Discourses of Disabled Peoples Organisations - Theo Blackmore and Stephen Lee Hodgkins.

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Introduction

This chapter considers the discourses of Disabled Peoples' Organisations (DPOs). Drawing on the work of Michel Foucault and Pierre Bourdieu we explore the rise of the disabled people's movement in recent history, the development of DPOs and their gradual colonisation, moving from a radical political and social movement to pseudo government agents. Using notions of power and resistance from Foucault, and capital, field and habitus from Bourdieu, opportunities and challenges for DPOs are explored. These are critically considered in terms of the implications for the project of impairment-management, inclusion, and the preservation of the cultures of disabled bodies, minds and identities.

Disabled Peoples' Organisations in the UK

The history of disabled people and their organisations in the UK is a very brief one. There

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are clear instances where collectives of disabled people have mobilised for political aims – e.g. war veteran protests, or the blind workers strike in Derry, Northern Ireland in 1939 (O' Cathain, 2006). The first manifestations of political activism by disabled people can be traced to the nineteenth century (Braddock and Parish, 2001:13). One of the first self-advocacy organisations was the 1890 British Deaf and Dumb Association (BDDA). The BDDA initially organised in direct response to the International Congress's sign language ban, and the view that deaf persons did not need to be involved in matters concerned with them. This political movement sharply contrasted with the contemporaneous exploitation of disabled people as freak show attractions, and the ascendancy of the eugenics era (Braddock and Parish, 2001).

In the 19th century, disability became a subject of study and research (Alt, 2004). This moved the experience of disability away from the subjective, individual experience towards an objective stance which dehumanised the experience of disability. Braddock and Parish describe the 19th century as the century of institutions and interventions (Braddock and Parish, 2001:39). Schools and institutions for persons with physical disabilities, deafness, blindness, mental illness, and intellectual disability took root throughout Europe and North America. Professionals developed differential diagnosis to particularise disability and devised treatment interventions and educational schemes focused on specific impairments. The medical notion of defining and classifying disability became thoroughly accepted in this century. However, the segregation of individuals with similar impairments also afforded disabled people opportunities to begin

to develop group identities. By the close of the nineteenth century, deaf people

advocating for manual education and control of their own schools had begun to coalesce

into the first disability political action groups. The emergence of this militant positioning

can be seen elsewhere, such as the blind workers protest on February 28th 1939 in Derry,

Northern Ireland (O' Cathain, 2006). Led by McDermott and McGoven protesters

marched from their workplace to the town hall with banners reading 'Blind, but not to the

hard facts of life' as an action against the low pay and poor employment conditions.

However, with disability conceptualised as an extraordinary medical problem came the

view that biophysical 'abnormality' or 'maladaptation' leads to, or is the cause of, social

'abnormality' or 'maladaptation' (Hughes, 2002:60). In other words, to be defined as a

'flawed' body is simultaneously to be defined as incapable of adequate social

participation. The increasing segregation of disabled people into separate provision, away

from the mainstream of life, would have reinforced and strengthened this link between

physical and social maladaption. This dominant discourse about disability led to the

eugenics movement in Europe and America, and the sterilisation and segregation of large

numbers of disabled people (Braddock and Parish, 2001:38-39). Nazi Germany offers the

most extreme example of the eugenics movement, where about 200,000 people, in

particular those with a mental illness or congenital malformation, were exterminated in

the hospitals and death camps because of their disability (Ravaud and Stiker, 2001:502).

It was not until the 1960-70s in the United Kingdom, with the rise of liberatory identity

politics, that disabled people began to self-organise in a significant way and offer an alternative discourse of the body and mind. In the 1960s and 1970s there was a very strong tradition of charitable fund-raising in the disability sector, which was controlled by non-disabled people, and relied solely on projecting the disabled body and mind as deserving and needy. Anti-discrimination legislation had yet to be created. Disabled People's Organisations (DPOs) – created, controlled, and populated by disabled people - began to challenge the established medicalised, individualistic, and tragic disability discourses. DPOs were, and are, created, and controlled by disabled people in response to needs and wants, defined by themselves, for themselves. This created a unique organisational culture that embraced and valued the voices and experiences of disabled people from the perspective of equality and dignity.

The story of the lobby by disabled people in the UK begins with Paul Hunt's (1972) letter to the Guardian newspaper, which led to the creation of the Union of the Physically Impaired Against Segregation (UPIAS) and the beginnings of the social model of disability (Pfeiffer, 2000) as expressed in the UPIAS Fundamental Principles of Disability (1975). This document is regarded as the 'year zero' (Shakespeare, 2006:14) of the social model of disability in the UK. Other organisations led and controlled by disabled people formed around the latter part of the 20th century included the Disablement Income Group in 1965, Disablement Information and Advice Line in 1978, the United Kingdom Disabled People's Council (UKDPC, formerly British Council of Disabled People, BCODP) in 1981, the Direct Action Network in 1993 and others. Each

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contributed to an increased recognition of disability as a collective identity marker and minority grouping that was subject to prejudice, discrimination and exclusion. These organisations provided community development and leadership for disabled people, often developing solutions and running projects to advocate inclusion and equality.

To root this new political and social movement firmly within the control of disabled people, strict guidelines were created to define DPOs, their constituents, and their authenticity. The British Council of Organisations of Disabled People, later known as The United Kingdom Disabled People's Council, defines a DPO as 'an organisation whose constitution requires it to have a membership and managing board with a majority of disabled people, and whose objectives are the rights and equality of disabled people. DPOs subscribe to the social model of disability and are committed to the human rights of disabled people. DPOs work for the empowerment of disabled people either implicitly or explicitly' (UKDPC, 2010:1).

In the 1970s the disability rights movement took a very firm stance about whether an organisation could truly call it an organisation 'of' or 'for' disabled people. The British Council of Organisations of Disabled People – which later became the United Kingdom Disabled Peoples' Council – created stipulations for organisations 'of' disabled people to include a management committee made up of a majority of disabled people.

In England, DPOs have experienced significant growth and diversification since the

1970s. The UK has an ever-increasing number of voluntary sector organisations, ranging from small community groups to international charities with bases in many countries. DPOs represent a minority within this sector, with the estimated number of DPOs in England ranging between 650 - 1000[1]. Their impact has been huge, furthering a radical social policy agenda and redefining meanings of social care, independent living and inclusion. Within current government legislation and initiatives there is a drive to populate public services with DPOs, to root statutory services within the populations served, and to drive forward the project of inclusion for disabled people. DPOs are currently positioned as essential drivers for social policy reform. This can be seen as the professionalisation of DPOs and represents their colonisation as pseudo-governmental bodies. It can also be seen as an attempt to mainstream aspects of the disabled body, mind and lifestyle through state guided intervention.

In 1972 at the University of California, Berkeley, USA, the first Centre for Independent Living (CIL) was established initially as a self help group run by disabled people to increase participation and access to the academic experience. From this the development of local CILs were seen as relevant for improving the lives of disabled people. Significant also was the American Congressional amendment of the Rehabilitation Act 1978 to establish 'comprehensive services for independent living' (Barnes, Mercer & Shakespeare, 1999: 148). By the 1980s British DPOs, the Derbyshire Coalition of Disabled People and the Hampshire Coalition of Disabled People had each developed

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Centres for Independent Living, the latter forming largely out of 'Project 81'.

Project 81 was a 'consumer-directed housing and care' initiative, managed by disabled people. Here a group of disabled people convinced the local authorities that the financing of residential care could be re-appropriated and used to resource community support options (Barnes et al, 1999: 149). Disabled people convinced the Local Authority to hand over money and resources directly to disabled people, instead of merely paying for them to live in care settings. This set a new, radical social policy standard and brought together social care professionals and disabled people to create a new policy initiative. This specific initiative marked the birth of the independent living movement in the UK and can be seen as responsible for the introduction of the current 'personalisation' agenda and approach to social care reform.

The European Network on Independent Living was formed in 1989, following which the United Kingdom Disabled Peoples Council set up the United Kingdom Independent Living Committee to forward the campaign for disabled people to have a the right to independent living. In 1996 the National Centre for independent Living was set up by UKDPC to focus specifically on policy development and to lobby government on direct payments, which was put on the statute books through the Community Care (Direct Payments) Act in 1996[2]. As a result many local DPOs were awarded contracts to deliver direct payment support services to disabled people. These contracts have contributed to

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significant growth and sustainability for DPOs. This echoed the call by Vic Finklestien for disability professions to become truly allied to the community and set a radical social policy standard, whereby passive users move to the role of active self direct support managers (Finklestein, 1999). A key text 'Independent futures' (Barnes & Mercer, 2006) critically evaluated disabled people-led services, identified challenges facing their development, and listed the added value such organisations bring to the delivery of support services for disabled people. Independent living has proved to be a powerfully resistive discourse charging the issue of impairment with much political capital (Barnes, 2002).

We will now explore some key concepts from the work of Michel Foucault and Pierre Bourdieu, and then apply these understandings to current issues concerning Disabled Peoples Organisations in the UK. Foucault's work is relevant to DPOs through his commentary on power and resistance, and how oppressive norms of knowledge can be critically reworked and their meaning undone so as to understand alternatives. Such as disabled peoples collective identity and the way their organisations have established activities around social model principles in recent years. The work of Bourdieu's is useful in this respect in the way it provides explanatory power for the capital resources at play within human actions and interactions. These capital transactions can be fruitfully examined internally within disabled peoples' organisations and their everyday acts, as well as externally within capital transactions between DPOs and other organisations and the world at large that contribute to social change and policy reform.

Michel Foucault (1926 – 1984)

While Michel Foucault (1926 – 1984) lived with HIV and produced two significant volumes, *The Birth of the Clinic* (1963) and *Madness and Civilisation* (1961) that give a history of the development of structural conditions that made visible and oppressed the 'abnormal' body and mind, he was not known in his lifetime as a disabled person, neither personally nor politically. Since his death however, a number of studies have considered the relevance of Foucault's work to the phenomena of disability and impairment (see Tremain, 2005). Foucault's work has also generated a critical qualitative research method know as foucauldian discourse analysis (Carabine, 2001). This offers a lens through which to identify and read discourses as both subject to, and productive of, aspects of power and knowledge. For Foucault, discourses are considered as systems of representations and signifiers.

Key to Foucault's work is the drive to question everything, partically spelling that which is considered natural and inevitable. He asserts his stance as 'hyper or pessimistic activism' (Tremain, 2005: *vii*) and although his work can be positioned as structuralist and/or post-structuralist, as he rejected these labels he is perhaps better considered a critical theorist. This resistance to traditional philosophical categories and positions, along with his overall rejection of objectivity, in any form, has invoked critique and disapproval. Part of the criticism is that Foucault's work is nihilistic and suggests a

passivity in relation to human action, conduct and politics. However, there is value in his work in the way in which his ideas illuminate the darker aspects social control and regulation. Through which we can become aware of everyday dangers that permeate human oppression, and so make 'ethico-political' choices to resist them (Tremain, 2005).

Central to the work of Foucault is the relationship between power, knowledge and discourse. For Foucault, power is a productive and shared resource, operating across the realm of social life, ever persistent in the transmission of knowledge forms and regimes of truth. In this way the expression of power through human action is never centrally located nor specific. Neither is it only negative, seeking to control, but can be reformative, generating pleasurable alternatives. Rather power circulates through a web of human social relations, connecting and engaging people as both the oppressed and oppressor, the liberated and liberator, the ethical and unethical, the powerful and the powerless.

Foucault further asserted certain types of power, such as biopower and disciplinary power (see Foucault, 1972: 1975: 1976). Biopower is a technology, emerging in the late eighteenth century for managing populations, by the surveillance and record keeping of our births, deaths, reproduction and dysfunction. Disciplinary power is the mechanism or training of the actions of bodies to produce and regulate desired behaviours, through the construction of particular space, time and structure. Such as the construction of psychiatry and the establishment of the asylum (Foucault, 1961). Only through power is

truth, and the knowledge of truth achieved and maintained as realistic and factual aspects of the human experience. Power organises and wields itself to be known as true, through a regime of truth, or truth game. Thus humans can never know objective truth, because its very expression is also an assertion of social control. We never tell the truth, rather we reveal ourselves according to our variable positioning in space, time and structure. Such as the reluctance of humans to accept mental health issues as an inevitable aspect of human life, rather than something that must be treated, managed and corrected (Foucault, 1961). Crucially, Foucault also asserted that, linked to power is also resistance to it. Power can be subverted and reclaimed into positions of resistance that rework oppression and create everyday opportunities for equality and liberation to emerge. Contrary to the nihilist criticism Foucault receives, this suggests that no matter how powerful or oppressive a system maybe, it can be resisted. The social model, the disability discrimination act and direct payments can be seen as moments of disabled peoples' resistance to their degradation and institutionalisation. This is because, in line with Foucault's thinking, resistance can be seen as ultimately an expression of power. Power is taken as agentic and relative, not centralist nor oppositional but part of, and connected to unique struggles and fluctuations in truth values.

For Foucault power/knowledge are expressed through discourse. Discourse, is a system of representation and signifiers, where rules and practices apply to set the tone and detail of what, and how topics and concepts can be constructed. This includes the text and spoken words, but also other signs, forms and mediums of expression, such as the body,

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or a map. However, language is not to be taken as value neutral, nor merely a linguistic concept, but rather considered as a form of social action and knowledge practice (Foucault, 1972). Discourse provides a way of speaking and knowing things through language. Statements or concepts of certain knowledge objects, such as disability that drift towards, or support common institutional strategies or ideological patterns are drawn from shared repertoires and discursive formations. Therefore, 'the statement (*of disability)* is not in itself a unit (*of reality or meaning)*, but a function that's cuts across a domain of structures and possible unities, and which reveals them, with concrete contents in time and space' (Foucault, 1972: 87, *our italics*). It is only discourse that produces units and objects of knowledge, does so it certain ways, without which meaning about them can not exist. This does not deny our realities of, say disability, but rather reminds us that they are versions of it, variable, influenced and related to actions in previous times, spaces and structures. So, disability discourses are cultural discourses.

Through a Foucauldian lens therefore, disabled people and their impairments become artefacts of knowledge interaction immersed in historical, social and political structures that have been instrumental in regulating and organising the human body and mind within a context of economy, civil society and community. Foucault's work reveals disabled people as subject to the power of the norm regulating systems that favour ability and rationality and posit the discursive boundaries and pathologies of dysfunctional bodies and minds. The contribution of Foucauldian theory to disabled peoples lives has been argued elsewhere as limited in that it has a tendency to presume disabled people are

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merely subjected to power, and not agents of it (Hughes, 2005). This overlooks as Hughes suggests the reconstruction of disabled peoples status and equality that liberatory social movements have achieved in recent years. Disabled people have organised themselves as a voice of change through the formation of a political collective movement and establishment of their formal organisations. Using Foucault, the actions and achievements of DPOs can be read, as resisting and countering disability oppression, as well as being part of the production of both emancipatory and disciplinary power. These are not just in the grand ideas, such as the social model or legislative change, but also in the personal moments of acceptance and pride about impairment that DPOs work constantly too communicate in their daily work. However, part of the difficulty with Foucault's work is found in its dark and nihilistic implication of humankind. Indeed as he stated 'not everything is bad, but everything is dangerous' (Tremain, 2005: vii) suggesting the need to be ever watchful of ourselves as simultaneously both the oppressed and oppressor. But this is not a bad thing to bear in mind. For DPOs it is an important message to reflect upon as they increase their activities to deliver services for disabled people and are written into state governing policy.

We will now examine the work of Pierre Bourdieu.

Pierre Bourdieu (1930 – 2000)

Pierre Bourdieu (1930 – 2000) focused on an individual's use of resources, or capital,

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within communities of interest, to resist, adapt and utilise. Bourdieu's work has been used in many disparate fields since his death to illuminate the dynamics of social conduct and interaction, and has had an enormous impact on a variety of different fields of academic enquiry (Fowler, 2003:487). Bourdieu's theory of practice uses the notions of field, capital and habitus to explain and understand human action and interaction. In his 1979 work *Distinction: A social critique of the judgment of taste*, Bourdieu produced an equation that expresses 'practice' as the combined effect of habitus, capital and field.

To explore Bourdieu's theory of practice in relation to Disabled Peoples' Organisations (DPOs), we will start with Field.

Bourdieu represents the objective world as field. Field is defined as, '...a network, or a configuration, of objective relations between positions objectively defined…' (Bourdieu and Wacquant, 1992:72-73). For our analysis we can construct many different fields within which DPOs operate, from the macrocosmic, national field of governmental legislation and policiy initiatives, to the local level of individual DPOs interacting with their local authority, with other DPOs , User Led Organisations (see UKDPC, 2010) and other third sector service providers (depending on the field-specific, local project).

The second element of Bourdieu's theory of practice is the notion of capital. For Bourdieu, the social world is accumulated history - he states that if the social world is not to be reduced to a discontinuous series of instantaneous mechanical equilibria

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between agents who are treated as interchangeable particles, one must reintroduce into it the notion of capital (Bourdieu, 1983:242). And this means capital in all its forms, and not solely in the one form recognised by economic theory. All forms of capital can be accumulated, or lost, from one moment to the next.

Bourdieu uses many different forms of capital, both explicitly and implicitly in his work. The notion of capital relates to resources that can be 'traded' or exchanged for other useful resources. The traditional notion of capital relates to economic capital, whereby money can be exchanged for particular, useful goods or services. For this study we will define three different forms of capital in relation to the work of DPOs.

Economic capital, relates to the financial resources held by, or accessible to, DPOs. Some DPOs have relatively large amounts of financial capital at their disposal. Those operating on a regional level that deliver independent living services, like advocacy, direct payments or employment support have been most financially successful and can boast annual incomes of £2 million+. Others however can be unfunded, or have a relatively small annual income of up to £15k [Disability LIB 2007].

Social capital, relates to social networks and connections between individuals and organisations. These social connections, or ties, can facilitate, or hinder, the transmission of useful resources to a DPO. This is where the adage 'it's not what you know but who you know' comes from. DPO social capital can derive from the contacts between a DPO

and its stakeholders. These stakeholders include disabled people, disability services, state policy makers and budget holders, other equality and voluntary sector organisations/bodies, and the wider society and community.

Cultural capital, relates to the skills and knowledge held within the DPOs. This includes the understanding of the social model, disability equality training, access auditing, disability arts, pride and also the resources to connect and share positive identities with other disabled people.

Bourdieu used capital to illustrate relationships of power within field-specific settings. By examining the capital resources of DPOs we can reveal the ever-changing locations of power and influence in the various fields.

Habitus

The third element of Bourdieu's (Bourdieu, 1977:77) theory of practice is the notion of Habitus. This is a description of the individual's internal make up, what Bourdieu calls their savoir faire. This can include several aspects of a DPO, including; its internal workings, and how and what it does (e.g. does the DPO employ disabled people? What is the underlying ethos of the DPO - is it a campaigning body, a service delivery body, an arts organisation, or a combination of these things? etc) ; its public face (e.g. how does the DPO present itself to the world? Does it look professional? etc.) The organisational habitus will vary from DPO to DPO. Each will have its own, specific habitus.

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The three elements of field, capital and habitus all influence, and are influenced by, individually and in combination, the way the DPO acts and interacts with the world. This reciprocality exists throughout a DPO's fields of interaction, and is ultimately illustrated by the DPO sectors creation of the social model of disability as a result of the interactions of the fields on individual disabled people. This Social Model of disability eventually influenced and changed the fields within which DPOs operate. Bourdieu illustrates this influence and reciprocality through the metaphor of the 'Game'.

The Game

Bourdieu conceptualises the accumulation, or loss, of power and influence in the language of the game (Bourdieu, 1979). This reflects his belief that the location of power and influence within human activity is relational, and in a constant state of flux and change.

This is a very useful analogy to make in relation to understanding DPO activity, and it deserves some explanation. In a card game (the field of interaction), the players (DPOs) are all dealt cards (capital) (Lareau and McNamara, 1999:39). However, each card and each hand have different values. Moreover, the value of each hand shifts according to the explicit rules of the game (the field of interaction) that is being played (as well as the way the game is being enacted). In other words, a good hand for blackjack may be a less valuable hand for gin rummy. In addition to having a different set of cards (capital), each

player relies on a different set of skills (habitus) to play the cards (activate the capital). By folding the hand, a player may not activate his or her capital or may play the cards (activate the capital) expertly according to the rules of the given game. In another game, the same player may be dealt the same hand, yet because of a lack of knowledge of the rules of the game, play the hand poorly.

Bourdieu's analogy of the game is useful when examining DPO activity, as it can illustrate which games the DPO plays well, and which ones it plays less well. This can help to describe how power shifts from the government agencies to the DPO, and vice versa, or from one DPO to another or other voluntary sector organisation, or from DPOs to disabled people.

Disabled Peoples Organisations; Power and Capital

Having briefly outlined Foucault's notions of power and resistance, and the capital, field and habitus of Bourdieu, we will now consider this in further detail in relation to the DPO context. This explores the rise of disabled people's resistance in recent history, the discourse of independent living, the development of DPOs as radical social movement organisations to their professionalisation as pseudo government agencies and the challenges this poses.

In 1972 the Union of the Physically Impaired Against Segregation (UPIAS) was formed

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as a direct result of Paul Hunt's letter to the Guardian newspaper. This organisation had clear, political goals, namely to change the way that disability was perceived and responded to within civil society. Again, like the BDDA the members of the group came from similar backgrounds in that at least two of the organisation's membership were living in segregated settings. In the case of both of these organisations the shared social experiences brought these people together to share social and cultural capitals and influence political change. The habitus of these early DPOs was political. It is clear that the practice of these early DPOs is an effect of actions and interactions which are shaped simultaneously and in equal measure by the habitus and capital of agents, as well as the context and dynamism constituted by their shared participation in a common field.

The political organisation of disabled people over about four decades in the UK has contributed to an increase in campaigns and the active promotion of disability equality. The uniting factor behind these organisations was the increasing desire for official recognition, and acceptance, of the social model of disability as a counter position to the excessive surveillance and gaze of medicine over the bodies, minds and lifestyles of disabled people.

Notable in this history is the UK anti telethon demonstrations of the 1990's recorded in the disability current affairs TV programme '1 in four'. Outside of the LWT studios in London over the weekend of nationally broadcasted TV fundraising, disabled people came together and chanted 'choices and rights', & 'rights not charity'. The footage

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captures the now Baroness Jane Campbell of Surbiton, Mike Oliver the first Professor of Disability Studies, Activist Johnny Crescendo and TV presenter Chris Tarrant. This represents a key moment of resistance mobilised by a collective of disabled people. What was refuted was the representation of disabled people as helpless, needy and dependent. The protest is interesting as it is not about the closure of factories, loss of jobs or withdrawal of benefits. It is about challenging mainstream representations of disabled people as unfortunate and pitiful. This is one of many examples of disabled people exerting power and resistance, forcing virtual fractures in traditional benevolent discourses of disability, and a collective organisation that challenges discrimination and enshrines the human rights of diverse bodies, minds and lifestyles.

An 'independent living' approach to disabled peoples support and inclusion asserts the distinction between 'physical' dependency and 'social' dependency. The former is linked to impairment and the latter to not having control over one's life due to reliance on others for support (Morris, 1992; 2004). The discourse of independent living challenges the ideology of disabled people as dependent and repositions the boundaries of autonomy and human agency. Disabled people's independent living needs include achieving accessibility in all areas of the everyday; environment, transport systems, information, housing, education, employment, provision of equipment, technical aids, personal assistance, self-advocacy (through advocacy, counselling and peer support) and economy (Morris, 1992; 2004).

Bourdieu's theory of practice suggests the position in which a DPO finds itself can be dependent on a set of factors over which the DPO has control, and also on other factors that DPOs cannot control. The very early days of the disabled peoples movement in the UK, with the creation of the British Deaf and Dumb Association (BDDA) and actions such as the blind workers protest of 1939 (O Cathain, 2006), show how organisations can be contextual, responding to field-specific and clearly identified needs. Groups of disabled people formed as a result of the common fields in which they found themselves and their common interest in changing these fields. They created a strong sense of shared social capital, created new forms of cultural capital based around their disability activism, and reacted to change the field. The people who came together to form these organisations had similar backgrounds and situations, in that they were living and working in segregated settings. This segregation helped create the strong bonding social capital links between the individuals, leading to a sense of shared purpose.

The independent living discourse is radically different from previous discourses which position disabled people as passive recipients of services – including residential accommodation – which is created, and directed, by non-disabled people. The discourse has shifted to place the disabled person at the heart of his or her own life, in control and making key decisions. It is through the political mobilisation of disabled people as a movement that this discourse was appropriated, changed, and re-posited. In their appropriation of the discourse DPOs changed the discourse cultural capital, and redefined the policy debates. Over time these new discourses, new debates and new understandings

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have been re-appropriated by the political elites, in an attempt to maintain political and structural dominance. It is a measure of the success of the DPO political and social movement that these mainstream political parties are now using phrases such as 'Nothing about us without us' within their own political discourse.

A significant achievement of DPOs is that their emergence has marked out the self defined, authentic voice of impairment, and offers new terms of reference for disability knowledge. Through the positing of an alternative disability discourse, enshrining the language of barriers within the social model of disability and the rallying slogans of 'rights not charity', 'choices and rights' and 'nothing about us without us', DPOs forced new understandings into traditional disability discourses. DPOs represent the creation of new political, social and artistic bodies, with discourses that give impairment the opportunity to be reimagined, viewed as resourceful, and endowed with economic, cultural and social capitals. Through a Foucauldain lens this can be seen as representing a specific resistance to power forms concerned with the disability subject and context (see DREYFUS H. AND RABINOW P 1982).

By examining the movement of capital we can see how DPO power and control shift over time. When holding the reigns of power and control, DPOs can influence the policies and attitudes of the broader population. For example before the 1970s, power was located away from DPOs. Disabled people were often institutionalised, living, working and being educated in institutional settings. During the 1970s, DPOs began to seize capital and

power, by forming organisations and making sure their voices were heard. DPOs shaped

the way disability is conceptualised, giving voice to medical and social model discourses.

This was the first time that disabled people articulated their versions and interpretations

of disability. Over time DPOs became recognised as the places where expertise in relation

to disability and disabled people were located. DPOs became centres of disability cultural

capital. As social capital relationships between DPOs and local and central government,

and other organisations were strengthened, the social, health and education agendas

began their transformation. Disability cultural capital shaped these agendas from one of

exclusion as the norm, to one of inclusion as the norm.

As future policy initiatives are developed, implemented and communicated as more

efficient and effective ways of enabling independence, disabled people and their

organisations will be involved in the creation of new professions and institutions. The

extent to which these will be successful is dependent upon on how representative and

allied the new professions and institutions remain to the community. Mike Oliver (2009)

alerts us of the recent rise of a compromised disability industry, the break down of

disabled peoples culture, and thus the loss of voice and ownership of their diverse bodies,

lives and minds.

From a cursory glance at the political situation in the UK, it appears that the local,

regional and national fields within which a Disabled People's Organisation operates are

constantly changing. For example at the time of writing (November 2010) we are in the

middle of several major policy shifts in the social care field. These have come about from a combination of the previous Labour government's Personalisation agenda (e.g. Improving the life chances of disabled people 2005, Putting People First 2007, Right to Control Trailblazers 2010), together with the new coalition government's attempts to dramatically reduce departmental spending. The Personalisation agenda explicitly encourages User Led Organisations (ULOs) and DPOs to become service delivery structures. As a result many DPOs have entered into contractual relationships with their local authority, and have consequently moved from being agents provocateurs, campaigning for change, to become trusted Local Authority allies.

As the broader policy discourse shifts, those DPOs who are most able to make similar discourse shifts to align themselves with the broader dialogue stand to benefit the most. In order to be effective within this political discourse each DPO needs to establish strong social capital links with their Local Authority. These contacts are often made between individuals, rather then between specified job descriptions. As staff move – and Local Authority staff tend to move far more frequently than the staff within DPOs – these contacts can be broken. This can make it very hard to sustain relationships, and to create firm foundations on which to build contractual relationships. And as the policy discourse shifts from government to government the cultural capital required in an organisation also shifts.

The more nimble DPOs who are able to make these shifts will be better able to take

advantage of new opportunities, including new funding streams, that become available.

These DPOs are often relatively large, professional, and can be constituted as companies

limited by guarantee. They often access several funding streams simultaneously, and

manage their affairs very professionally through paid staff. At the same time many DPOs

are battling with the continuing need for campaigning activity, often against government

agencies, whilst also receiving funding from them. This can create a discourse friction

within an organisation which, on the one hand needs to be close to a Local Authority to

establish good working relationships, whilst also maintaining a distance to be able to

campaign, perhaps against the same authority.

The political field can have massive consequences for how a DPO operates. Add to this

the economic field, where all organisations, from government departments to smaller,

voluntary sector organisations, are struggling for funding. This difficult financial

situation is forcing organisations to create new ways of working, to restructure internally,

and to provide services in new ways. There is little consistency in regional field activity

across the UK. Some local government areas and regions deliver a plethora of services

through DPO partners, while others are do very little, or no, such activity. While central

government policy currently encourages DPO participation, local government may not.

Through national bodies and organisations DPOs may attempt to influence change,

though there are very few formal channels through which this influence can be enacted

on a national scale. It therefore falls upon individual DPOs to adapt to shifting political,

economic and regional field variations, or to fail. Indeed while the current

personalisation agenda provides new opportunities for DPOs, it has also increased competition and there are recent examples of established DPOs closing as they lose contracts to other DPOs.

So the field, capital and habitus relationships between, and within, DPOs, Local Authorities, and other players in the broader game, are in a constant state of flux and change. The dynamism within Bourdieu's theory of practice is useful here, in that field, capital and habitus are constantly engaging and re-engaging to create dynamic fluid situations, where adaptability and discourse re-alignment are continuously required. The DPOs who are able to engage in this fluid discourse will be the DPOs who are able to thrive in these situations. The DPOs who are able to present a stable façade to the outside world, whilst managing change effectively and coherently, will be the DPOs who succeed. The DPOs who can invest in their internal habitus development to accommodate this constant change will be the DPOs who survive.

For the past twenty years in the UK the government, and other, institutions have begun to re-seize the political disability discourse, capital and power and to shape the agenda to suit their needs (see Burton and Kagan, 2006). In an attempt to mainstream disability equality the government colonised the social model, adopting it throughout various departments, and using it to justify their shaping, and cutting, of social and health care provision. For example the current Personalisation agenda has the social model at its core. For the UK government Personalisation represents the destruction of the power and

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control of the state, through the dismantling of the structures of the state, particularly in relation to disability and disabled people Residential institutions are closed in favour of individual living in community settings, special schools are closed in favour of mainstream education, and much disability medical provision – for example physiotherapy services – is restructured to offer an individual service rather than group activity. The individual is the expert, while structural changes allow for downsizing, and even elimination of entire departments. As the field is changed, and as capital resources shift and change, so the DPO organisational habitus has had to change. There is a continuing professionalization of the DPO sector with many organisations changing from small-scale social gatherings into major budget holders with million pound plus annual turn overs.

The assimilation of the social model and independent living discourses by traditional disability charities and government, represents the colonisation of the disabled peoples' social movement and the emergence of a disabling corporatism. For Foucault this reflects the operation of power, and in this case disabled peoples resistance to it. This is partly as a result of the success and clarity of disabled people's articulation of their voices and experiences in recent years, but also because disability is as much about impairment as it is about a significant industry. In this way the discourses and principalities of disabled people are not only mapped upon their bodies, lives and minds but also in the economic resources and regulations that govern their actual and potential actions.

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Conclusion

This chapter has considered discourses of Disabled Peoples Organisations. Using notions of power and resistance from Foucault, and capital, field and habitus from Bourdieu, the emergence of DPOs and their challenge of the negative positioning of impairment and articulation of inclusive and independent living alternatives were explored. While DPOs have much to be proud of and celebrate, inclusion and equality is far from achieved and realised by the diverse range and broad community of disabled people. As mainstream political and financial opportunities for disabled people and DPOs increase, new struggles will no doubt emerge. Inequality is clouded within colonised spaces that attend to corporate interests and attempt to re-brand the disabled body, mind and lifestyle as part of the political and economic project of impairment management and inclusion. As disabled people's visibility and palatability have increased, the discourses of their organisations have been embraced in policy and industry. However, the emergence of disabling corporatism, as Oliver (2009) terms it, suggest the assimilation of disabled peoples discourses, i.e. social model and independent living, have lost their once radical ethos.

This 'corporatisation' is double edged, for while it enables the development of inclusion technologies, it subsumes the independent bodies, minds and lives into a broader economic agenda of service consumption. Further work that maps crucial texts and moments that politicise the oppression of impairment and expose the abuses, may be useful to illuminate everyday practices and processes that invalidate the human diversity.

Considering the dilemmas of disabled peoples' identity and the mainstreaming of disability a new language of resistance is required to further the inclusion agenda. This is so that the broadest collective of people who are associated with impairment and disability can come together and push for positive social change. This will include how disability rights works for older people, disabled prisoners, those with addictions and others with unfamiliar disability identities.

Perhaps this new language of resistance should emphasise crimes and breaches of human rights articles now that the UK has signed the Convention of Rights of Disabled People and is thus obliged to ensure compliance.   However, there are challenges and it should be noted that the articulation of any new language of resistance is a discursive construction, so will be only work to represent a specific position for particular audience and thus be subject to rebuttal and dispute by mainstream views. Therefore it not only risks then being cosseted as authentic cultural capital by those on the inside wanting out, but also assimilated and colonised by those on the outside wanting in. This becomes then not something of resistance, but rather a new style of power and its potential to radicalise inclusion policies is lost as disabled people find they have now come full circle. The danger being that the once radical, resistive ideas of disabled people, are now turned against themselves as some find acceptance in the mainstream through the success of their organisations, but others with social disputed characteristics remain marginalised, ignored and excluded.

Notes

. Actual numbers of DPOs in UK are unknown. Estimates between 650 – 1000+ are based on Maynard-Campbell (2007) and Disability LIB (2007).

2. Rather than having the state provide social care services, direct payments are a UK financial resource given to some disabled people which they use to organise and fund their own support provision.

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Glossary terms

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Discourse - Discourse, is a system of representation and signifiers, where rules and practices apply to set the tone and detail of what, and how topics and concepts can be constructed. This includes the written and spoken words, but also other signs, forms and mediums of expression, such as the body, or a map. However, language is not to be taken as value neutral, nor merely a linguistic concept, but rather considered as a form of social action and knowledge practice (Foucault, 1972). Discourse provides a way of speaking and knowing things through language. For Foucault power and knowledge are expressed through discourse.

Disabled Peoples Organisations (DPOs) – an organisation with a majority of disabled people in its membership and managing board whose objectives are to further the rights and equality of disabled people. DPOs subscribe to the social model of disability and are committed to the human rights of disabled people. DPOs work for the empowerment of disabled people either implicitly or explicitly and provide a range of activities. These are typically community based such as advice, advocacy, representation, research, policy development, campaigning, inclusive design and other initiatives.

Power - For Foucault, power is a productive and shared resource, operating across the realm of social life, ever persistent in the transmission of knowledge forms and regimes of truth. Neither is it only negative, seeking to control, but can be reformative, generating pleasurable alternatives.   Foucault further asserted certain types of power, such as biopower and disciplinary power (see Foucault, 1972: 1975: 1976). Biopower is

a technology, emerging in the late eighteenth century for managing populations, by the surveillance and record keeping of our births, deaths, reproduction and dysfunction. Disciplinary power is the mechanism or training of the actions of bodies to produce and regulate desired behaviours, through the construction of particular space, time and structure.

Resistance - Power can be subverted and reclaimed into positions of resistance that rework oppression and create everyday opportunities for equality and liberation to emerge. Contrary to the nihilist criticism Foucault receives, this suggests that no matter how powerful or oppressive a system maybe, it can be resisted.

Capital - For Bourdieu, the social world is accumulated history - he states that if the social world is not to be reduced to a discontinuous series of instantaneous mechanical equilibria between agents who are treated as interchangeable particles, one must reintroduce into it the notion of capital (Bourdieu, 1983:242). And this means capital in all its forms, and not solely in the one form recognised by economic theory. All forms of capital can be accumulated, or lost, from one moment to the next.

Field - Bourdieu represents the objective world as field. Field is defined as, '...a network, or a configuration, of objective relations between positions objectively defined…' (Bourdieu and Wacquant, 1992:72-73).

Habitus - This is a description of the individual entity's internal make up, what Bourdieu calls their savoir faire. This can include several aspects of an entity, including its internal workings, and how and what it does and its public face.

The Game - Bourdieu conceptualises the accumulation, or loss, of power and influence in the language of the game (Bourdieu, 1979). This reflects his belief that the location of power and influence within human activity is relational, and in a constant state of flux and change.