which further knowledge and the creation of new avenues of thought will emerge. These will be celebrated by the people who are part of it and supported by those on the outside.

Young members should be enabled to challenge the rhetoric and practices that currently limit participation, particularly when access is restricted because a youth perspective is deemed unnecessary, ill-founded, or superfluous. To achieve inclusion, there is a need to consider the importance of safe spaces and to review how they can exist or be built upon within the existing organisation of the DPM. This issue is highlighted in a number of ways by young respondents. Regina, a young respondent, referenced networks and programmes that offer young people an introduction into campaigning and activism. An alternative is offered to the radically, politicised groups within the Movement that appear judgemental and intolerant of the ideas and opinions of younger and new members. Regina acknowledges that these networks may not be part of the DPM, yet they are accessible to and supportive of young disabled people. She continues by calling for the Movement to become democratic and for all members to take responsibility and ensure everyone is equal within the DPM. Similarly, Margaret, a young respondent, believes the Movement does not offer support to young disabled people for them to share ideas, nor does it encourage contributions. She demands that the DPM create a "hub" for people to support one another and contribute to the development of campaigns. Polletta (1999) argues for small-scale settings that are part of a social movement while detached from the authority and control of dominant groups; the settings are occupied by individuals who generate the cultural challenge that precedes or accompanies political mobilisation. Such settings are typically referred to as "safe spaces" (Gamson 1996; Coleman 2016), "open spaces" (Haug 2013), and "dense subcultural networks" (Diani 2013).

Whereas much of the literature pertaining to safe spaces explores their application as part of the way people's movements mobilise, the attention here is on the emergence and trajectory of safe spaces within a social movement. The DPM is an established entity, with a history and presence in addressing the social injustices encountered by disabled people. However, young respondents highlighted their difficulty in formulating their own ideas in the context of learning or understanding the historical actions of past activists and groups. They referenced how established figures and their organisations would control and direct their learning process or dismiss their views because of naiveté and a connection to traditional charities, which have a problematic history with regard to disabled people's emancipation. This raises a prominent concern over how safe spaces are utilised by disabled people as part of their activism.

There is limited research into disabled people's development and occupation of safe spaces (Bertilsdotter Rosqvist, Brownlow, and O'Dell 2013; Hodkinson 2014; Johnson 2014), as there is no literature examining the use of safe spaces by young disabled people within existing, established social movements. Scholars within Disability Studies and Social Movement Studies should address this in future research. This creates a dangerous assumption that the protection offered by the DPM, which can provide young disabled people with security and support to resist dominant social groups that reinforce marginalisation, should go unquestioned.

What is being argued should not be interpreted as a call for more numerous youth networks. Whilst important, youth networks are not organised for the reasons outlined above. Some respondents from the established figures group called for young disabled people to have the resources and enthusiasm to establish separate networks; this is a valued recommendation and, to some extent, is already replicated in the UK and globally (Global Youth Network; ENIL Youth; Inclusion Network). However, current examples typically reflect the challenges highlighted throughout this research: young people are predominantly discussing youth issues, which supplement the demands and activities of the influential members in order to reinforce the contemporary appeal of their agendas. It is important to create a distinction between safe spaces and youth networks because the latter are typically established in collaboration with influential, older figures and their organisations. As outlined by Hillary, a young respondent, youth projects are generally, in terms of resources and overall direction, coordinated by established members within the DPM. Introducing the notion of safe spaces into the Movement must extend beyond individual organisations' taking responsibility to provide such spaces for young members and newcomers. It requires a concerted effort by established figures within the Movement to initiate discussion as to how safe spaces can be created to support young disabled people to engage in disability activism.

This does not discount the importance of youth networks within campaigning organisations as there are a number of benefits and positive aspects, such as: increased self-confidence, a greater sense of agency, and enhanced social networking (Roker, Player, and Coleman 1998; Thackeray and Hunter 2010). Many of these youth networks are located in existing organisations and lead to pressure on young disabled people to align with the ideas and narratives proposed by the organisation's leadership, a perception raised by the young respondents.

Sisters of Frida (2016) provide a reference point for what could be envisioned. Established as a collective of disabled women, it aims to provide new and accessible ways of sharing experiences, building mutual support, and exploring the intersectional aspects of identity. Their commitment to creating a platform and building a vision in which disabled women are empowered, celebrated, informed, connected, and valued reflects the argument here for repositioning young disabled people within the DPM. The Sisters of Frida's approach is to disrupt the current expectations of thus imposed upon disabled women, with a commitment to resisting power and privilege. Although this is one example, Todd (2018) calls for the DPM to create safe spaces for newcomers to disability activism. This requires DPOs to become central hubs, facilitating discussions pertaining to new ideas regarding disability rights. Todd recommends having flexible opportunities within existing organisations that allow for non-politicised disabled young people to learn and explore the existing principles to which the DPM currently expects members to subscribe. The latter point is, arguably, a demand to explore the intrinsic relationship between safe spaces and archives.

Further action is necessary if young disabled people are to influence the direction of the Movement. The development of safe spaces should be proposed, organised, and controlled by young disabled people. Safe spaces are essential to support young disabled people's participation. Established figures and their organisations will need to provide opportunities for young disabled people to engage with diverse groups and prioritising this issue to the wider membership. It should not be underestimated that a proposal for new and improved safe spaces will challenge parts of the existing DPM membership. Considering the current fragility and internal politics surrounding disability activism (Oliver 2013; Jacobs 2016; Pulrang 2018), safe spaces for newcomers could be seen as an attempt to threaten existing members' positions; it suggests some members are complicit within a system that perpetuates the challenges encountered by young disabled people. Regardless, if achieved, such expansion would be a chance for young disabled people to question the trajectory of the Movement of their own accord. It would lead to a review of the actions and ideas of the current membership, determining how they affect the possible directions to emancipation devised by young people. This would establish a new set of expectations among the membership, wherein young members of the DPM may choose to read, watch, listen to, and debate with other young people. They will be able to choose to challenge and criticise the ideas of the past, reinterpret the contemporary debates, and offer new avenues of emancipatory action. Ultimately, it is about supporting young disabled people to learn about the past and to operate on a platform of choice.

Through safe spaces, young disabled activists may encourage and support one another also to consider the mistakes made by past activists and organisations, given that perceptions change over time and experience. They may question how previous DPM members have occupied various positions of authority within political, economic, and cultural structures. Their deductions will broaden their knowledge to provide a clearer understanding of how some established figures, including their organisations, appear hostile to them, due to a legacy of betrayal, marginalisation, and exploitation. It is important for newcomers to be aware of such aspects, to prepare for when this inevitably happens again; however, to move forward requires young disabled people to explore what is possible and what may become possible, which necessitates using the resources on offer from organisations that may have a troubled history with specific contingents of the Movement.

If young disabled people choose to use the resources on offer from traditional charities, as acknowledged in some of the interviews with young respondents, then their doing so may reinforce the perceived hostility and anger from some established groups and influential figures. The safe spaces would provide young activists with the opportunity to process the information and become aware of the history surrounding such reactions; nevertheless, safe spaces are paramount if young disabled people are to develop new demands and create resistance-based practices to the contemporary issues that reinforce marginalisation. Drawing on the data, Janet emphasised the need to support young disabled people – particularly people from black and minority ethnic backgrounds – to come together and share experiences in order to recognise that there is commonality among young activists. She calls on the DPM to consider how young members should be supported to engage in activism. Furthermore, Rose, a young respondent, suggests young disabled people need time and space to engage in the Movement and it is essential that they are supported not to feel ashamed or scared by identifying as a disabled person.

This research is the evidence base for demonstrating that change is required. I say this because there is no research exploring young disabled people's experiences of the DPM and the challenges they encounter when participating in the Movement. To improve young disabled people's position within the DPM, the existing membership should identify and specify the ways in which it will protect young people's contributions from hostile or negative feedback. However, this research contends that such an approach could be realised only if the Movement remains committed to the social model of disability yet couples this with an alternative understanding. Rather than recognise it as a tool, the model should be perceived as an oppositional device.

8.3 Social Model of Disability

When reviewing the operational basis of the social model of disability, what was once deemed to be an interpretation of disability, according to a collective of disabled activists (UPIAS 1975), has now undergone extensive critique that leaves it fluctuating between “useful” or “useless” as a way of describing disability. Furthermore, the model is bastardised, which includes its becoming hijacked by the State and utilised in a disciplinary manner (Beckett and Campbell 2015) or as a form of dogmatism associated with the exclusionary measures of determining whether an individual is part of the DPM (Shakespeare 2006).

The social model is key to addressing the concerns and challenges raised by respondents in relation to DPM membership and organisation. During the interviews, there was no indication that the model should be abandoned, as has been suggested by Shakespeare and Watson (2001). Some of the young respondents did call for opportunities to debate the application of the model. They wanted to understand how it was relevant in their lives and whether it could still describe the process and experience of isolation and exclusion from society. This research argues that the desire by some respondents to debate the social model is not a reinforcement for the arguments to reclaim or revise it (Allan 2010; Owens 2015). Instead, it demonstrates the restricted participation of young disabled people to engage proactively with the prominent ideas and concepts of the DPM. It is a reaction, by each young disabled person, to build their own connection with the model, rather than have it imposed upon them by established groups and members. Young members can seek to understand how the model operates and be encouraged to expand their own ideas on how to resist contemporary structures of oppression.

The proposal is to support young disabled people to consider resistance-based practices, as well as to build the collective vision to realise disabled people’s emancipation. However, it will only be achieved if the social model is understood as an “oppositional device” (Beckett and Campbell 2015).

8.3.1 *Positioning the Social Model as an Oppositional Device*

Chapter Two provides a review of oppositional devices, a concept inspired by art and political activism (Holmes 2007). Within Disability Studies, it is presented in order to understand how disabled people create resistance practices and focus on particular goals. As Beckett and Campbell (2015, p. 273) argue, "through positioning the social model as an oppositional device, we are able to analyse the various operations that it performs in the Movement, the distinct and unique questions that the social model allows us to ask and the specific fields of resistance that it opens up". They continue by suggesting this will be useful to activists because it provides opportunities to reflect upon the successes of the DPM, and also to identify both the challenges ahead and the strategies required to address these. This research supports the argument to reposition the model as outlined. Although respondents did not specifically reference oppositional devices, they spoke about the importance of demonstrating disabled people’s struggle to exist within a social world that produces extensive disabling barriers. For this reason, there is scope to argue that this empirical research extends the work of Beckett and Campbell and provides the next intervention along the line of utilising the model as an oppositional device.

Scholars and activists have noted the considerable tension among members of the DPM, as the members continue to articulate demands to address the systematic marginalisation and discrimination encountered by disabled people (Shakespeare 2006; Wilkinson 2009). Others – including activists – suggest it is time to reflect on the historical achievements of the DPM to ascertain how it will advance the struggle for disabled people's emancipation (Dodd 2014; Levitt 2017). I agree that abandoning the social model will be likely to destabilise an already fragile Movement. Young members already experience restricted participation when attempting to explore the social model. If the pressure to show unwavering commitment to the model were to turn into an expectation that they should dismiss it, without their forming part of the discourse to arrive at that decision, the frustration and anger felt by young disabled people will undoubtedly intensify. Even more detrimentally, newcomers would encounter a social movement that appears to grapple with an existential crisis consumed by internal politics, rather than one mobilised to challenge social injustices. In order to improve participation within the DPM there is a need to support young disabled people to offer ideas for the future by promoting the social model as a way of showing possible responses to the questions: what needs to be resisted, how can it be resisted, and what should be the alternative?

It is argued that such an approach is already taken; activists determine the causes of disabled people's marginalisation, mobilise to demonstrate against the cause, and provide recommendations and demands to address the issue (Sepulchre 2018). However, as highlighted in this research, young disabled people are rarely invited or allowed to be part of the process. Instead, they feel pressured to agree with those who have identified the cause, are advised by established figures on ways in which they should demonstrate, and are requested to provide recommendations that will improve the situation for young people: a limited involvement. For this reason, the oppositional device approach offers a way forward. It reconfigures the role of the activist and can provide opportunities to focus on developing resistance practices. It would lead to young disabled people's having prominent positions within the Movement, which will include exploring the causes of disability and developing solutions to the barriers encountered by disabled people. Beckett's and Campbell's proposal has, to date, remained at a conceptual level. They draw on existing literature to understand the various operations of the social model, as an oppositional device, and conclude by suggesting it will be of use to activists. Thus, there are two significant approaches to interpreting the data and findings in this research, both of which agree with Beckett's and Campbell's conclusion.

Firstly, the premise of the oppositional device is reflected in young respondents' understanding of disability and disability activism. Respondents discussed how the model is essential for campaigning and activism. Nevertheless, some, such as Richard, a young respondent, question whether it has become associated with improving disabled people's social position without extensively critiquing the existing economic and political structures. When positioning the social model as a "tool", there is a concern that it is hijacked and used in a disciplinary manner by the State (Beckett and Campbell 2015). Rachael, an established member, is quoted as stating the social model is a tool for activists to utilise in their campaigns and strategies. Whilst this position is acknowledged, and certainly not rejected, the emphasis here is on the better outcomes achieved by positioning it as an oppositional device. At that point in the interview, Rachael had never come across the idea of the oppositional device so it was not introduced nor assessed alongside the notion of the social model as a tool. Subsequent research is required to ascertain how activists would develop their campaigns and activities once introduced to the idea of the oppositional device. Rose, a young respondent, talked about the need to understand how disability equates to a lack of freedom. She lists a number of social processes to emphasise her point, including financial instability and reduced employment opportunities. In these examples, respondents want the model and the Movement to highlight various forms of marginalisation and reinforce the importance of resistance. Richard provides the example of young disabled people's interaction with oppressive medical assessment procedures and the feeling of liberation once young disabled people become aware of a social movement that challenges these institutions and their approaches. For all of the young respondents, the social model facilitated their understanding of the DPM and its role in asserting a need for change.

The second approach is to acknowledge that the connection between oppositional devices and disability has emerged through academic discourse and analysis. Taking into account the concerns and challenges raised by respondents with regard to the role of academia in the DPM, this research is a call for activists to explore the social model as outlined by Beckett and Campbell. With this approach, the research findings outline a number of challenges encountered by young disabled people, which require attention, if contemporary and future disability activism is to benefit from conceptualising the social model as an oppositional device. This will go some way towards addressing the concerns highlighted by respondents such as Kate, who claims the DPM is weakening its overall position by preventing young disabled people's opportunities to explore the significance and use of the social model.

With greater awareness of and support for understanding the model as an oppositional device, it is argued that young disabled people will primarily interact with disability activism as a way of creating resistance practices and promoting an alternative means of being and participating within the social world. The importance of participating in the DPM, for example, in order to develop a shared identity (Kelly 2010), will also be understood as a form of resistance against the social structures that reinforce ableism. Rather, the various reasons for participating within disability activism, as identified through the exploration of interlinking social movements, is captured by a central theme of resistance. The priority to resist, through various capacities, becomes the focal point; it unites members and their organisations. This builds on the objectives outlined by Gabel and Peters (2004) and Gabel, Peters, and Symeonidou (2009), who posit that the notion of resistance is apparent across the various paradigms employed to explain the premise of disability. In practice, this means the diverse reasons for disabled people's engaging in disability activism may appear separate, even contradictory, yet all are united if the DPM articulates its purpose as a form of resistance to the inherent ableism within the social world. This means using the social model to describe how resistance is created and sustained, whilst offering members – in this case, young disabled people – the support to create pathways that disrupt current ableist practices and suggest what the alternatives could be.

So far, it is argued that the findings support the proposal to reposition the social model from being a tool to serving as an oppositional device. This will provide strategies to resist the extensive forms of oppression and strengthen the position of the DPM within the social world, thus would improve young disabled people's access to and participation within the Movement. To achieve this, the DPM, most notably established figures and their organisations, would need to acknowledge the challenges encountered by young people. However, little would be achieved if young disabled people were merely informed that they must act on this proposal. Instead, it is essential they have an integral part in determining whether this proposition is desirable for and useful to the DPM. This requires further investigation and should be read as a call for further research.

At this point I want further to unpack young respondents' understanding of disability and activism, arguing that it is necessary to incorporate such thinking into the strategies that aim to improve young disabled people's participation within the Movement. Doing so will also strengthen the argument surrounding the social model as an oppositional device, as I focus on how young respondents discussed disability in terms of resistance and the challenge this poses for those who perceive themselves as non-disabled.

8.3.2 *Disability Activism and the Social Model*

As highlighted in Chapter Five, increasing young disabled people's participation in activism necessitates disrupting the current social, political, and cultural structures that frame contemporary understanding of youth. Nevertheless, the premise of disability affects how individuals perceive themselves (Priestley 2003) and requires consideration if the DPM is to emphasise the importance of resistance-based practices. All young respondents explained how it felt to be referred to as a "young disabled person"; it was particularly interesting to note how the majority rejected internalising the negative and devalued experiences associated with disability. Instead, they explained how this emerges as a consequence of the way the social world is organised. This is significant because it provides an opportunity to challenge normative practices and expectations placed upon disabled people, as produced and reinforced by an ableist narrative.

Young disabled people involved in disability activism should question what must be opposed in order to realise disabled people's emancipation. Positioning the social model as an oppositional device provides further clarity to activists, especially newcomers to the DPM, because it demonstrates how the concept and experience of the concept and experience of disability has the power to challenge the existing structures that reinforce social control and order. Respondents discussed personal and collective examples of how disabled people are stigmatised and isolated; I argue it is useful to read such narratives alongside the pressure to conform to normality. Furthermore, I argue it is the responsibility of the activist to demand that everybody, disabled and non-disabled, question their interactions with existing political, economic, and cultural structures then determine how these may reinforce the extent of disablement.

This approach situates the DPM as demanding that we escape the illusion of normality by, as Regina, a young respondent, argued, becoming a mirror to question those who deliberately or inadvertently ignore oppression thus, knowingly or unconsciously, prevent emancipation. Social movement members are there to challenge those existing practices that perpetuate contemporary understanding of social order and function. This is what disability activism can indeed achieve and it is what the social model can ensure. Thus, the role of the social model as an oppositional device is to shatter the illusion of normality, to provoke people to question why they conform and adhere to the social practices that are detrimental to disabled people's lives.

Disability activism must illustrate the process of "othering" (Loja *et al.* 2013), by returning to the notion of ableism and focusing on the structures of discrimination and exclusion that establish a hostile environment for disabled people. It must show how there is complicity within social structures, perpetuating this fractured and dysfunctional social world that exploits and marginalises groups that are not favoured under the lens of ableism. As Wolbring (2008) argues, through ableism, specific cohorts of people have justified an elevated level of rights and status over others. Thus, reinforcing the illusion of normality. It is the role of the DPM to challenge this; further, it must acknowledge how the collective organisation of the social world has led to some representations of disabled people appearing as acceptable: by those who reinforce the deeply-rooted beliefs underpinning ableism, showing how they are adaptable and normalised. There are depictions of disabled people who "triumph over adversity" (Mintz 2009). There is the disabled student who succeeds despite the overhaul of the assessment procedures, the Paralympian who achieves in their chosen sport or the volunteer who raises money for a local charity that has lost its funding: they are promoted, even celebrated, because their actions will have limited disruption over the current social structures. Transfer their experiences to a critique of social security in the neoliberal era, or the demand by the DPM to develop an inclusive education system, and the reactions change. There is less sympathy, closer scrutiny, and the demonisation of disabled people who struggle or challenge (Briant, Watson, and Philo 2013; Cross 2013).

Disabled activists can still remain focused on addressing structural issues associated with the exploitation and marginalisation of disabled people. Calls for radical transformation of existing social structures are still valid with this approach. More so, such ideas act as a foundation for young disabled people to critique, challenge, and further explore in their process of developing alternative futures. According to Robert, an established member, disabled activists should devise and initiate radical action in order to create outcomes that will improve the social position of disabled people. He demands that the Movement stop reinforcing a sense of normality through its campaigning, instead mobilising to value difference. Robert argues that the DPM is weakened by being complicit with the existing social structures that create incremental change, which does not benefit all disabled people.

Understanding the social model as an oppositional device leads to the importance of recognising the DPM as a social movement that is relevant to both disabled and non-disabled people. The social model, I argue, is just as applicable to non-disabled people, who are marginalised and discriminated against because of the collective organisation of the social world. However, the fields of resistance that are opened up to disabled activists must extend to illustrate how non-disabled people are exploited within the existing social structures. This highlights the concerns outlined by Margaret, a young respondent, who discussed how essential it was for the DPM to reach out and include non-disabled people as part of its demands for change. If the Movement is to articulate a vision for inclusion, it must highlight and acknowledge the unjust and discriminatory practices affecting those who can be identified as allies of the DPM. As Young (2001) argues, the aim of activism should not necessarily be to reach a shared agreement amongst capacitive agents; rather, it is to stimulate public debate and ensure reflection must take place on certain issues. Thus, improving young disabled people's participation within the DPM necessitates developing ideas that will not only improve the social position of disabled people, but will also draw attention to the precarious situation encountered by many – including those who do not identify as disabled.

For the Movement, this necessitates a review of how it is organised. The DPM could and should use the prominent issue of youth participation as a way to facilitate such debate. This point requires further consideration, especially alongside the findings, because it questions how the Movement at present reacts and responds to the actions and ideas of individual activists. As raised in the interviews, respondents encounter negative feedback or feel attacked by established figures and their organisations if they appear to jeopardise or weaken the DPM's demands. By focusing on the significance of resistance, it is possible to identify and support those members who become isolated, scattered throughout the social world insofar as the mechanics of oppression and normality continue. The activities of individual campaigns, which may appear flawed or unnecessary, then become part of a collective social movement. Their history, affiliation to organisations, and skills become a useful tool for the DPM to use as part of its strategy for emancipatory change. It also brings into question the role of allies within the Movement, an issue that was not the focal point of this research although does require attention (Katt 2010; Blahovec 2015).

8.4 Conclusion

The chapter provided a summarised account of the challenges encountered by young disabled people as they attempt to participate within the DPM. The challenges were grouped around three themes: membership, organisation, and future considerations. They highlighted how young disabled people are restricted by the DPM in their efforts to engage in discussions and campaigns that require a "youth" perspective. If younger members provide ideas and opinions that are counter to those of established figures and their organisations, they are deemed to be naïve to the complexities surrounding disability politics. This was particularly the case when exploring the social model of disability. Young disabled people wanted opportunities to critique its purpose within activism and social movements, but were prevented from doing so, because established figures would argue that younger members would weaken the significance of the model. Young members highlighted their desire to engage in the DPM while requiring accessible routes to learn about the historical and contemporary debates surrounding disability activism.

The chapter argues that the DPM is required to address these and other specific challenges if it is committed to ensuring young disabled people are valued, respected members with opportunities to influence the emergence and dissemination of key demands and campaigns. Such a response is essential because contemporary literature highlights the lack of opportunities for young disabled people to engage in disability activism. Existing members and their organisations are best placed to reflect on strategies thus far to improve recruitment and retention of newcomers to the Movement. The specific challenges raised, from membership to future considerations, require different avenues of investigation. Any action taken must include the collaborative involvement of young disabled people and their existing networks. However, by returning to key literature, and aligning it with respondents' views and ideas, the research proposes a suitable way forward, one that would reposition young activists in the DPM and address the concerns raised by young respondents.

Should the DPM demonstrate its commitment to supporting the participation of young disabled people, the mobilisation of young activists could then centre on opportunities to challenge existing social practices, those rooted in the beliefs underpinning ableism. However, more importantly, it will ensure young disabled people are supported and encouraged to propose creative alternatives that will bring disabled people closer to emancipation. This is key because young respondents highlighted how the mere description of youth restricted their participation within the DPM, as they were predominantly involved only when a youth perspective was required. Furthermore, any attempt by young members to debate and explore the prominent ideas associated with disability activism led to accusations of naiveté from established figures and their organisations. Most notably, this was in reference to the social model of disability.

The significance of the social model was referenced by all respondents, with all young respondents acknowledging its importance in helping them to understand their identity as disabled people. It is necessary to consider how the social model should be positioned in order to improve young disabled people's access to and participation in the DPM. It is proposed that the social model can more usefully be understood as an oppositional device, an idea conceptualised by Beckett and Campbell (2015). This would assist disabled activists to understand how resistance practices are established and what particular goals are trying to be achieved through the existence of the DPM. It is argued that this research extends Beckett's and Campbell's idea by exploring young respondents' understanding of disability and disability activism. Young disabled people's participation within the DPM enables them to take such an understanding and create resistance practices that promote an alternative way of being, existing, and participating within the social world. This is crucial in resisting current social practices that reinforce ableism and develop activities that highlight the extent of marginalisation encountered by various groups. Through the proposals set out in this chapter, activism would facilitate how young disabled people critique the current structural functioning of society. They are able to offer counter rationalities to dispel the illusion of normality and show that disability is a permanent state of resisting ableism.

The next, and final, chapter will summarise the entire thesis and offer avenues for further research. It will reinforce the assertion that this research should be interpreted as part of a wider discourse surrounding the future of disabled people's activism.

9. Conclusion

At the outset of this thesis I explored the prominent debates pertaining to disabled people's situation in contemporary society, focusing on the politicisation of disability and the intrinsic aspects affecting young disabled people's participation within activism and campaigning. This was followed by a review of social movement literature that charted the development and existence of (new) social movements, and how the DPM is understood in this field of study. Building on this, I offered an original account of key challenges encountered by young disabled people as they attempt to participate in the UK DPM. I achieved this by positioning the challenges around three central themes: membership, organisation of the Movement, and future considerations that will affect sustainability. By returning to the existing literature, I was able to propose a way forward. It is one that will address the concerns raised by respondents as well as prompt discussion – within and outside of academia – on young disabled people's position within the DPM. As a result of this research, I have contributed towards an understanding of youth and disability activism by illustrating challenges encountered by British young disabled people as they attempt to participate in the UK DPM. Furthermore, I argue that the Movement can address the challenges by positioning the social model as an oppositional device. This would require activists to explore the premise of resistance in their activities and campaigns. It is also argued that the DPM will direct members to consider alternative possibilities to the current marginalisation encountered by disabled people. Such possibilities can be explored and form part of existing and new strategies for activism, campaigning, and protests – building new alliances when necessary. Focusing on resistance practises, with emphasis on what can be possible, will strengthen the DPM and facilitate disabled people’s emancipation.

In an attempt to provide an in-depth analysis of the questions under investigation, it was decided that interviews would take place with young disabled people and established leaders in the DPM. The purpose of this was to ascertain current direction, points of contestation, and opportunities to improve young disabled people's position. I noted apparent points of frustration held by young respondents as they attempted to engage in disability activism and campaigning. Most notably, this pertained to the notion of youth and the social model of disability. I have argued that their participation is restricted, based on the contemporary understanding of youth engagement. This is problematic because their involvement is deemed necessary providing they offer a young person's perspective on the issues raised. Furthermore, any attempt to critique or challenge existing demands made or strategies used by the DPM is regarded as weakening the position of the Movement, due to established members' perception of young members appearing naive and uninformed about disability activism. This led to expectations of them to absorb (somewhat) inaccessible literature about the DPM and the debates that underpin contemporary thinking on disability and marginalisation. The social model of disability was raised as an example to reinforce this point. Whilst essential to young respondents' identity as a disabled person, there was an expectation to accept passively the dominant understanding of the model as offered by established figures and their organisations.

Central to my argument is how to address the challenges raised by respondents. The research must be useful to the existing DPM and any disabled person who is interested in activism and social movements. For this reason, it is encouraged for the reader to view the central themes, including their derivatives outlined in Chapters Five to Seven, as separate avenues of investigation and action. This is because I consider the research transferable. It is not my intention to make grandiose universalising claims, it is a study to further discussion on young people's participation in the DPM. However, I propose a way forward to improve young disabled people's participation, as an attempt to further discussion and action within the DPM, academia and in activist networks.

I propose that young disabled people be supported to offer critical reflections on the future of disabled people's social position. This approach, whilst focused towards the future, will initiate action in the present. It provides an opportunity for young disabled people, as active members of the DPM, to envision a preferred future that disrupts ableism and builds upon the existing demands and activities of the current membership. This has the potential to challenge the contemporary understanding of youth, which is reflected currently in young disabled people's access to and participation within the DPM. Rather than being perceived merely as "nearly adults", their involvement is to explore alternative possibilities that will address existing disabling barriers. Such an approach reasserts the purpose of disability activism, demonstrating to newcomers why the DPM must employ strategies to resist current practices that perpetuate the marginalisation of disabled people. I argue that young disabled people are best placed to drive this narrative, as is reflected in the respondents' passion and commitment to challenge the practices that has led to their experiences of injustice. Should the DPM follow this approach, it necessitates action to address the challenges highlighted by young respondents in this research – such as issues pertaining to accessing archived material. In order for members to debate and explore ideas about the future, there must be opportunities to reflect on the historical activities and contextualise these within the contemporary situation.

However, this is complicated by how the social model of disability is understood within the DPM. Young respondents were discouraged from debating the model, as it was assumed they would weaken its effectiveness as a tool to realise social change. The arguments to justify such discouragement also reinforce this contemporary understanding of youth, suggesting young disabled people are too naïve and inexperienced to recognise the significance of the model. Thus, I suggest that if the DPM is committed to addressing the challenges outlined throughout the thesis then it should reconsider how the social model of disability is understood. Rather than as a tool, it would more usefully be understood as an oppositional device – as proposed by Beckett and Campbell (2015). They suggest it would support activists and the DPM to create resistance practices and to focus on particular goals towards realising disabled people's emancipation. Their idea suggests that the social model provides disabled activists with opportunities both to reflect upon the successes of the DPM and to identify the challenges ahead and strategies through which to address these. Key to my research is that Beckett’s and Campbell's work has remained at a conceptual level. Therefore, this research provides empirical data to extend their idea and reinforce the argument for understanding the social model as an oppositional device.

The research is important because it is the first study to explore specifically young disabled people's contemporary position within the UK DPM. It investigates young disabled people's experiences and views on the Movement, with a focus on highlighting the elements that restrict their participation. It is essential that the challenges be addressed, otherwise the DPM will struggle to include young disabled people, value their input, and support their personal progression as activists and politicised individuals. As a result, there is now an opportunity to acquire further understanding on youth and disability activism by conducting research into the proposal that I have mentioned. Before outlining considerations for future research, it is appropriate to consider the limitations of this study.

9.1 Study Limitations

With regard to the methodology, Chapter Four provides a comprehensive account of the research process. It reflects on the significance of the sample and the methods employed to collect the data. Here, I want briefly to highlight the research design and consider how the study was limited in its adoption of the core principles underlying EDR. Stone and Priestley (1996) offer a detailed account of what is expected if research is to contribute towards disabled people's emancipation. This study is limited in that I did not reverse research hierarchies and ensure disabled people controlled the research process. It was very much my research, my research aims and objectives, and my interview schedule, with an expectation that respondents would engage proactively with the agenda that I had outlined. The research design did not satisfactorily review the privilege and power I hold as a researcher. A shift to a co-productive strategy, ensuring young disabled people were involved at every point in the research process, would have been welcomed, but was not feasible due to time constraints and a lack of resources. Furthermore, such limitations give rise to questioning the level, if any, of benefit respondents and the wider disabled community gain from the design, development, and dissemination of my research. The thesis would fail to reflect Oliver's (1992) demand that EDR should provide immediate improvements in the material conditions of life for disabled people; however, it is argued that the research is indeed beneficial, as it focuses on ensuring the DPM is an effective, sustainable, and inclusive social movement. Improving disabled people's living conditions necessitates having a movement that accurately reflects such traits.

It can be argued that the research failed to capture the intrinsic challenges encountered by specific cohorts within the disabled people's community. This is in light of the arguments pertaining to the hierarchy of impairment and the failure by the DPM to address issues of diversity. During the interview with Janet, she informed me that my research questions "barely scratched the surface" of highlighting the challenges encountered by black and minority ethnic disabled activists. Although a valid comment, it should be acknowledged that my research set out to explore the situation encountered by young disabled people and did not attempt to investigate issues for specific groups. For this reason, I have suggested that the challenges highlighted should be explored through other research methods to provide clarity as to the significant issues affecting young disabled people’s trajectory into activism and social movements.

9.2 Future Possibilities

It is my intention that this research be received by the DPM as a call for immediate action with regard to young disabled people’s participation within the Movement. I want there to be discussion and reaction by established figures to the outlined challenges that restrict young disabled people from engaging with disability activism. Young disabled people must have a valued, respected position within the DPM and it is the responsibility of current members– alongside young disabled people – to build the foundations to increase participation. If activists and scholars do not agree with my findings, or with the method of analysis I have employed to arrive at the findings, then I welcome the opportunity to debate and consider alternative lines of enquiry. The most important point is that we, disabled activists, act immediately to improve participation and protect the DPM from ceasing to exist.

This research provides one part of the complex narrative that seeks to improve young disabled people's participation in the DPM. As an activist and researcher, I recognise a multitude of avenues to disseminate and continue discussion on the ideas raised throughout the research process. The priority is to ensure the key findings are provided to young disabled people, and to established figures and their organisations within the DPM; as a result, five approaches have been identified. Firstly, every respondent will be offered an informal meeting to go through the key arguments outlined in Chapters Five to Eight. This will be an opportunity to answer points of clarification, acknowledge subsequent reflections post-interview, and identify potential future collaborations. Secondly, it is my intention to explore alternative formats to capture the key findings, such as through video documentation and podcast recordings. In a similar approach taken by Hevey (2016) in his documentary *The Fight for Life*, the identified themes would be part of a commissioned film providing political commentary and analysis on young people's participation within social movements. Thirdly, a collaboration with LDA and NDACA would lead to opportunities that captured the importance of youth and disability activism. Alongside the articles and exhibitions that explore disabled people's struggle for emancipation, there is potential to challenge readers and audiences to engage with the issues highlighted by respondents. Disabled people and their allies would be prompted to question what action can be taken, both individually and collectively, to improve young disabled people's participation within the DPM. Fourthly, a series of articles and a monograph would be published that unpacked the complexity surrounding young disabled people's participation in the DPM. This would take account of the relationship between academia and activism, as well as the influence of political ideology upon the organisation of the DPM. The intention is to stimulate discussion within academia, questioning the responsibility of academics to support the sustainability and effectiveness of the Movement. Finally, the recent national and European events to explore key issues pertaining to disability activism, such as the National Disabled People's Summit (Oulds 2017) and European Freedom Drive (ENIL 2017), provide platforms to discuss the future of the DPM. This would be an opportunity to raise the challenges encountered by young respondents and seek collaborative strategies among newcomers, established figures, and their organisations, to provide solutions to the challenges raised.

In terms of future research, there is a lack of intersectional analysis of the challenges that restrict young disabled people's participation within the Movement. This focus could highlight how aspects of membership, organisation, and future considerations are experienced differently by young disabled people with differing backgrounds and identities. As highlighted by Janet’s statement earlier in the chapter, it is not my intention to reinforce the false assumption that disabled people are a homogenous group. Nor do I dismiss the importance of exploring how various forms of oppression and privilege can affect young disabled people's participation in and access to the DPM. It is essential to perceive the findings as an instalment along a line of much-needed research to understand the complexity surrounding young disabled people's experience of activism and social movements. This also means that Social Movement Studies would benefit from drawing upon research captured within Disability Studies, as there is surprisingly little research about the DPM in such disciplines.

To summarise: the research has identified challenges that restrict young disabled people’s participation within the DPM, and has proposed a suitable approach to address such challenges. I am arguing for the DPM to facilitate young disabled people’s opportunities to develop their ideas about preferred futures that will bring about the removal of disabling barriers. To realise disabled people’s emancipation requires immediate action, which is part of a long-term plan. This approach will initiate action in the present, as the DPM develops strategies and campaigns to work towards and build upon the ideas suggested by young activists. Understanding the social model as an oppositional device provides an effective way of supporting DPM members to consider what needs to be resisted, within current social structures, and what the alternatives could and should be.

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Appendices

Appendix One: Respondent Information Sheet

LIVERPOOL JOHN MOORES UNIVERSITY

Title of Project

These Days Are Ours: Exploring Young Disabled People's Experiences and Views of the Disabled People's Movement

Name of Researcher and School/Faculty

Mr Miro Griffiths, Graduate Teaching Assistant and PhD Researcher,
School of Humanities and Social Science, Liverpool John Moores University

You are invited to contribute to a study. Please read this sheet carefully and let me know if you require any further information. You are under no obligation to accept this invitation and should only take part if you wish to do so. Thank you for your attention.

If you require the information sheet, consent form or any other material relating to this study, in an alternative format then please contact Miro Griffiths. Documents are in 'Word Doc Formats' to ensure they are accessible to screen reader technology; however, a voice recording of the text can be provided. Unfortunately, due to resource limitations, Braille and easy read versions are not available; nevertheless, if you require such formats then please contact Miro Griffiths who will discuss your access requirements and attempt to meet them as best as possible.

1. What is the purpose of the study?

To explore how young disabled people are active in addressing barriers experienced by disabled people, and the importance of the Disabled People's Movement to lead campaigns and challenge current agendas that impact on disabled people's participation and inclusion within society.

2. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do you will be given this information sheet and asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw will not affect your rights/any future treatment/service you receive.

3. What will happen to me if I take part?

Participation involves being interviewed by a researcher (Mr Miro Griffiths) for approximately two hours, in which you will be asked a number of questions relating to your view and experiences of Disability Rights and the Disabled People's Movement. The interview will be recorded with a Dictaphone/computer software. The whole study should last no longer than two hours and thirty minutes. This may appear a long time but it takes into account the possibility of any comfort or support breaks that may be required during the interview process.

4. Are there any risks / benefits involved?

You will have the opportunity to contribute to a piece of research which is expected to develop recommendations for addressing recognised barriers and support the involvement of young disabled people within the Disabled People's Movement.

There are no known risks to participating.

5. Will my taking part in the study be kept confidential?

All data recorded during the research will be made anonymous. Hard copies of personal data will be stored in locked cupboards or filing cabinets and any electronic data containing personal information will be stored securely on Liverpool John Moores University password protected computers. Personal data will not be stored on USB drives or other portable media and will not be stored on home or personal computers.. Your data may be used in the analysis section of the research; however, your personal details will not be associated with the presented data. After five years all data will be destroyed.

This study has received ethical approval from LJMU's Research Ethics Committee

Research Ethics Committee Reference Number: 15/HSS/021

Date of Approval: 14/01/2016

Contact Details of Researcher

Mr Miro Griffiths MBE BSc MA AFHEA

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If you have any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate.

Appendix Two: Advertisement

LIVERPOOL JOHN MOORES UNIVERSITY

PARTICIPANT LETTER/EMAIL/POSTER

Mr Miro Griffiths MBE BSc MA
Liverpool John Moores University
John Foster Building
80-98 Mount Pleasant
Liverpool
L3 5UZ
p: 07835 413 238
e: M.Griffiths2@ljmu.ac.uk

Hello,

My name is Miro Griffiths and I am a PhD Researcher at Liverpool John Moores University. I am currently conducting research into young disabled people's participation and/or interest in the Disabled People's Movement.

I am wondering whether you would like to take part in the study?

I intend to interview fifteen people across the UK who meet the following criteria:
- You identify as a disabled person

- Participants are born and living in the United Kingdom

- You identify as young disabled people, aged between 18-30 and consider yourself interested/or in the Disabled People's Movement

OR

You are considered a leader/influencer/established member within the Disabled People's Movement

If you decide to participate, we can arrange an interview that will last up to two hours approximately, at a time and place which is convenient for both of us. Before taking part, I am more than happy to answer any questions you might have and there is an information sheet attached to this letter. There is no requirement for you to participate so if you would rather not be involved then it is absolutely fine and you do not need to contact me at all!

If you have any questions or would like to take part in the study, could you please contact me (details are above).

I look forward to hearing from you.

Yours faithfully, Mr Miro Griffiths

If you require the information sheet, consent form or any other material relating to this study, in an alternative format then please contact Miro Griffiths. Documents are in 'Word Doc Formats' to ensure they are accessible to screen reader technology; however, a voice recording of the text can be provided. Unfortunately, due to resource limitations, Braille and easy read versions are not available; nevertheless, if you require such formats then please contact Miro Griffiths who will discuss your access requirements and attempt to meet them as best as possible.

Appendix Three: Consent Form

LIVERPOOL JOHN MOORES UNIVERSITY

CONSENT FORM

Title of Project

These Days Are Ours: Exploring Young Disabled People's Experiences and Views of the Disabled People's Movement

Name of Researcher and School/Faculty

Mr Miro Griffiths, Graduate Teaching Assistant and PhD Researcher,
School of Humanities and Social Science, Liverpool John Moores University

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights. ☐

3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐

4. I agree to take part in the above study and the interview will be recorded with a Dictaphone/computer software. ☐

5. I understand that parts of our conversation may be used verbatim in future publications or presentations but that such quotes will be anonymised. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature
Name of Person taking consent	Date	Signature
(if different from researcher)		

Appendix Four: Interview Schedule

LIVERPOOL JOHN MOORES UNIVERSITY

Interview Questions (Young People)

Welcome and Formalities –

Provide background to study, and go through information sheet and have them sign consent form before starting.

Need to reassure that personal narratives will not be included as they can be easily identified - highlight importance of anonymity. More interested in what they speak about conceptually and philosophically.

Give a quick run through of what will be discussed and ask them to introduce themselves (cover the following):

- Can you confirm your name?
- What's your age?
- How would you define your gender?
- What area of the country do you live in?
- Do you consider yourself to have an impairment/health condition?

Questions –

Identifying as a young disabled person:

- What does the term disability mean to you?

(link to disability rights, other people's responses, identifying as a YDP)

- How would you define the DPM?

(DRM difference, membership status)

Getting involved in disability issues and the DPM:

- So take me through the process as to how you became involved in the DPM?

(influential figures during that phase, current influential figures, 'leaders' term and skills required, why involvement)

Current involvement in the DPM:

- Do you collaborate with other young disabled people in the movement and is that important?

(other description of involvement, types of activities and campaigns)

Structure of the DPM:

- What are the main principles of the DPM?

(relevance/implication of social model, decision-making processes, influencers, sense of solidarity/disagreement, DPM concerns)

- Where would you go if you wanted more information on the history or current workings of the DPM? How easily accessible is the information?
    - Do you feel the Movement’s activities are being archived? [Is that important, who has ownership of that, what are the consequences]?
- Is it important for non-disabled people to be aware of a social movement of disabled people in terms of DR?
- Do young disabled people care for a movement and why [Researcher Notes: basis of care in the present situation, links to a past we reimagine and future we hope to experience]?
    - Is there two way process linked to what the person gets and what the Movement gets from them? Is this important?

Now and the future:

- What would you say are the current priorities for the DPM and how do you feel about them?

(feeling of control over direction, involvement of youth - known barriers/support, own support for inclusion)

- Do new members of the DPM inherit a ‘world’ rather than create a new one?

(Prompts: own leadership status - within/others, life outside involvement)

Formalities Continued –

Questions? Clarify when transcript will be processed and if they want to receive it - Change of name in the text, Use of quotes, PhD published.

LIVERPOOL JOHN MOORES UNIVERSITY

Interview Questions (Influential Figures)

Welcome and Formalities –

Provide background to study, and go through information sheet and have them sign consent form before starting.

Give a quick run through of what will be discussed and ask the following:
name, age, gender, area, impairment/health condition

Questions –

Identifying as a disabled person:

- What does the term disability mean to you?

(link to disability rights, other people's responses, identifying as a YDP)

- How would you define the DPM?

(DRM difference, membership status)

Getting involved in disability issues and the DPM:

- So take me through the process as to how you became involved in the DPM?

(influential figures during that phase, current influential figures, 'leaders' term and skills required, why involvement)

Structure of the DPM:

- What are the main principles of the DPM?

(relevance/implication of social model, decision-making processes, influencers, sense of solidarity/disagreement, DPM concerns)

- Where would you go if you wanted more information on the history or current workings of the DPM? How easily accessible is the information?
    - Do you feel the Movement's activities are being archived? [Is that important, who has ownership of that, what are the consequences]?
- How has the movement achieved public prominence? Has it influenced public perceptions of the DPM's struggle and vision?

- Do young disabled people care for a movement and why [Researcher Notes: basis of care in the present situation, links to a past we reimagine and future we hope to experience]?
    - Is there two way process linked to what the person gets and what the Movement gets from them? Is this important?

Analysing the movement:

- What provided a foundation for action that eventually led to the DPM's existence?
- Throughout the DPM's history, who are the key influential figures leading protests, producing literature and working to create change?
- Where there collective voices, i.e. organisations and groups working together? How did their relationships develop and did any breakdown?
- Can you recount any significant actions or events that affected the direction of the movement?
- Where was movement formed and what was happening in the country at the time? And at the international level?
- Do the individual member's expression of their struggles and disablement differ from the wider movement?
- How have groups formed within the movement?
- What ideologies have been embraced to facilitate the sharing of the DPM's vision?

Now and the future:

- What would you say are the current priorities for the DPM and how do you feel about them?

(feeling of control over direction, involvement of youth - known barriers/support, own support for inclusion)

- Do new members of the DPM inherit a ‘world’ rather than create a new one?

(own leadership status - within/others, life outside involvement)

- Going back to one of my earlier question about leaders, would you say there are young people in current leadership positions in the movement? How have they achieved that status?
- Take me to a moment in the future, how does society function?
    - What are the opportunities for disabled people, particularly young disabled people?

Questions? Clarify when transcript will be processed and if they want to receive it - Change of name in the text, Use of quotes, PhD published.