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## **Abstract**

This paper focuses on the self-organisation of disabled people and specifically addresses issues around the self-advocacy of people with learning difficulties. It reviews a wide range of UK-based literature around the topic of self-advocacy by including academic texts as well as sources stemming from the disabled people's movement more generally.

The work is guided by the assumption that the recognition of and support for self-advocacy that has been popular amongst government bodies as well as professionals in recent years creates a dilemma for people with learning difficulties as it was the same institutionalised forms of social organisation and welfare provision they were originally protesting against. It therefore relates self-advocacy to wider issues concerning the self-organisation of disabled people in the UK and addresses three main points: the development of self-advocacy in the UK, its relation to the wider disabled people's movement and the connection which self-advocacy has to service delivery more generally.

The first two chapters of the paper focus on general issues around definitions of disability, learning difficulties and self-advocacy as well as the historical development of the self-organisation of disabled people in the UK. The third main chapter considers analytical accounts toward self-advocacy by reflecting on its status as a new social movement but also highlights the connection of self-advocacy and the empowerment discourse.

Results point out that the connection of self-advocacy and service delivery needs to be observed critically and highlight the risk that government recognition and professional support poses for self-advocacy. The paper shows that a rhetoric of self-advocacy and empowerment is not enough for practical changes in the life of disabled people. Also, the benefits of a social model approach towards disability are highlighted regarding the relationship between the general disabled people's movement and self-advocacy more specifically.

## Table of Contents

<b>ABSTRACT .....</b>	<b>2</b>
<b>1. INTRODUCTION .....</b>	<b>5</b>
<b>2. KEY TERMS .....</b>	<b>10</b>
2.1 DISABILITY .....	10
2.2 LEARNING DIFFICULTIES .....	12
2.3 SELF-ADVOCACY .....	17
2.4 SUMMARY .....	23
<b>3. THE SELF-ORGANISATION OF DISABLED PEOPLE IN BRITAIN .....</b>	<b>25</b>
3.1 THE DISABLED PEOPLE'S MOVEMENT .....	26
3.2 THE DEVELOPMENT OF SELF-ADVOCACY .....	33
3.3 THE RELATION OF SELF-ADVOCACY AND THE DISABLED PEOPLE'S MOVEMENT .....	38
3.4 SUMMARY .....	44
<b>4. ANALYSING SELF-ADVOCACY .....</b>	<b>46</b>
4.1 SELF-ADVOCACY - A NEW SOCIAL MOVEMENT? .....	46
4.2 SELF-ADVOCACY AND EMPOWERMENT .....	53
4.3 SUMMARY .....	65
<b>5. CONCLUSION .....</b>	<b>67</b>
<b>BIBLIOGRAPHY .....</b>	<b>72</b>

## 1. Introduction

Since the publication of the White Paper *Valuing People* (DoH 2001), self-advocacy has been on the government's agenda in the UK. Only recently, a new three-year strategy for people with learning difficulties was created: *Valuing People Now* (DoH 2009) stresses the importance of self-advocacy and provides objectives and funds for further developments, for example for the creation of a quality tool for self-advocacy groups and for the support of leadership of people with learning difficulties. Within this document, self-advocacy is defined as "people coming together to speak up for themselves" (DoH 2009: 100).

Also the services for people with learning difficulties have come a long way since the middle of the 20<sup>th</sup> century, when people were institutionalised under horrifying conditions (CHAPELL 1997). Many people with learning difficulties have left those institutions and moved into smaller group homes or even their own flats. They engage in self-advocacy groups and speak up on behalf of their own matters (MITCHELL 2006). Today, a lot of service workers consider themselves as allies to people with learning difficulties and ideas such as empowerment and self-

advocacy are prominent amongst health and social care professionals (BERESFORD 2006).

However, the recognition of and support for self-advocacy from government and professionals is an ambivalent, even paradoxical issue as self-advocacy is first and foremost the activity of people with learning difficulties. The phenomenon is rather complex, as GOODLEY (2000: 13-14) points out:

“The self-advocacy movement is complicated, a container for a variety of struggles and a context not so easily understood as relating directly to the self-empowerment of its main players - self-advocates with learning difficulties.”

Hence, although self-advocacy relates to the actions of people with learning difficulties themselves, it is based on a diversity of backgrounds and brings different discourses together. As a multi-dimensional matter, it relates to concepts such as rights, choice and autonomy (McNALLY 2002). The promotion of self-advocacy therefore may sound simple and straightforward but if looking closer, different values, aims and objectives come into the picture. The broad support for self-advocacy then may not even be informed by original goals of people with learning difficulties but may have a more hidden agenda such as legitimating professional involvement (ASPIS 1997).

This problem is linked to ownership in a more general sense. The disabled people's movement has voiced complaints that ideas which originally were formulated by disabled people have been applied and used in ways which contradict their original content (OLIVER & BARNES 2006). This claim however has not been considered more closely in relation to the self-advocacy of people with learning difficulties. Here lies the aim of the undertaken work: It wants to be a contribution to a better understanding of the recent prominence of self-advocacy by analysing different discussions behind it and relating it to the political action of disabled people more generally.

The overarching research question can therefore be formulated as follows: *How and in what ways does self-advocacy of people with learning difficulties relate to further issues regarding the political action and self-organisation of disabled people?* The main question can be broken down into three smaller queries:

- *What is self-advocacy and how has it developed in the UK?*
- *How does self-advocacy relate to the wider disabled people's movement?*

- *How is self-advocacy linked to service delivery for disabled people?*

Due to the research focus, the method to be applied in order to answer those questions is a theoretical analysis of a variety of sources such as academic books and journal articles, policy documents, electronically published documents and texts written by disabled people. The main focus lies on UK based literature starting from the middle of the 20<sup>th</sup> century.

The paper consists of three main chapters: In Chapter 2, the relevant key concepts for this work will be addressed. Hence, major approaches to defining disability, learning difficulties and self-advocacy will be considered and critically evaluated. After having discussed approaches towards defining self-advocacy in general, the focus in Chapter 3 will be specifically put on the self-organisation of disabled people in Britain. To begin with, the disabled people's movement will be considered from a general point of view and subsequently, the argument will move on to a more specific reflection on self-advocacy of people with learning difficulties. The third part of the chapter addresses the relation between the disabled people's movement and self-advocacy. Chapter 4 then is concerned with theoretical accounts behind self-

advocacy. A closer look on to whether the self-organisation of disabled people and more specifically self-advocacy constitute a social movement will be undertaken in its first part. The second part of the fourth chapter considers the link between self-advocacy and empowerment. By discussing differing discourses behind empowerment, ambivalences which also are immanent in the discourse of self-advocacy can be highlighted.

Conceptualising this work mainly as a theoretical one is in as far problematic as self-advocacy can, first and foremost, be understood as practice owned by people with learning difficulties. However, it is believed that by placing self-advocacy in the context of issues relating to the political actions of disabled people and questions about service delivery in the welfare state more generally, ambivalences which are inherent in the current debate about the self-organisation of people with learning difficulties can be highlighted. Furthermore, a possible threat that the interest of government and professionals poses to the ownership of self-advocacy can be clarified. Clearly it cannot be the aim here to make normative judgements on how self-advocacy should be done however.

## **2. Key Terms**

This chapter aims for placing self-advocacy within a framework of understanding disability. The first section addresses definitions of disability and adopts a social model perspective. In the second section, the idea of learning difficulties will be discussed and critically analysed. Finally, a clarification of the concept of self-advocacy will be undertaken and main points will be summarised.

### **2.1 Disability**

As collective action, self-help and hence self-advocacy are opposing an individual understanding of disability (OLIVER 1996), a social model perspective is applied in the context of this work. The term 'social model' was coined by Michael OLIVER in 1981 (OLIVER 1981). This approach, derived from a disabled people's movement definition established in the 1970s by the Union of the Physically Impaired Against Segregation (UPIAS), distinguishes between impairment and disability (BARNES & MERCER 2003). Whereas impairment relates to an understanding of the physical, cognitive and sensory dimension, disability is

“...the disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.” (UPIAS 1976: 14)

The relocation of the cause of disablement from the individual to society has made the social model one of the most important tools in the fight for disability equality (BARNES & MERCER 2003). However, it cannot explain the causes of disablement or offer a social theory of disability (FINKELSTEIN 2004).

These issues are addressed within different theoretical accounts. A variety of perspectives with different ontological and epistemological backgrounds - materialist and idealist - have been developed (PRIESTLEY 2003). Whereas idealist accounts emphasise the role of culture in the creation of disability, materialist approaches focus upon structural and economic forces. From a materialist point of view, disability can be defined as oppression which society enforces on people with impairments (FINKELSTEIN 1980; OLIVER 1990). OLIVER (1990) provides a detailed analysis of how the mode of capitalist production as well as the ideological mode of thought have created an individual understanding of disability. The organisation of wage labour and the free market economy have promoted an individualised notion of disability. Furthermore, the rise of scientific medicine has led to it being used as mechanism of social control and has played a major part in the creation of the oppression of people with

impairments. This medicalisation has had major impact on the lives of disabled people as it has determined welfare policy, the provision of individual technical aids, education and the distribution of work (ibid.).

However, the focus on structural issues, the neglect of social divisions such as gender, ethnicity and race, the reluctance to address experiences of impairment and the missing interest in the social construction of the impaired body have led to a variety of criticism towards the social model of disability and materialist accounts linked to it (BARNES, MERCER & SHAKESPEARE 1999). The case of learning difficulties has repeatedly been addressed within those debates and will be elaborated further below. It shall be noted here that the demand of considering impairment issues has been rejected by some proponents of the social model due to its original aim to be “a pragmatic attempt to identify and address issues that can be changed through collective action, rather than medical or other professional treatment” (OLIVER 1996: 48).

## **2.2 Learning Difficulties**

The term ‘learning difficulty’ is used here instead of terms like ‘learning disability’ or ‘intellectual impairment’ as it is preferred by those in the self-advocacy movement. A reason is pointed out by

a British self-advocate: “If you put ‘people with learning difficulties’ then they know that people want to learn and to be taught how to do things” (quoted in SUTCLIFFE & SIMONS 1993: 23).

In the White Paper *Valuing People* (DoH 2001), a learning ‘disability’ is defined as including:

“...a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.” (DoH 2001: 14)

It is further stressed that low intelligence is not the only factor for determining whether somebody has learning difficulties, but “social functioning and communication skills” (DoH 2001: 15) also need to be considered. Hence, this definition entails two of the key components which also have traditionally been used for diagnosing learning difficulties from a medical point of view. RYAN and THOMAS (1987) identify those as: low intelligence, social incompetence and maladaptive functioning. However, all of the three can eventually be deconstructed and factors located in the socialisation, education and institutionalisation of so-labelled people are major influences that need to be considered. Hence,

the basis for the diagnosis of learning difficulties is historically and socio-culturally influenced (GOODLEY 2000).

Thinking in terms of the social model outlined above, the term 'learning difficulties' describes a category of intellectual impairments. However, seeing learning difficulties solely as biological impairment category is not appropriate. As ABBERLEY (1987) suggests, naturalised notions of impairment need to be questioned as the location of difference in biological deficits individualises the humanity of certain people and neglects the importance of social circumstances. There is a considerable body of literature discussing the social construction of learning difficulties and showing that it is a rather "fuzzy concept" (HARRIS 1995: 341).

The problems connected generally to a biological understanding of impairment have been highlighted in poststructuralist accounts by TREMAIN (2002), SHAKESPEARE (2006) and others, often through applying Foucauldian theory. YATES, DYSON & HILES (2008) stress the problematic notion of constituting individual subjectivity as pre-social and argue that the individual and his or her impairments are never separable from

the social world and the knowledge it is constituted of. The creation of learning difficulties is hence inevitably linked to the medical and psychological discourses it was created by. Also according to TREMAIN (2002: 34), a Foucauldian perspective can show the historical contingency of impairment and describe its materiality as “naturalized *effects* [sic] of disciplinary knowledge/power”. She therefore regards impairment not as a biological or pre-cultural but as a discursive category. GOODLEY (2001: 225) develops key points of an “epistemology of impairment” in relation to learning difficulties, stressing inter alia the social character of impairment, the necessary appreciation of different notions of ability in sociological approaches, the importance to include the accounts of people with learning difficulties into social theorising and the consideration of discursive powers and material formations of normality and abnormality. Therefore, according to GOODLEY and RAPLEY (2002: 135), learning difficulties “must be understood relationally, historically, practically and critically”. They suggest to analyse both impairment and disability as political as well as social aspects of disablement and undertake a deconstruction of the category of learning difficulties by showing that specific criteria aligned with it such as acquiescence and syndrome-specific

behaviour violate the personhood of so-labelled people. They argue for a social theory of impairment which brings “impairment and disability together as co-existing *social* and *political* [sic] facets of disablement” (ibid: 138). However, it remains unclear why this postmodern social theorising is necessary as “part of the political struggle against disablement” (ibid.). Furthermore it is questionable how GOODLEY’S and RAPLEY’S (2002) quest for a social theory approach of impairment actually differs from suggestions by materialist writers such as OLIVER (1996), who - albeit stressing the importance of a concentration on disability - proposes to develop a social model of impairment in response to the criticism of the social model of disability.

McCLIMENS (2005) describes how attitudes towards learning difficulties have changed within the past centuries from it being considered first a moral, subsequently a legal and finally a medical problem. He stresses the influence of science, especially in the decades from the 1860 onwards, in creating classifications and taxonomies of individuals which led to a medical, individualised understanding of learning difficulties and disability in general. Looking at the historical position of people with learning difficulties, it becomes clear that their status as subjects

and their personhood has been even more contested than that of people with physical or sensory impairments (PARMENTER 2001). Several authors have identified the intertwinement of reason and value at the heart of the idea of modernity as specifically problematic for people with learning difficulties; the lack of reason that was ascribed to them has led to the description of their otherness and the neglect of their personhood (WASSERMAN 2001).

### **2.3 Self-advocacy**

An advocate is “one who pleads, intercedes, or speaks for, or in behalf of, another”, also “one who defends, maintains, publicly recommends, or raises his voice in behalf of a proposal or tenet” (OXFORD ENGLISH DICTIONARY 1989: n.pag.). As BRANDON (1995) points out, most parts of the population are in need of an advocate at one or several stages in their lives, e.g. when consulting a solicitor. For HENDERSON and POCHIN (2001), advocacy is a process of identification with and representation of a person’s affairs which aims for the enhancement of rights and entitlements and is conducted by someone who does not have a conflict of interest. Hence, key elements are the interpersonal partnership and the objective to achieve a positive outcome at the

end of the advocacy process; this can be either an increase of empowerment or a more concrete success.

In relation to disabled people,

“...advocacy involves a person(s), either an individual or group with disabilities or their representative, pressing their case with influential others, about situations, which either affect them directly or, and more usually, trying to prevent proposed changes which will leave them worse off.” (BRANDON 1995: 1)

However, the reason why advocacy is of particular importance in relation to disability lies in the discrimination (BARNES 1991) and oppression (FINKELSTEIN 1980; OLIVER 1990) disabled people face. As a group which has systematically been excluded from society, disabled people have been forced to fight for equality and their rights as citizens. From the disabled people's movement's point of view, it can be questioned which types of advocacy are appropriate in representing disabled people's case without perpetuating their dependence (HENDERSON & POCHIN 2001).

BRANDON (1995) identifies three basic forms and several subtypes of advocacy: paid or professional advocacy, self-advocacy and unpaid or amateur advocacy. The subtypes further identified have different implications for disabled people. Those

are inter alia peer advocacy, citizen advocacy and collective advocacy. Especially citizen advocacy has often been mentioned as root of contemporary advocacy but also been rejected by disabled people (HENDERSON & POCHIN 2001). It was developed in the US and mainly influenced by WOLFENSBERGER as scheme with volunteers acting in the interest of persons with problems in expressing their needs (WOLFENSBERGER 1972). It is closely linked to WOLFENSBERGER's concept of Social Role Valorization and aims for the empowerment of socially devalued people by connecting them with a volunteer with higher social status (ibid.). Citizen advocacy also assumes a potential conflict between individual interests of 'vulnerable' people and the service systems that are designed to address their needs. The citizen volunteer is supposed to advocate in the interest of the 'vulnerable' person and represent his/her interests against the service system. Although the scheme cannot be discussed here sufficiently, it shall be noted that especially the normative necessity of a volunteer with a higher social status has been criticised (HENDERSON & POCHIN 2001). Furthermore, the assumption that disabled people are in need of non-disabled people to advocate for them has been rejected as devaluing in itself and enforcing dependence rather than empowerment (ATKINSON 1999).

Self-advocacy is another one of BRANDON's (1995) three basic forms. Although not specifically restricted to people with learning difficulties, the term has been used mostly to refer to the actions of people labelled in this way. It can be characterised as umbrella term that is applied to refer to rather different facets of the actions of people with learning difficulties in a political context. A popular definition, which was adopted during the Second National Annual North American People First Conference in Nashville, Tennessee, states:

“Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is supporting each other and helping each other gain confidence in themselves to speak out for what they believe in.” (cited in DYBWAD, 1996: 2)

Self-advocacy hence means working against discrimination, increasing choice and independence, creating an awareness of rights and responsibilities, citizenship and mutual support amongst disabled people. Those are also some of the objectives of the wider disabled people's movement (see Chapter 3).

GOODLEY (2000) points out that the common basis of most definitions is the reference to self-determination.

Definitions of self-advocacy usually refer to actions on an individual as well as a group level (WILLIAMS & SHOULTZ 1982; SUTCLIFFE & SIMONS 1993; GOODLEY 2000). On an individual level, self-advocacy is described as the expression of opinions, the knowledge about rights and the ability to make choices in one's lifestyle in a variety of settings (SUTCLIFFE & SIMONS 1993). A majority of the literature focuses on collective aspects, mainly in group contexts (WORREL 1987; CRAWLEY 1988; BERSANI 1996; DYBWAD 1996; McNALLY 2002). Many studies have drawn upon a group typology which was published by People First of Washington State. It identifies the independent group model as most beneficial and criticises the service-system model as posing the most problems and being the least influential (CRAWLEY 1988; SIMONS 1992; WORREL 1987). However, GOODLEY (2000) highlights problematic issues around those rigid typologies. His data on self-advocacy in the UK shows that such a typology tends to simplify issues surrounding the work of many self-advocacy groups. His qualitative analysis of the life stories of self-advocates as well as the observation of the work done by different self-

advocacy groups highlights the complexity of self-advocacy. He names it the “politics of resilience” (p.199) to interrelate political implications of self-advocacy with individual effects in people’s lives.

A contested issue is the involvement of professionals in self-advocacy. A considerable corpus of literature deals with the role of supporters or advisors of self-advocacy groups (WORREL 1987; CLARE 1990; SIMONS 1992; SUTCLIFFE & SIMONS 1993). Most of these sources focus on the status of advisors and how this influences their role. Professionally led self-advocacy is understood as problematic due to potential interest and role conflicts arising for the advisor. Favoured is the idea of an independent supporter who is only accountable to the self-advocacy group. However, GOODLEY (2000) contests this and highlights the importance that the advisors’ understanding of disability has in regard to their working style: The most important influence is whether they define disability from a social or an individual model standpoint rather than their professional role.

## 2.4 Summary

To conclude this chapter, the interrelation between the discussed key concepts disability, learning difficulties and self-advocacy will be highlighted: From a social model perspective as developed by UPIAS in the 1970s and subsequently theoretically elaborated by FINKELSTEIN (1980) and OLIVER (1981; 1990), disability is regarded as the oppression and exclusion that people with impairment face in current capitalist social structures rather than as individual biological property. Learning difficulties can be described as individual intellectual impairment category. However, the main criteria used for the individual diagnosis of learning difficulties, which are low intelligence, social incompetence and maladaptive functioning (RYAN & THOMAS 1987) are based on a historical and socio-cultural rather than a biological foundation. Therefore, the case of learning difficulties has been used in postmodern arguments which criticise the impairment-disability divide and the biological foundation of impairment. Although the term 'learning difficulties' is problematic, it is the one preferred by most people labelled in this way and will therefore be used in the context of this paper.

From a social model standpoint, disability as oppression requires political and legal action rather than traditional care and welfare provision. Self-advocacy, one of three basic advocacy forms, can be placed in this context. It refers to disabled people acting on their own behalf, but has been used in particular to describe individual and group activities of people with learning difficulties. Most definitions refer in some way to the self-determination of self-advocates, either in making individual choices or in taking political action.

Having clarified the basic major concepts, the argument will now move on to regard the self-organisation of disabled people in a specific socio-historical context by looking at the developments which took place in Britain.

### **3. The Self-organisation of Disabled People in Britain**

This chapter addresses the self-organisation of disabled people in Britain which has emerged in the 20<sup>th</sup> century. After focusing on the general development of the disabled people's movement, an outline of the history of self-advocacy will be given. Finally, the relation between self-advocacy and the wider disabled people's movement will be considered.

The term 'disabled people's movement' is used to refer to the self-organisation of disabled people. Whereas during the 1980s, a distinction between disability and disabled people's organisations was less clear, the fact that ideas developed by disabled people were adopted by traditional charities and organisations requires now a distinction between conventional disability and disabled people's organisations (OLIVER 2009).

This distinction also reflects differences in the objectives, membership and leadership of those organisations (BARNES & MERCER 2001): Disability organisations - or organisations for disabled people (OLIVER & BARNES 1998) - are following a traditional paternalistic approach towards disability, they are usually led by non-disabled people and focus mainly on the

service provision for particular groups of disabled people, most often identifying them by their impairment. Disabled people have only very limited control over those organisations which are often dominated by professionals. On the other hand, disabled people's organisations - or organisations of disabled people (OLIVER & BARNES 1998) - are characterised as a variety of associations which follow a more pro-active and self-help approach, consist of grassroots-type groups and advocacy agencies and are controlled by disabled people (BARNES & MERCER 2001).

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

Having sketched the difference between disability and disabled people's organisations, the argument will now move on to give a short historical overview over the development of the disabled people's movement in Britain.

The "foundation stones" (CAMPBELL & OLIVER 1996: 61) of the British movement are two groups, the Disablement Income Group (DIG) which was founded in 1965 by Berit MOORE and Megan DE BOISSON and the Union of the Physically Impaired Against Segregation (UPIAS), created in 1974 (BARNES & MERCER 2010). Although the DIG was a focus for political action and attracted the attention of activists and academics at the end of the 1960s and

beginning of the 1970s, new groups emerged after an unsuccessful attempt to campaign for a comprehensive disability income and due to the dissatisfaction with the influence of non-disabled people within the group (BARNES & MERCER 2001).

The second basis, UPIAS, originated from the activities of Paul HUNT and Vic FINKELSTEIN in the 1970s. They were not satisfied with the income-focused work of the Disability Alliance (DA), a group which campaigned for a comprehensive disability income (CAMPBELL & OLIVER 1996). HUNT was the first disabled person in the UK to write about disability issues (HUNT 1966). By posting a letter to the Guardian, Hunt was able to attract the attention of other disabled people and a process, which eventually led to the establishment of the UPIAS in 1974, began. Although never attracting a big number of members, the intellectual work done by the organisation is regarded as the theoretical basis of the disabled people's movement in the UK (CAMPBELL & OLIVER 1996). As outlined earlier in section 2.1, the UPIAS document of 1976 with its distinction between impairment and disability is regarded as the basis for the social model of disability.

Several factors influenced the rise of the disabled people's movement: In contrast to the majority population, disabled people had not experienced risen living standards in the decades after World War II. Furthermore, traditional organisations very often promoted segregation and their hierarchical structures denied power to disabled people. Also, under the impression of external happenings such as the rise of the civil rights and women's movement in the US, the consciousness amongst disabled people began to rise (CAMPBELL & OLIVER 1996). Another factor was the importance of residential homes in creating an atmosphere where large numbers of disabled people began to doubt their institutionalisation and to cooperate (ibid.).

Apart from the above-mentioned organisations, other single impairment groups, which can better be characterised as self-help instead of political groups, as well as local organisations that focused on Independent Living (IL) emerged during the 1970s and 1980s (CAMPBELL & OLIVER 1996). The wish for a body that could enable coordination amongst the different groups began to grow stronger and finally in 1981, the British Council of Disabled People (BCODP) was founded (ibid.).

The development is summarised by CAMPBELL & OLIVER (1996: 80):

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

OLIVER & BARNES (2006) list three big ideas of the disabled people's movement which were also part of BCODP's work: the social model of disability, independent living and rights in the form of anti-discrimination legislation. By the end of the 1980s, about 130 organisations of disabled people were affiliated with the umbrella organisation BCODP and it had become one of the key members of the international organisation Disabled People International (DPI) (OLIVER & BARNES 2006; DRIEDGER 1989). Hence, the BCODP was the only representative voice of disabled people in Britain and subsequently managed to campaign for anti-discrimination legislation. A research report focusing on the discrimination that disabled people in Britain face was funded by the BCODP (BARNES 1991) and in 1995, the Disability Discrimination Act (DDA) - still based on an individual understanding of disability though - finally became law (BARNES &

MERCER 2010). CAMPBELL & OLIVER (1996) judge the achievements of the BCODP very positive as they see it as main responsible body for an emerging conscience of disabling barriers, human rights for disabled people, for identifying charities and institutions as part of the process of oppression and for promoting a positive disability identity.

Publicly acknowledged were also the campaigning activities of Direct Action Network (DAN), a coordinating body for peaceful direct action founded in 1992. It targeted different parliamentary constituencies and in 1997 even Downing Street for mass demonstrations and protest (OLIVER & BARNES 2006). The main focus of public protests lay upon media portrayal of disabled people and accessibility of public transport (CAMPBELL & OLIVER 2006).

By the 1990s, links with universities also had led to the emergence of disability studies as an academic discipline. Its foundations were laid by activists of the disabled people's movement and disability studies "has become a thriving academic discipline and has arguably never been in a stronger position" (SHELDON 2006: 3). Disability theorists who are significant within

academia as well as the disabled people's movement have established a new, sociological approach to disability as outlined earlier. The relationship between those theorists and the movement has also been subject to discussions (GERMON 1998; OLIVER 1996; SHELDON 2006).

A decline of the disabled people's movement after the mid-1990s has been observed. OLIVER & BARNES (2006) name different contributing reasons: One major point, as they suggest, is the fact that traditional disability organisations which originally opposed disabled people's ideas rethought their positions and took the main responsibility in implementing the DDA whilst ignoring the disabled people's movement's concerns regarding legal comprehensiveness and enforceability. BARNES & MERCER (2006) suggest that the disabled people's movement had, due to its focus on oppositional politics, no experience in participating in institutionalised political processes and hence under New Labour's equality initiatives, the charities stepped in to fill the gap. This, they conclude, led to a political isolation of the BCODP, as the government and the big charities had taken over the movement's ideas and funding became more problematic due to the government's commitment to fund its own initiatives instead.

According to OLIVER & BARNES (2006), other factors which prove to be problematic are the deaths of important members of the movement, problems with the implementation of IL because the National Centre for Independent Living (NCIL) is not directly accountable to disabled people and the decline of local coalitions of disabled people due to funding problems. They suggest that although progress in regards to legislation and the rights of disabled people seems apparent in the last decades, barriers and disablism still exist and the now dominant rights-based approach is not enough to tackle the oppression of disabled people. Within those developments, charities and traditional organisations have secured their influence and new non-accountable boards have been created which themselves are at risk of taking part in disabled people's oppression. The authors warn therefore:

“Name changes, tidying up their language and employing token disabled people cannot disguise the underlying reality that these agencies are interested primarily in self preservation and that they will say and do anything that is politically expedient in order to retain their influence in Government circles.” (OLIVER & BARNES 2006: 11)

Furthermore, organisations of disabled people are increasingly professionalised. Marginalisation and the incorporation into

institutionalised structures are hence considered as the main threats to the disabled people's movement (OLIVER 2009).

### **3.2 The Development of Self-advocacy**

Before taking a closer look at the developments that took place in Britain within the last decades, the general history of the self-advocacy movement will shortly be sketched. The section focuses on the development of more formal types of self-advocacy although individual resistance and 'speaking up' have been practised long before more organised forms emerged (TILLEY 2004).

The origin of the global movement is mostly dated back to developments in Sweden during the 1960s. During this time, the involvement of professionals led to a promotion and more formal organisation of self-advocacy (GOODLEY 2000). In Sweden, self-advocacy is linked to ideas around the normalisation of service provision for people with learning difficulties, a concept on social policy reforms coined by Bengt NIRJE. He was, in his function as secretary of a charity, responsible for the foundation of 24 leisure groups of people with learning difficulties and university students who increasingly also became politically active (PERSKE 1996). The Swedish activities became internationally known due to

NIRJE's report *Toward Independence* during the 11<sup>th</sup> World Congress of the International Society of Rehabilitation of the Disabled in Dublin in 1969 (DYBWAD 1996).

The world's biggest organisation led by people with learning difficulties, People First, was originally formed in North America. A self-advocacy group in Oregon coined this name by stressing the importance of being perceived as a person first. A national umbrella organisation that united the groups, which had existed since the 1970s, called Self-Advocates Becoming Empowered, was founded 1991 in Nashville, Tennessee (BERSANI 1996). North American authors very often relate self-advocacy exclusively to the existence of People First groups. However, this does not apply to the British context in such a strict sense as will be shown later on.

The earliest factors influencing the establishment of self-advocacy in Britain can be dated back to the beginning of the 1970s: With *Our Life* in 1972 and *Listen* in 1973, the Campaign for the Mentally Handicapped, later renamed into Values into Action (VIA), hosted two so-called participation events (HERSOV 1996). Connections to US People First groups led a decade later

to the publication of the book *We Can Speak for Ourselves* (WILLIAMS & SHOULTZ 1982). The first independent self-advocacy group, People First London and Thames, was established in 1984 after delegates had attended a conference in the US. This local organisation established itself subsequently as one of the most influential self-advocacy groups in the UK (HERSOV 1996). In 1988, the Second International People First Conference was held in Twickenham in England and in 1990, the first UK self-advocacy conference took place (ibid.). SIMONS (1992) estimates the number of self-advocacy groups in 1992 at about 500. However, due to the lack of a national organisation and a small number of groups operating independently, the group of London and Thames tended to speak nationally for People First. This created a certain amount of animosity. Hence in 1994, an England People First conference was held to set up a national representative organisation (WALMSLEY & DOWNER 1997).

Links to the disabled people's movement were made when People First London and Thames joined the BCODP in 1992 (CAMPBELL & OLIVER 1996). However, self-advocacy groups have also cooperated with more traditional charities and organisations. HERSOV (1996) recounts that funding for the London People First

group was received from the Joseph Rowntree Foundation, the Mental Health Foundation and the King's Fund and that there has been substantial cooperation with traditional charities. Also, resources made available from the Department of Health have helped to establish national structures of self-advocacy in the 1990s (WALMSLEY & DOWNER 1997). After the publication of the White Paper *Valuing People* in 2001, substantial funding was given to citizen advocacy as well as self-advocacy organisations. Funds received from the Department of Health were distributed to support the establishment of a national self-advocacy infrastructure in cooperation with VIA (GOODLEY 2005). Until 2005, 43 citizen and self-advocacy organisations across England had received support by this fund and local authority support for advocacy schemes was doubled (GREIG 2005).

Although some authors understand self-advocacy solely as consisting of independent or People First groups (e.g. PERSKE 1996, DYBWAD 1996), the British movement has also origins in trainee committees and other groups which were established in service institutions such as adult training centres, hospitals, group homes and day centres (GOODLEY 2000). Already in 1988, groups in service settings were fairly common with about 60 percent of

adult training centres having a self-advocacy group (CRAWLEY 1988). Their relevance is judged differently: Whereas CRAWLEY (1988) criticises their limited agenda, DOWSE (2001) sees them as only way in enabling people, who spent a major part of their life in segregated service settings, in participating politically. As individuals may have - for reasons as different as socialisation, education or impairment - diverse levels of awareness of their needs, rights and the possibilities for involvement in political processes, they may also be unaware of their position in society and do not identify as part of the wider disabled population. However, engaging in issues relating to their everyday life may make sense for them. Also GOODLEY (2000) stresses the importance of service-related groups and favours an understanding of self-advocacy as heterogeneous phenomenon. WALMSLEY & DOWNER (1997) see a positive evolution from earlier service-based to subsequently more independent groups. Those questions are not limited to the group organisation however, they link into a broader discourse of how self-advocacy is understood and by whom it is owned. Therefore, they will be considered in the course of the paper more intensely.

### **3.3 The Relation of Self-advocacy and the Disabled People's Movement**

It was shown that the British disabled people's movement goes back to developments in the 1960s and 1970s and has experienced a growth and institutionalisation in the form of BCODP in the 1980s. People with learning difficulties also started to organise in a variety of settings from the 1970s onwards and a national network of self-advocacy groups has been established since the 1990s. Within the last decade, self-advocacy has been on the government's agenda. The argument will now move on to consider the relation between the two types of self-organisation and reflect on the representation of people with learning difficulties in the wider disabled people's movement. Representation issues have been a general problem for the movement beyond the involvement of people with learning difficulties. They concern mainly criticisms of it being wheelchair-oriented and neglecting diversity within the disabled population, e.g. concerning gender, sexual orientation and ethnicity (BARNES & MERCER 2010).

During the early years of the disabled people's movement, although calling for alliances amongst different oppressed groups,

people with learning difficulties were not explicitly included. The Union of the Physically Impaired Against Segregation states in point 22 of its policy statement (UPIAS 1975: n.pag.):

“The particular forms which oppression takes in this society differ somewhat for each distinct oppressed group. Some, such as people who are called ‘mentally handicapped’, or those ‘mentally ill’, clearly have a great deal in common with us. Full membership of our Union is however based simply on the fact of physical impairment. This is because we believe the important thing at the moment is to clarify the facts of our situation and the problems associated with physical impairment.”

People First and hence the first independent organisation accountable to people with learning difficulties finally joined the BCODP about two decades after this statement, in 1992. As people with learning difficulties have been included into campaigns and direct protest actions in the 1990s, self-advocacy can, according to DOWSE (2001), be described now as part of the disabled people’s movement as well as a distinct collective in its own.

The work of the BCODP has not been central to the interests of people with learning difficulties however (CAMPBELL & OLIVER 1996). People with learning difficulties were one of the impairment groups which was involved only on the periphery and have not

held important positions within the movement (BERESFORD & CAMPBELL 1994). ASPIS, an activist with learning difficulties (quoted in CAMPBELL & OLIVER 1996: 97) states:

“People with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren’t disabling in the same way as disabled people without learning difficulties. We want concentration on our access needs in the mainstream disability movement.”

CAMPBELL & OLIVER (1996: 96) acknowledge in this context that “following the social model, the disabling barriers to political participation are less severe for wheelchair users than for people with other impairments“ and suggest that it is a challenge for the disabled people’s movement to address those barriers. This is also highlighted by DOWSE (2001), who states that for some people with learning difficulties, service-based self-advocacy groups remain the only way of participating politically if the barriers in the disabled people’s movement are not addressed.

WALMSLEY (1997) identifies different theoretical backgrounds of the disabled people’s movement and self-advocacy. Whereas the social model of disability is important for the disabled people’s movement, the field of learning difficulties has been dominated by

ideas of the normalisation of services and labelling theory approaches which were mainly supported by professionals in the 1970s and 1980s. She suggests that through the evolution of self-advocacy and some involvement of people with learning difficulties in the BCODP, there have been changes from the 1990s on and the contrasting sets of ideas gradually were broken down. However, she also points out that activities of self-advocacy groups, such as the anti-labelling campaign of People First, were built on ideas of labelling theory rather than the social model of disability.

CHAPPELL (1997) criticises that literature springing from the disabled people's movement largely ignores issues of learning difficulties and hence an inclusion of matters regarding people with learning difficulties can only be assumed implicitly. She stresses the neglect of literature concerned with learning difficulties and the omission of people with learning difficulties' experiences (ibid.).

Inclusion into the more theoretical academic and political debate is an issue which needs further consideration. The particular problems that people with learning difficulties face in

controlling the analysis of their own experiences raises the question whether this is grounded in their impairments or due to others, e.g. academics and people without learning difficulties, not enabling them in an appropriate way (WALMSLEY 1997). Taking part in academic and political debate on equal terms however, is effectively an agenda of normalisation as it implicitly assumes that “people with learning difficulties must heroically rise above the impairment and join in a conspiracy to deny that their intellectual limitations matter” (WALMSLEY 1997: 75). WALMSLEY doubts whether the limitations people with learning difficulties face are really all socially created and claims that in academic and political debate, people with learning difficulties will always remain disadvantaged. Although partnership and inclusion are possible, there remain specific forms of oppression:

“It is not just a matter of time, resources, technology and positive attitudes. It is not just a learning difficulty, the sort we are too ready to say we share because we too have learning difficulties. It is where normalisation has not got all the answers. This is an area where oppression and exclusion take a distinct form for people with learning difficulties, and if they are to take their place alongside other disabled people [...] it’s something that has to be addressed.” (WALMSLEY 1997: 75)

Those issues have even intensified with globalisation in the early 21<sup>st</sup> century as for example a growing service and information

industry demands more literacy skills and accumulated knowledge of the population (DOWSE 2009).

It also has to be considered that the self-advocacy movement is far from being a homogenous collective and requires a consideration of representation issues itself. WALMSLEY & DOWNER (1997) discuss issues of diversity and state a danger of self-advocacy being exclusionary and representing specific interests, especially as the self-advocacy movement is dominated by white men with mild learning difficulties. Specific issues they highlight are relating to gender, sexual orientation, race and ethnicity, severe impairments and communication difficulties (ibid.). These issues of representation, the recognition of difference and distinct identities can therefore be seen as being placed on a continuum which is not limited to the disabled people's movement but links into broader issues of diversity within groups. BARNES & MERCER (2010) state that recently, politics of representation focusing on diverse identities have become more important than material issues focusing on equality and justice in social movements. A balanced combination of the identity and material issues poses therefore a challenge for the future of the self-advocacy and the disabled people's movement.

### 3.4 Summary

To conclude this chapter, it is important to sum up some points: Self-advocacy and the disabled people's movement can be seen as own distinctive forms of self-organised collectives of disabled people. However, they also interrelate as neither of them is closely defined and both are formed by people with diverse identities. Taking into consideration the theoretical basis of the disabled people's movement, the social model of disability, there is however a common focus for all disabled people as they experience oppression:

“...organising according to impairment suggests that impairment is the dominant problem for disabled people, and ignores the shared experience of oppression which unites disabled people.” (SHAKESPEARE 2006: 157)

Hence, the social model may be one that unifies all disabled people and does not force them to deny their distinct identities at the same time. This argument asks for the inclusion of people with learning difficulties in the disabled people's movement. The chapter also has shown that in reality, issues of representation have not been solved satisfactory and that the early hope of creating an inclusive disabled people's movement based on the common experiences of oppression has not been realised yet (OLIVER 2009).

It further has to be noted that self-advocacy has developed with close relationships to professionals and services. This certainly is a point which makes it distinguishable from the disabled people's movement, as the latter is mainly opposed to professionalism and traditional service provision. How self-advocacy can actually be characterised by applying a more theoretical background, which relation it has to service provision and professionals and what implications can be derived from that will be discussed in the next chapter.

## **4. Analysing Self-advocacy**

So far, it was demonstrated that self-advocacy is far from being a straightforward issue and that there are many controversies surrounding the self-organisation of disabled people and people with learning difficulties. This chapter focuses on analytical accounts which help to get a better understanding of self-advocacy. They originate from different theoretical and ideological positions; it is hence important to understand the implications that can be derived of those for the situation of people with learning difficulties. The accounts come from discourses as different as understanding the politicisation of disabled people on the one hand and conceptualising services on the other hand. The first section of the chapter will address issues of political movements and relate this to self-advocacy, the second section places its focus on empowerment and service provision and the third section gives a summary over the main findings.

### **4.1 Self-advocacy - a New Social Movement?**

The self-advocacy movement has been characterised as social movement (BERSANI 1996; ATKINSON 1999; GOODLEY 2000). Also

the wider disabled people's movement has been described in this sense (CAMPBELL & OLIVER 1996), however there is considerable debate as to what constitutes a new social movement (BARNES & MERCER 2010). The arguments presented here will concentrate on the disabled people's movement first before considering self-advocacy more specifically.

The disabled people's movement has been characterised as "a new social movement in that it is beginning to offer disabled people a democratic and political voice; something we never had before" (CAMPBELL & OLIVER 1996: 23). This argument goes back to criteria established by MARX & McADAM (1994). They create a framework to understand social movements by asking whether the movement's activities have resulted in any political or economic changes, specific legislation was achieved, alteration in the public has been generated and whether there were any new organisations or institutions created (ibid.). CAMPBELL & OLIVER (1996) show that the disabled people's movement fulfils those criteria: It has given disabled people a voice in political and economic questions, it has promoted laws such as the DDA and the 1996 Community Care (and Direct Payments) Act and it has impacted on society via direct action as well as by creating

organisations such as the BCODP. Therefore, the British self-organisation of disabled people can be judged as a social movement. Furthermore, to decide whether it constitutes a new social movement, one needs to consider:

“...the extent of the consciousness raising and empowerment amongst disabled people, the extent to which disability issues are raised internationally, and the promotion of disability as a human and civil rights issue.”  
(CAMPBELL & OLIVER 1996: 168)

This argument is supported by illustrating firstly the establishment of disability arts and cultural consciousness which has had an empowering educational influence. Secondly, considering the role of the BCODP in Europe and in DPI, the movement does have an international dimension. BARNES and MERCER (2001) stress furthermore the diversity that exists across the globe in political questions by pointing out the American movement's focus on consumerism and self-reliance which differs from the British citizenship approach. For judging the third criterion, the extent to which new social movements ensure human and civil rights for their members, CAMPBELL & OLIVER (1996) mention the links to other civil rights organisation and the involvement of the BCODP and DPI in human rights issues; a recent example would be the involvement of disabled people in the development of the UN

Declaration of Rights of Persons with Disabilities (2006) (BARNES & MERCER 2010).

Hence, due to being marginal in regards to established politics, undertaking a critical assessment of society, being based on post-materialist and acquisitive values and due to its international character, the disabled people's movement can be judged as new social movement (CAMPBELL & OLIVER 1996; BARNES & MERCER 2001). There are however others, such as SHAKESPEARE (1993), who have opposed. Although he suggests that some of the arguments brought forward in social movement theory point to the disabled people's movement as being a new social movement, e.g. being based on values like autonomy, rejecting ideas of passivity and objectification and challenging central institutions and structures, SHAKESPEARE conceptualises the disabled people's movement as a liberation movement. For him, it is concerned equally with questions of interests, resources and politics and hence also material values, conventional political processes and mobilisation due to particular interests. The focus on structural issues, social security and material needs also leads BECKETT (2006) to the judgement that the characterisation of the disabled people's movement as a new social movement is

inappropriate. Her research furthermore highlights a lack of clarity regarding the existence of a distinct disability culture and disability identity which results therefore in problems when analysing the self-organisation of disabled people as a new social movement (ibid.). Also PRIESTLEY (1999) is insecure whether the disabled people's movement can be called a new social movement or should, due to its questioning of the relations of production and reproduction of disability, be subject to class-based analyses. BARNES and MERCER (2010: 274) give a detailed analysis of recent developments regarding the disabled people's movement and highlight that:

“... the disabled people's movement demonstrates both radical and conventional sides. [...] Yet, for most disabled people, what is important is not whether the disabled people's struggle is categorised as either 'new' or 'old' style politics but that it sustains and enhances the extraordinary vitality and impact of disability politics built up over recent decades.”

Although considerable less attention is paid to whether self-advocacy can be defined in terms of new social movements, there are a few positions to be taken into consideration here. BERSANI (1996) characterises self-advocacy as a new social movement and bases his evaluation on a framework developed by JOHNSTON et al. (1994). They suggest that in those movements, members go

beyond typical social roles, that movements represent a strong ideological change, that they entail the rise of new identity dimensions, which may have been considered as weaknesses before, and that the individual-collective relationship is blurred.

According to BERSANI (1996), this is the case for the self-advocacy movement as it fulfils all those criteria. However, his analysis bears several problems. First of all, although referencing SHAKESPEARE (1993), he does not distinguish between social movements in general and new social movements in particular. After asking the question “Is self-advocacy a new social movement?” (BERSANI 1996: 265), he goes on to write: “features that may help us determine that self-advocacy is in fact a social movement” (ibid.). He does not consider arguments concerning the material or post-material value basis of self-advocacy as it was discussed above in regards to the disabled people’s movement. Also, his judgement of a positive dimension of identity seems rather undifferentiated, as he bases it on stickers, posters and slogans of the wider disabled people’s movement rather than considering experiences of people with learning difficulties. Thirdly, although stating that self-advocacy is about leadership of people with learning difficulties, he still links it to consumerism and

hence to services: “Surely the consumers of human services standing up, organizing and saying that they want control over their lives is a departure from former social roles” (BERSANI 1996: 265). Finally, regarding the blurred relationship between individual and the movement, BERSANI (1996) points out that self-advocates always relate to themselves as well as the movement. He judges it as positive that some advocates hold paid positions and are professionals themselves. Considering, as outlined in 3.1, that professionalisation and institutionalisation have become major problems for the disabled people’s movement recently, BERSANI’S argument seems therefore rather problematic.

GOODLEY (2000: 14) expands BERSANI’S analysis based upon the same framework but raises questions which highlight some limitations. These questions concern the influence of advisors on the role of self-advocates, the actual change of professional practices and social structures which lie behind terminological alterations, whether positive identities go behind campaign slogans and the importance of the collective and formal group on self-advocates’ experiences. He furthermore criticises the fact that BERSANI’S analysis is based solely on People First groups but neglects self-advocacy which takes place in other settings. An

important point, which is raised but not further discussed by GOODLEY (2000), are the political implications that stand behind self-advocacy. Moreover, if applying the framework of MARX & McADAM (1994) self-advocacy can hardly be judged as a distinct new social movement (DOWSE 2001). If however it is considered as part of the wider disabled people's movement, the discussion about its status as 'old' or 'new' social movement applies to self-advocacy as well. As pointed out earlier, self-advocacy is also closely connected to services and professional involvement. But then, describing it as social movement is rather problematic. These issues need to be considered in more detail in order to understand discourses around self-advocacy. This will be done in the next section.

## **4.2 Self-advocacy and Empowerment**

The rise of self-advocacy is not only considered as a political movement or part of the disabled people's movement:

“The continued growth of Self Advocacy in Britain is due to some extent to the agenda of community care reform evident from the mid 1980s. [...] It required the views of people with learning difficulties to be taken into account and so self advocacy became an integral part of the service delivery process.” (DOWSE 2001:130)

Hence, especially self-advocacy in service contexts links to ideas of empowerment and community care and overlaps to some extent with discourses around service provision in the welfare state more generally (GOODLEY 2000). This section explores some of those issues more deeply by focusing on the concept of empowerment and looking at underlying ideologies which are relevant in the context of self-advocacy.

Empowerment is, as JACKSON & HYSLOP (2003) suggest, a rather unclear concept. It has gained prominence in recent years, in personal as well as in policy issues and can be used to describe an objective and a process of emancipation but also the act of giving power to somebody (BERESFORD 2006). Hence, there are diverse and partly contradictory meanings attached to it; it is linked to various discourses with consumerist and professional approaches being more prominent than the one of disabled people (ibid.).

Consumerist approaches to empowerment are connected to a redefinition of service provision in the welfare state which has taken place at the end of the 20<sup>th</sup> century under influence of the New Right. In the UK, this is linked to the establishment of

'community care' policies from the late 1980s onwards (BERESFORD 2006). The phrase 'community care' was originally introduced by the Report of the Royal Commission on Mental Deficiency of 1954/57 and although there was no precise definition given, the term has been used by subsequent governments. Now, it signifies the redefinition of welfare and introduction of a managerial strategy for service provision as well as a market strategy for the private and voluntary sector which was legally launched with the 1990 NHS and Community Care Act (OLIVER & BARNES 1998). This two-fold approach's aim was to encourage a more user-centred service delivery as well as to increase consumer choice between services (BARNES & MERCER 2006). BERESFORD & CROFT (1993) stress that this set of ideas puts a rather conservative emphasis on the strengths of traditional communities and highlights self-help, independence and informal support as important for citizenship. This translates into consumerist ideas of commercial service provision. The users of services are seen as customers and their status is reframed by the application of market logic within welfare provision. Individual choice and competition are regarded as important for this concept of consumerism (ibid.).

Hence, consumerist notions of empowerment are

“... based on developing consumer rights, which would give citizens real and measurable powers over state services. [...] The political New Right conceived of empowerment in terms of equalizing the citizen’s relationship with state provision.” (BERESFORD 2006: 595)

In this consumerist understanding, empowerment means to enable individuals to vocalise their preferences, to choose amongst different services and to elect another provider if the received service is not satisfying. The implementation of community care in the UK has maintained an individual understanding of disability and not overcome old power imbalances (PRIESTLEY 1999).

The idea of empowerment has also gained relevance in health care and social professions. BERESFORD (2006: 596) speaks of the “professionalization of empowerment”. Here, the focus lies on the role of the professional who is to help the service user or client to become more empowered; professionals are considered as being able to empower individuals as well as groups (ibid.). In this context, empowerment is not of reflexive meaning anymore; it is either done by somebody else or to somebody else and hence does not entail one’s own actions. Consequently, the moral value

is also applicable to the professional because empowering somebody else is perceived as doing something positive (BAISTOW 1995). This understanding then establishes professionals as being increasingly important to the process of user empowerment and simultaneously puts it at the centre of the professional legitimacy (ibid.). The language, goals and means of empowerment in this context are defined by professionals (DOWSON 1997). By adopting the empowerment rhetoric, professionals are able to react to insecurity about their status and to gain new credibility and legitimate the work they do “as a rationalisation for virtually any of their work for, or with, people with disabilities” (RAMCHARAN & BORLAND 1997:xi). Moreover, professional approaches are particularly concerned with individual empowerment, in the sense of helping people to change their behaviour and attitudes rather than addressing social structures (BERESFORD 2006). Some approaches of professional empowerment distinguish between three connected dimensions: psychological, service-initiated, and social whereby professional empowerment relates to the first and second one (BYRT & DOOHER 2003).

Three central elements of the above mentioned empowerment approaches can be distinguished: Firstly, what under a traditional welfare and medical understanding was considered as patients or clients is renamed as service users or consumers. Secondly, empowerment is objectified as if it could be delivered to somebody and thirdly, empowerment is understood as welfare management (OLIVER 1996).

On the contrary, the understanding that is important to the disabled people's movement defines empowerment as reflexive and self-transformative process: "The oppressed are not empowered: they take power" (DOWSON 1997: 107). Based on personal and collective support, skills, knowledge and common experience, it contributes to the transformation and emancipation of participants in new social movements who resist against their oppression (BARTON 2001). Empowerment therefore has a political meaning. As OLIVER (1996) points out, empowerment does then imply individual as well as collective aspects and is understood as a collective process that enables individuals to transform their consciousness. Therefore, it relates to overcoming internalised oppression (BARNES & MERCER 2006). Collective empowerment of disabled people poses a threat to professionals

as well as to the traditional charities and the voluntary sector as it means disabled people speaking for themselves rather than being represented by third parties (OLIVER & BARNES 1998). Consequently, the idea also links to democratic participation in society and the equal involvement in service provision (BERESFORD & CROFT 1993). Instead of seeing involvement as the exercise of consumer choice, emphasis is put on general democratic rights of disabled people. Empowerment is part of a struggle for equal rights, opportunities and inclusion into society (RAMCHARAN & BORLAND 1997). It is more than a personal process as it relates to wider structures in society.

It was shown that the term empowerment paradoxically entails very different understandings. Whereas in the sense of the disabled people's movement, it is defined as reflexive process and structural aspects are regarded as the key not only to achieve political change but also individual transformation, consumerist and professional understandings of empowerment are mainly concerned with individual dimensions linked to services. Understanding empowerment in the sense of consumer rights and the professional delivery of services however does put it in a context where it loses its political and transformative element.

Paradoxically, unless oppression and power inequalities which are inherent in the service practice are addressed, a shift towards empowerment or the involvement of service users remains only rhetorical (JACKSON & HYSLOP 2003). The opportunistic way professionals and the voluntary sector are reacting to ideas of empowerment in taking them on and placing them at the centre of their legitimacy in order to avoid the limitation of their power is a highly problematic aspect within the discourse of empowerment (OLIVER & BARNES 1998).

Also, what originally was a synonym for the political movement's search for the emancipated self has shifted into a neo-liberal technology of citizenship. An unfortunate, even paradoxical combination is the coincidence of disabled people's ideas of self-determination and autonomy with neoliberal notions of rationality and competence (DOWSE 2009). In the latter sense, empowerment therefore is a therapeutic instrument, transforming individual's capacity to live a self-determined, responsible and autonomous life. Being inspired by ideas of self-determination as well as by the market, empowerment therefore holds ambivalent notions of constraint as well as freedom (ibid.).

How does this link to self-advocacy? When looking back to section 2.3 and how self-advocacy is defined and conceptualised, it becomes clear that in many definitions, empowerment and self-determination are at the heart of the argument. “A key aspect of empowerment is the role of self-advocacy” (GOODLEY 2005: 335). Therefore, it needs to be considered which ideological arguments are prevalent in current conceptualisations of self-advocacy and how this links to original notions of self-advocacy that were coined by people with learning difficulties.

Thinking about the key point of the consumerist argument, self-advocacy limited to service provision then is an instrument to enable people with learning difficulties in exercising their rights and choices as consumers. As ASPIS (1997: 652) points out:

“Self-advocacy has become a tool to find out what people with learning difficulties think of services rather than to challenge the philosophy of services and system that creates them and their inherent limitations. As a consequence the service provider limiting [sic] the scope of what self-advocates are able to speak up about.”

If people are able to empower themselves only through collective action and appropriate information, limiting self-advocacy to self-determination and speaking up without a consideration of the

broader context, social structures and the education of people about their legal rights is problematic.

Also, the recognition of self-advocacy by the government has to be considered more closely. The proposed funding for independent self-advocacy schemes promoted in the White Paper *Valuing People* (DoH 2001) may lead to the homogenisation of self-advocacy as only certain types of groups are supported: Those are currently the ones operating outside of service settings and meeting the funding requirements (GOODLEY 2005). It has been argued by CAMPBELL & OLIVER (1996) that independence of government funding is an important necessity for the success of political disability activism. When self-advocacy has to prove itself to funders by being evaluated and monitored (RAPAPORT et al. 2005), one has to ask how much control people with learning difficulties really have in it any longer.

The close link of self-advocacy and service provision contributes not only to a limited scope of the agenda but justifies also the involvement of professionals: If professionals are the key to deliver empowerment to people, then they are also necessary to deliver self-advocacy to people with learning difficulties. Hence,

legitimizing professional involvement in self-advocacy as being necessary to empower people with learning difficulties is problematic:

“... self-advocacy cannot be a liberating experience if its process and contents are being managed and controlled by the same people who have the power to oppress those who have been labelled as having learning difficulties.” (ASPIS 1997: 653)

This argument does not reject the necessity of supporters for self-advocacy groups in general, however it raises questions about who is in control over the process and content of self-advocacy. DOWSON (1997) agrees and points out that powerful groups historically have rarely given their power away freely; hence it is appropriate to be critical whether there are prospects for real change if professionals hold on to their power and dominance. Also, when self-advocacy as empowerment is delivered by professionals in specific contexts, this is problematic as it limits self-advocacy to certain settings such as monthly group meetings. GOODLEY (2005) prefers the idea of resilience when conceptualising self-advocacy as this is not only limited to activities in the context of groups but does also stretch to any situation in life.

It is important to consider the context of self-advocacy beyond empowerment and 'speaking up' or 'making choices'. Self-advocacy groups:

“...allow people to 'have a voice'. They [*people with learning difficulties, M.N.*] are 'involved'. This is undoubtedly better than being excluded and ignored; but it does not, by the standards of most citizens, come anywhere close to having power. How many of us - those enjoying an ordinary life - would be satisfied that our rights as tenants, employees or consumers were secure if they were safeguarded by nothing more than a promise that we would be 'consulted'?” (DOWSON 1997: 118)

Hence, if self-advocacy is not to be redefined by government policies and service professionals in terms which are not those originally formulated by the self-advocacy movement, the everyday reality of people with learning difficulties needs to be considered. The ambivalence of the empowerment discourse has shown that limiting ideas to self-determination and autonomy are dangerous as they form a part of neoliberal ideologies. Addressing structural issues of oppression and equality as done by the disabled people's movement therefore are a necessary supplement to speaking up and making choices.

### **4.3 Summary**

This chapter has focused upon two different analytical approaches towards self-advocacy. The first section considered whether the disabled people's movement and self-advocacy can be characterised as new social movements. It became clear that although some authors have advocated for such a standpoint, especially the value basis and the notion of a distinct disabled identity have been debated in the case of the disabled people's movement. Furthermore, it was shown that analyses which describe self-advocacy as distinct new social movement are rather problematic. Considering that self-advocacy can be - despite representation and accessibility issues - linked to the disabled people's movement, it is argued here that debates focusing on the latter can also be applied to self-advocacy.

However, self-advocacy is not only understood as political movement but also relates to discourses around service provision and community care; this was explored by focusing on the idea of empowerment. Three different notions of empowerment were highlighted: consumerist, professional and political. Whereas the latter, the one coined by disabled people in the context of the self-advocacy and disabled people's movement, contains structural as

well as self-transformative elements, the former two approaches towards empowerment remain mainly apolitical as they focus on the individual.

Those three different understandings can also be applied to self-advocacy. In a consumerist sense, self-advocacy can be regarded as way of enabling people with learning difficulties to exercise their consumer choices. The professional promotion of and support for self-advocacy raises the question whether this is really supportive for people with learning difficulties or whether it rather is a way of legitimating the status and power of professionals. Service provision for people with learning difficulties, although having adopted the rhetoric of civil rights and empowerment, still is based on notions of welfare and care (BARNES & MERCER 2010).

This chapter has shown that limiting self-advocacy to service provision and legitimating professional delivery of empowerment through self-advocacy poses a threat to more political notions as it makes it hard to address structural issues of inequality and oppression.

## **5. Conclusion**

This work has addressed issues around the self-organisation of people with learning difficulties by investigating the relationship of self-advocacy and the wider disabled people's movement as well as theoretical ideas behind self-advocacy. A close investigation of the discourse around self-advocacy was necessary because it was assumed that government and professional support, as occurring within the past decade, transform the self-advocacy of people with learning difficulties into a paradoxical issue: On the one hand, recognition and support from official bodies shows that the activities of people with learning difficulties are taken seriously and their voices are being heard, on the other hand, institutionalised structures and segregated service provision are causing the marginalisation of people with learning difficulties in society.

In order to gain a deeper understanding of the phenomenon of self-advocacy, its relation to the political struggle of the wider disabled people's movement was addressed. Three foci were chosen for the undertaken UK-based literature analysis: definitions of self-advocacy and its development in the UK, the

link to the wider disabled people's movement and the connections between self-advocacy and service delivery.

Chapter 2 addressed three key concepts which were relevant for this work: According to the social model, disability is not an individual phenomenon but the oppression that people with impairments experience in capitalist societies. The impairment category learning difficulties however has proven to be rather complicated and its biological basis has been contested, especially in postmodern accounts. It can be considered as a social construct which unites physiological, physical and socio-historical elements in itself. Finally, definitions of advocacy and self-advocacy were explored. It was shown that advocacy for disabled people by non-disabled people is judged as problematic as it may be dependency-creating. Self-advocacy on the contrary refers to people acting on their own behalf. It has been used to refer to the self-organisation of people with learning difficulties and their 'speaking up' on individual and group level. A common element in many definitions is the idea of self-determination and empowerment. Self-advocacy is linked to a social model as in this sense, disability needs to be addressed by collective action rather than medical or professional treatment. Self-advocacy as

collective action of people with learning difficulties can be seen as a step in this direction.

Chapter 3 highlighted the historical development of the self-organisation of disabled people in Britain by focusing especially on developments from the second half of the 20<sup>th</sup> century on. First of all, the important distinction between disability and disabled people's organisations regarding their aims, leadership and membership was discussed. As traditional disability organisations provided care for instead of representation of disabled people, those began to self-organise from the 1970s on. The disabled people's movement experienced a growth and institutionalisation in the 1980s and 1990s and successfully campaigned for the introduction of anti-discrimination-legislation. However, some observers have reported a decline over the last decade; one of the main reasons suspected for this is the institutionalisation of disability campaigning. It is seen as a cause for the marginalisation of the disabled people's movement in mainstream politics. Self-advocacy as a distinct form of self-organisation has grown since the 1970s. The activities of people with learning difficulties have received government recognition and support, especially after the publication of *Valuing People* in 2001. The

consideration of the relationship between the disabled people's movement and self-advocacy undertaken in Chapter 3 highlighted the underrepresentation of people with learning difficulties in the BCODP and accentuated the problems associated with representation and issues of diverse identity in both movements. The simultaneous following of common aims and adequate representation of diverse identities is one of the main challenges for the future political activism of disabled people.

Chapter 4 considered theoretical accounts towards self-advocacy which conceptualise it as political, (new) social movement on the one hand and regard it as part of the service sector on the other hand. It was shown that it is not clear whether the disabled people's movement can be described as new social movement, these doubts are also valid for self-advocacy as analyses undertaken so far have not been satisfying. By analysing the idea of empowerment, one of the key aspects of self-advocacy, it was highlighted that different understandings exist: Whereas consumerist and professional accounts limit the scope of empowerment to the service sector and regard it in an individualised way, empowerment in the sense of political movements also allows for the consideration of social structures

and stresses an inherent self-transformative element. Consequently, government support for self-advocacy may be tokenistic if it limits it to service provision and legitimates professional involvement.

By providing insights into issues and dilemmas surrounding self-advocacy, it can be concluded that if self-advocacy is understood as political process, which enables individuals to self-transformation and empowerment, it makes sense to pay attention to its links to the wider disabled people's movement. Both, the disabled people's and the self-advocacy movement have to come to terms with a difficult task however: On the one hand, there is the recognition of their demands by conventional politics, charities and health and social care professionals, on the other hand much of the original criticism was targeted against exactly those institutionalised forms of politics and welfare provision. Hence, collaboration and engagement in those 'traditional' structures has to exceed the limits of a positive disability rhetoric; this at the same time requires action against the same institutionalised structures and therefore will not be free of conflicts.

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