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**Advocacy for People with Learning Difficulties:
The Role of Two Organisations**

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Thesis presented for the degree of Doctor of Philosophy

The Open University, Faculty of Health and Social Care

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Advocacy for People with Learning Difficulties:

The Role of Two Organisations

Abstract

This thesis is about advocacy for people with learning difficulties. It has been undertaken through a detailed study of two different types of advocacy organisations - People's Voices (a situation-based, one-to-one advocacy group) and Talkback (a self-advocacy group). Both organisations are based in Buckinghamshire.

The research had two main aims. The first was to explore the values, principles and theories that underpin the work of advocacy organisations, and to consider how they are borne out in practice. This required a thorough analysis of organisational processes and relationships between group members. The second aim was to assess how advocacy organisations interact with and are shaped by the wider environment. This involved an in-depth examination of the local (historical and socio-political) context, as well as relations between the groups and external stakeholders – in particular, statutory bodies.

The research found that although members of advocacy groups are generally inspired by a similar vision, ideas about how this might be achieved varied among respondents.

Whilst the groups were guided by a strong set of values and principles, these were sometimes difficult to implement in practice – particularly with regard to how advocacy organisations are run. The thesis also showed that whilst advocacy organisations can and do direct their own agenda, they also face pressures from the wider environment – most notably through commissioning arrangements. In this way the thesis shed light

upon wider questions concerning the relationship between statutory bodies and the voluntary sector, in the health and social care field in England. The research revealed the complexity of advocacy organisations, and highlighted the need for more in-depth, localised studies.

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Many thanks to Talkback for granting me permission to include figures 3, 4, 5 and 6 in this thesis. All of these images were created by the Talkback team.

Chapter 1: Introduction

This thesis is an exploration of advocacy for people with learning difficulties. The research draws upon data from two organisational case studies in order to examine the claims made about advocacy, and to assess the ways in which such claims are (or are not) borne out in practice. The thesis considers the nature of relationships among members of advocacy organisations, and analyses how the groups interact with the wider environment. This study was developed using a qualitative multi-method framework, which actively sought the perceptions of a range of stakeholders. Primarily the thesis aims to produce knowledge about the practice of advocacy and thus build upon a small body of literature which has begun to evaluate different elements of advocacy through in-depth empirical and methodologically rigorous studies. It also aims to use the case studies as a means of exploring wider questions regarding the interface between health and social care policy and the voluntary sector in England.

The two organisations at the centre of this study are People's Voices (situation-based, one-to-one advocacy) and Talkback (self-advocacy). Both groups are based in Buckinghamshire. The organisations were chosen because of insights they could generate into current advocacy debates. This is discussed further in chapter 3.

This introductory chapter begins with a discussion on the somewhat elusive nature of the advocacy concept, and goes on to outline my rationale for undertaking this research. The chapter situates the research within the wider policy context and identifies the thesis aims. Finally it sets out the structure of the thesis.

1. Deciphering advocacy

Advocacy has been most concisely defined by Atkinson as “speaking up” – on one’s own behalf, or on behalf of others’ (1999: 1). Useful as this definition is, it also disguises a number of ambiguities and tensions within the advocacy concept. For example, ‘speaking up’ is a process – something which one does in order to be heard. This process is one which may facilitate the achievement of a host of wider aims for people, either as individuals, or collectively. But can this idiom be applied to those who cannot ‘speak’? The description begins to feel increasingly metaphorical and thus raises further questions. Who can meaningfully practise ‘advocacy’ and how can this be facilitated? How does advocacy actually *happen* in the context of an organisational setting? And who owns or controls the concept – particularly at a time when government is paying it increasing attention (Leason, 2005)?¹ ‘Advocacy’ for people with learning difficulties does not exist in a vacuum; it inhabits an arena of both policy and practice which is generating more interest than ever before in its short history. As a result, the concept of advocacy is increasingly ‘up for grabs’ as greater numbers of individuals, groups and institutions compete to define its values and direct its implementation (Henderson and Pochin, 2001: v).

Defining advocacy for people with learning difficulties in the context of this study is complicated by its division in much of the literature into different ‘types’ or ‘forms’ of advocacy. These have included self-advocacy; citizen advocacy; situation-based or crisis advocacy; peer advocacy; and collective advocacy and are generally treated as separate entities (Butler et al, 1988; Goodley, 2000a; Simons, 1993). As a rule of thumb

¹ Support for advocacy has been a central component in a number of recent government documents, most notably, the *Valuing People* white paper, 2001, the Mental Capacity Act, 2005, and *Improving the Life Chances of Disabled People*, 2005 (Prime Minister’s Strategy Unit).

in this thesis, I will make the distinction between ‘one-to-one’ advocacy (in which members of the community volunteer to advocate for people with learning difficulties, whether that be in short or long term partnerships) and ‘self-advocacy’ (whereby people with learning difficulties undertake activities in which they advocate for themselves – either individually or in a group). When the term ‘advocacy’ is employed, it is used to encompass both types of advocacy activity. However, it is clear that the notion of what advocacy actually *is*, remains mired in ambiguity. As such, this thesis aims to bring new insight and some clarity to the advocacy concept.

2. Why research advocacy now?

2.1 The limitations of existing research into advocacy

Like Henderson and Pochin (2001) I argue that there is an urgent necessity for researchers to explore the nature of advocacy in today’s social and political climate. Few would disagree with the notion that the aims of advocacy are a ‘force for good’. Numerous texts have highlighted its central purpose of securing the rights and protecting the interests of marginalised people (Garner and Sandow, 1995; Atkinson, 1999; Gray and Jackson, 2002; Thomas and Woods, 2003). However, as Henderson and Pochin have pointed out:

Advocacy is facing a series of threats and dilemmas. In part these reflect the difficulties which affect numerous voluntary sector activities, especially with regard to funding. But the problems also go deeper. As advocacy moves up the political agenda, so questions about the nature and quality of advocacy processes are thrown into sharp relief (2001: v).

This is coupled with a surprising lack of detailed empirical research into advocacy. Gray and Jackson argue that the absence of sustained critiques regarding the purpose and practice of advocacy has resulted in discussions about its role in contemporary society being steeped in a ‘conceptual fog’ (2002: 13). They suggest that if there is a ‘genuine commitment to providing people with learning disabilities with the means to express their views then there has to be more informed debate about how this can most effectively be achieved’ (Gray and Jackson, 2002: 13).

A few recent studies have begun to explore some of the complexities involved in the practice of one-to-one advocacy. For example, Atkinson and Forbat (2003) evaluated perceptions among multiple stakeholders with regard to organisations in Nottinghamshire, whilst Buchanan and Rumble (2004) explored the role of advocates in the lives of parents who have learning difficulties in Dorset. However, these studies are unusual, with much of the literature on one-to-one advocacy confined to surveys and writings on standards and guidelines (www.advocacyresource.net; www.bild.org.uk/advocacy). Henderson and Pochin (2001) have argued that the very nature of one-to-one advocacy has also contributed to the dearth of analytical research into the key questions affecting its development. They suggest that citizen advocacy in particular²:

has an inherent suspicion of academic research. It is felt that to research advocacy is to treat it as an “intervention” and to “clientise” those it supports,

² The citizen advocacy model has historically promoted the development of long-term social relationships between the advocate and the advocacy partner. Thus the advocate brings the person with learning difficulties into ‘the circles of ordinary community life’, as well as representing their interests and supporting them to manage changes or crises in their life (O’Brien, 1987). A fuller discussion on citizen advocacy can be found in Chapter 2, section 1.2. This thesis will demonstrate the ways in which People’s Voices differs from the citizen advocacy model.

thereby thwarting a key aim of citizen advocacy, which is to promote partners' access to and acceptance within, the life of the community. Second, the stress laid upon confidentiality by all models of advocacy has led to an understandable reluctance to discuss actual advocacy processes in the public arena (Henderson and Pochin, 2001: v).

Two recent PhD theses have produced in-depth knowledge about the inside workings of self-advocacy groups (Chapman, 2005; Clement, 2003), although these analyses were both undertaken with People First groups. Early conversations with Talkback members indicated that the organisation may be operating in different ways to People First groups. For example, unlike People First organisations, people with learning difficulties in Talkback do not hold official titles such as 'chief executive', 'treasurer' or 'chair'. What were the implications of this (if any) for the type of self-advocacy practised by the group? It was also apparent that Talkback worked with high numbers of people with learning difficulties across the county on a regular basis. For example, at the end of the fieldwork period, the group was supporting approximately 200 people with learning difficulties to self-advocate in Buckinghamshire. This again stands in contrast to People First organisations, which tend to comprise smaller numbers of individuals (Clement, 2003; Goodley, 2000). I was keen to explore *how* Talkback reached so many people with learning difficulties in the local area, and whether these organisational processes created a different 'model' of self-advocacy. Research into other types of self-advocacy groups currently remains thin, and so the contribution of this study to knowledge about self-advocacy is timely. As Clement (2003) argues, existing studies have appeared wary of critiquing the rhetoric of espoused aims. Walmsley and Johnson (2003) suggest that the lack of sophisticated studies in this field may be a result of inclusive research

practices which have discouraged researchers from engaging in rigorous analyses of self-advocacy for fear of isolating the very ‘subjects’ of that research.

Throughout the course of this study, I endeavoured to position People’s Voices and Talkback alongside other advocacy organisations, attempting some form of ‘benchmarking’ exercise. In practice, this proved to be a difficult challenge. The British Institute of Learning Disabilities (BILD) estimate that there are approximately 300 advocacy organisations operating at the current time (email correspondence with BILD, 2006). Brief details about some of the organisations’ activities can be found through advocacy networks, such as the Advocacy Resource Exchange, and links to individual organisations’ websites provide further information. However, it was virtually impossible to locate contextual details for the organisations – such as how, when, and why groups were founded. Mirroring the findings of Clement (2003), I found that very few people held such knowledge about their organisation. Whilst this limited my ability to draw comparisons between the case studies in this thesis and other groups, it reinforced my aim to find ways of elucidating this information from People’s Voices and Talkback. As this thesis argues, developing a deep understanding of the practice of advocacy is reliant upon knowledge of its origins and subsequent development.

Therefore I hope this study will encourage others to pay closer attention to the historical and geographical context of individual groups, so that researchers can begin to build a more comprehensive picture of the factors which shape advocacy.

2.2 My journey into the research

This study stemmed from my prior experience as a support worker for a Mencap day centre and from an ongoing academic interest in the development of voluntary sector

services for people with learning difficulties. My employment with Mencap encouraged me to undertake a research project in which I explored the growth of parent-based organisations for people with learning difficulties (Tilley, 2001). The research raised a number of critical questions about the impact of such groups on the experiences of people with learning difficulties, their historical influence on policy and practice, and the extent to which they were a product of the wider environment. My research also touched upon the ways in which parent-based groups like Mencap interacted with the growth of one-to-one advocacy and self-advocacy – and in doing so, inspired me to look more carefully at the experiences of this more recent voluntary ‘movement’ in the history of learning disability.

This growing personal interest coincided with the publication of *Valuing People* (DoH, 2001), which emphasised the important role that advocacy could play in executing the white paper’s vision. Advocacy was also emerging in a series of other government policies. For example, in 2002, a report was published in response to the *Reforming the Mental Health Act* white paper (DoH, 2000a) which recommended the professionalisation of independent advocacy for users of mental health services (Barnes et al, 2002). In 2003 the NHS launched its Independent Complaints Advocacy Services (ICAS) scheme (DoH, 2005). My experience as a Mencap employee alerted me to some of the challenges that advocates, self-advocates and supporters in self-advocacy organisations were likely to face when implementing not only their own values and objectives, but also those of policy-makers and academics. Coupled with the issues raised in my previous research, I was motivated to examine the organisational processes and external pressures which were influencing the philosophies and practice of an activity that was becoming increasingly high-profile. By its very nature, advocacy has the potential to truly enable people with learning difficulties to be influential players in

their own lives and within the wider advocacy movement. I wanted to look closely at the factors that might facilitate or constrain the achievement of such a vision.

3. Situating advocacy in the wider context: New Labour, voluntarism and Best Value

The significance attributed to voluntarism in recent political discourse makes an exploration of advocacy and its relationship to the state both timely and necessary (Henderson and Pochin, 2001). As Janet Newman has argued, under New Labour ‘the third sector of voluntary associations and self-help groups took on a new importance as a means of complementing – or replacing – state provision’ (2001: 145).

3.1 New Labour and the third way

New Labour came to power in 1997 propagating the ‘third way’; a renewal of social democracy which embodied a middle ground between the market individualism of neo-liberalism and the collectivist state-centred approach of past Labour governments (Giddens, 1998). The ‘modernising agenda’ was the means by which to achieve consensus on the articulation of third way values such as citizenship, democratic renewal, social inclusion and economic efficiency. This has resulted in an approach to services which places high value on performance targets, joined-up working, and participatory democracy, involving the dispersal of power through a plurality of organisations (Newman, 2001).

Within the realm of health and social care, this has been enacted through a range of fora which aim to transform local government (Newman, 2001), and in the rise of user groups that emerged through the consumerist ethos of the 1980s (Baggott et al, 2004; Barnes, 1997; Barnes et al, 1999; Fox et al, 2005). In relation to learning disability policy, the spirit of the *Valuing People* white paper (DoH, 2001) - with its focus on rights, independence, choice and inclusion - mirrors much of the broader New Labour vision. Whilst the impact of the white paper has been called into question (Mendonca et al, 2004; Buchanan and Tilley, 2005) it certainly aimed to be the vehicle through which the principles of the 'third way' would reach people with learning difficulties.

Valuing People also subscribed to the notion of participatory democracy in a variety of ways. Fyson and Simons argued that:

in a significant departure from usual policy-making processes, *Valuing People* explicitly aimed to involve all relevant stakeholders during both its creation and its implementation (2003: 153).

At the national level, service users were invited to contribute to decision-making and planning by linking up to the government's learning disability Taskforce, through the National Forum. At the local level, authorities were required to establish Learning Disability Partnership Boards (LDPBs), and high hopes were held for the boards' potential to truly reform the involvement of users and carers in the development of services (Fyson and Simons, 2003). In the context of such policy developments, Dearden-Phillips and Fountain (2005) argue that self-advocacy has taken the 'leading role in shaping the way people with learning difficulties and statutory providers communicate' (2005: 200). If this is the case, the ways in which such communication

occurs on the ground needs further exploration, and will hence be addressed in this thesis. The issue is of particular importance in the light of recent research which suggests that despite some evidence of good practice, the participation of people with learning difficulties in many LDPBs is quite often symbolic, and does not involve a genuine transfer of power (Clement, 2003; Fyson et al, 2004).

3.2 Rediscovering voluntarism: the role of advocacy in the third way

A key strand in New Labour discourse on the civil society has been its emphasis on community, voluntarism and self-help (see the Compact, Home Office, 1998).

Valuing People recognised the importance of voluntary advocacy organisations in helping to achieve its wider objectives of choice, independence, rights and inclusion for people with learning difficulties (DoH, 2001). It stated:

Effective advocacy can transform the lives of people with learning difficulties by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and play an active part in planning and designing services which are responsive to their needs (DoH, 2001: 46).

This passage highlights the ways in which government perceived formalised advocacy, and anticipated its potential to contribute to the wider project of developing a civil society which includes people with learning difficulties. The white paper pledged a total of £1.3million over three years to support the ‘infrastructure’ of self-advocacy and establish a ‘National Citizen Advocacy Network for Learning Disability’ in order to

‘work towards at least one citizen advocacy group in each local authority area’ (DoH, 2001: 47). The vision outlined in *Valuing People* was that a range of independent advocacy services would be available for people with learning difficulties, enabling them to choose the one best fitting their needs. Such a consumerist framework may have significant ramifications for advocacy organisations, particularly if the implementation of that framework is being directed by government, and not by people with learning difficulties (Walmsley, 2002). Similarly, as Clement (2003) has argued, self-advocacy organisations at the local level have become a way for social services authorities to access the ‘symbolic voice’ of people with learning difficulties on partnership boards. The government’s perception of advocacy in the twenty-first century thus raises the question of who shapes advocacy – an issue that is explored in this thesis.

3.3 Best Value policy: quality services and value for money

Despite the ring-fencing of some central government monies for advocacy, the majority of core funding still rests with local authorities, and to a lesser extent, the NHS (Henderson and Pochin, 2001; Jackson, 2005). What *Valuing People* failed to address was the complex nature of these local funding arrangements, particularly within the wider remit of Best Value (Buchanan and Tilley, 2005). Best Value was introduced in 1997 as a central tenet of New Labour’s modernising of the local government sector, and from April 2000 it has placed a duty on local authorities to ‘secure continuous improvement in the way in which they exercise their functions, having regard to a combination of economy, efficiency and effectiveness’ (DETR, 1999: 3). Although Best Value replaced the system of Compulsory Competitive Tendering (CCT) - a mechanism introduced in the 1980s with the aim of reducing costs and the monopoly of statutory providers at the local level (Ball et al, 2002) - as Means et al (2003) have argued, Best

Value goes far beyond the scope of CCT, as it extends to every activity of local government, including social services.

At the heart of Best Value is a performance management system which contains the means by which local authorities can conduct in-house reviews of all their services on a rolling 5-year programme, and design annual performance plans in order to achieve 'continuous improvement'. Alongside this internal review process, Best Value has developed a stringent regulatory system which subjects the performance of each local service to external auditing and inspection (Higgins et al, 2005). By measuring the achievements of local authorities' service delivery, against nationally defined performance indicators, inspection teams have the power to confirm the 'success' of local councils, or alternatively to highlight where services are failing.

3.4 Best Value and advocacy: contracts, outputs and funding

To date, there has been little research conducted into the ways in which the Best Value framework may be impacting upon the *Valuing People* agenda. However, there is some evidence that this policy is having a direct impact on advocacy schemes across the country, which are being encouraged to quantify activities that until recently have been accepted as almost impossible to measure. Henderson and Pochin (2001) have linked the relative decline of citizen advocacy and the concurrent rise in case-work advocacy in the UK as evidence of funders' preference for schemes which can be subjected to statistical comparative evaluations more easily. This view is supported by Jackson, who highlights the complexities posed by such developments on advocacy schemes:

In advocacy, whilst support provided by advocates may be practical in nature, other characteristics of citizen advocacy relationships – such as love, friendship, acceptance, respect and inclusion – are not so easy to assess and measure (2005: 23).

Best Value encourages different procurement regimes, but its regulatory and performance comparison underpinnings may be establishing a situation in which commissioners are increasingly likely to design ever more complex contractual arrangements with different types of advocacy organisations (Buchanan and Tilley, 2005). It has been noted that Best Value may not simply be regulating advocacy, but also altering its principles and practice (Henderson and Pochin, 2001). This is of particular relevance in relation to the power of commissioning departments to draw up the means by which advocacy is measured. This also has implications for the independence of advocacy schemes which have been re-constructed in commissioning speak as ‘services’ (Chapman, 2005). The origins, principles and values of advocacy may be particularly vulnerable to ill-considered managerialist approaches (Buchanan and Tilley, 2005). More empirical work is needed to explore exactly how commissioning strategies are impacting upon advocacy, and the procurement mechanisms that are being drawn upon in order to purchase advocacy ‘services’. These issues will be addressed in the thesis.

4. The structure of the thesis

The thesis consists of eight chapters:

Chapter 1: Introduction

Chapter 2: Literature review

This chapter reviews the literature relating to advocacy organisations. It focuses on the history of advocacy, its espoused aims, and the sociological theories which may have influenced its development. This chapter also considers some of the tensions in advocacy and how advocacy relates to the wider environment. The chapter highlights gaps in existing research, and indicates how they will be addressed in the thesis.

Chapter 3: The research process: methods and methodology

Here I review the literature that informed my choice of methods for the research, focusing upon qualitative approaches in learning disability research and organisation theory. I also set out my multi-method framework in detail, and explore some of the complexities that arose throughout the research process.

Chapter 4: The development of advocacy at the local level

This chapter presents my findings on the origins of People's Voices and Talkback, and the socio-political context in which they have developed. This chapter relates to my first research question: *What factors influence the development of advocacy in a local context?*

Chapter 5: The relationship between values, principles, theory and practice in advocacy

The focus of this chapter is findings related to group members' narrations of what drives the practice of advocacy in their respective organisations. It begins to unpack how the respondents understood the activities undertaken by their organisation, and thus addresses my second research question: *What is advocacy in practice?*

Chapter 6: Tensions and challenges in the practice of advocacy

This chapter presents my findings on some of the tensions and ambiguities that arose when the organisations' espoused aims were put into practice. In particular, I focus upon the issue of who runs advocacy organisations. This proved a significant site of contestation within organisational narratives. This chapter addresses the research question: *What are the tensions and challenges that arise in the practice of advocacy?*

Chapter 7: Advocacy and the external environment

My last data chapter reveals findings in relation to how advocacy groups interact with individuals and institutions beyond their organisational boundaries. In particular it focuses upon external stakeholder perceptions on advocacy, the nature of 'partnership' working, and the commissioning of advocacy. This chapter relates to my final research question: *How do relationships with external stakeholders impact upon organisations that practise advocacy?*

Chapter 8: Conclusion

This chapter draws together the main findings from the thesis and considers how these findings may be built upon in further research.

Conclusion

This chapter has proposed that advocacy organisations have, to date, been poorly documented and analysed. Existing studies tend to be ahistorical and lack consideration of specific geographical factors – an interesting omission considering advocacy’s overwhelmingly localised nature (Simons, 1992). More detailed empirical research is needed if advocacy is to avoid becoming something of an ephemeral phenomenon. This is of particular significance in the light of recent policy initiatives which I have suggested may be shaping advocacy in ways not yet fully recognised. Advocacy has undoubtedly been placed on something of a pedestal; discussed as a mechanism for not only establishing better services for people with learning difficulties (www.bild.org.uk/advocacy; Flynn and Ward 1991; Simons, 1995), but also as a means of achieving a more just and equal society, in which the very nature of the relationships between ‘disabled’ and ‘non-disabled’ people are deconstructed, and exposed in terms of their inherent power imbalances (Aspis, 2002; Roets et al, 2006). With such fervent claims about its transformational nature dominating the advocacy discourse, it is essential for researchers to take stock, and undertake considered critiques of how advocacy is manifested within organised environments.

I now turn to a review of the literature which has informed the development of this thesis.

Chapter 2: Literature review

Introduction

This chapter reviews the literature on advocacy for people with learning difficulties that has helped to inform the development of my research. The chapter highlights emerging themes and gaps within the existing literature, which are built upon and explored in detail throughout the thesis. I also appraise some organisation theory, which has provided a useful set of analytical tools to help evaluate various elements of organisational life at the two advocacy groups.

The chapter is organised under four main sections, each of which relates to a specific research question and findings chapter:

1. Telling the story: a history of advocacy for people with learning difficulties

This section reviews the literature that traces the historical development of different types of advocacy for people with learning difficulties. It serves as a scene-setter, but also reflects a broader position of the thesis which seeks to use historical data to increase the depth of understanding about the current issues facing advocacy.

2. Values, principles and theories in advocacy

This section explores the literature on the espoused values and principles of advocacy's proponents, and seeks to place such ideals within the broader theoretical developments that have influenced the learning disability field in the past three decades, most notably normalisation / SRV and the social model of disability. Organisation theory is drawn

upon to elucidate the theoretical and moral tenets which might be underpinning advocacy.

3. Tensions in advocacy

This section draws upon the literature to examine the tensions that arise in the practice of advocacy – for example, governance issues and different stakeholder perceptions of the reality of intellectual impairment. This section focuses on the literature which explores the internal dynamics of advocacy organisations.

4. The wider advocacy project: service tool or political force?

The final section of this chapter reviews the literature on advocacy's relationships with external stakeholders – most notably, statutory authorities. It considers the role of advocacy organisations in participative structures, and draws upon existing studies to highlight tensions and challenges that have arisen in this process. Like the three preceding sections, part 4 of this chapter also draws attention to current gaps in the literature and shows how this thesis will address them.

1. Telling the story: a history of advocacy for people with learning difficulties

This section reviews the literature on the history of advocacy for people with learning difficulties in the UK. It will help to contextualise many of the themes discussed in this chapter, and will identify factors which have both encouraged and inhibited the growth of advocacy. Drawing on O'Connor's (2000) work on embedded narratives (particularly those 'expanded' to consider broader socio-historical trends that are relevant to the

organisation) and the conjectures of critical realists such as Bryant (2000) I argue that it is important to reflect upon the historical knowledge of a particular phenomenon if we are to fully comprehend its complexities in the present. Whilst historical research on advocacy to date is both sketchy and reliant upon a narrative that has rarely been challenged (see Williams and Shultz, 1982; Flynn and Ward, 1991; Hersov, 1996; and Goodley, 2000a for examples), it is nevertheless important to tell the story again here, drawing on as many sources as possible and including additional information that I have acquired and analysed throughout the course of the research process.

1.1 Growth of a grassroots movement

Elsewhere (Tilley, 2006), I have argued that the development of advocacy is bound up with the broader historical story of grassroots voluntarism for and of people with learning difficulties. This grassroots phenomenon began in 1946 with the founding of the National Association for Parents of Backward Children (NAPBC). As Walmsley has argued, this organisation:

...symbolised a watershed in the history of voluntary organisations in the UK, from early twentieth century voluntary organisations, like the Central Association of Mental Welfare (CAMW), which sought to 'do good' from an abstract, rather lofty position, filling in gaps in state provision, to more grassroots movements which espoused an *advocacy* role for a major group of stakeholders, in this case the families of people with learning disabilities (Walmsley, 2000: 104, my emphasis).

I have characterised the development of this type of voluntarism as one in which ‘insiders’ (people with learning difficulties and their families) raised their political stake in the development of community-based services for people with learning difficulties – both ideologically and practically (Tilley, 2006). As the NAPBC – now known as Mencap – grew and developed a sophisticated organisational structure across the country, it gained a reputation as both a powerful campaigning organisation and innovative service provider (Rolph 2002; Rolph 2005). It also paved the way for the establishment of other parent-based organisations such as The National Autistic Society (1962), and The Down Syndrome Association (1970) whose membership and management structures (at least in the early years) were largely occupied by ‘insiders’.

Whilst these parent-founded organisations have undoubtedly developed strong national as well as local profiles, the grassroots story has not been confined exclusively to carers. Arguably the growth of formal advocacy, beginning in the UK in the 1970s, demonstrates the materialisation of another strand of voluntarism which gained momentum through the integration of both its ‘insider’ and ‘outsider’ perspectives. This refers to the combined input from a range of stakeholders, including users, carers, academics, professionals, and support workers, who have endeavoured to remain independent of statutory structures.

1.2 Citizen advocacy

The idea of organised ‘advocacy’ as a specific form of voluntary activity with a set of prescribed actions and values emerged at a particular historical point towards the end of the 1960s in the United States (Flynn and Ward, 1991). Within the learning disability field, the roots of the term ‘advocacy’ lie in the idea of the ‘citizen advocate’, first

discussed in response to the question asked by many parents at a 1966 United Cerebral Palsy Association conference: 'what will happen to my child when I am gone?' As Flynn and Ward (1991: 136) explain, citing Wolfensberger (1983a), citizen advocacy was perceived as providing one means of safe-guarding the interests of somebody with a learning difficulty, if nobody else was available or willing to do so. This concept was developed in line with broader contemporary critiques of institutionalisation, which had led to the growth of 'protective services'³ for people with learning difficulties in the US. However, a number of criticisms were levelled against such 'protective' agencies – namely their impersonal nature, and their conflict of interest with service providers (Helsel, 1973). Citizen advocacy was put forward as a 'new schema' – independent and voluntary in nature, with a focus on developing long-term relationships in which the advocate protected the interests of the 'protégé' (Wolfensberger, 1973). As schemes were set up with the aim of facilitating these 'partnerships' between people with learning difficulties and citizen advocates, the nature of the relationships began to widen, so that the advocate would be there to provide independent assistance to the advocacy 'partner' (the person with a learning difficulty) even if that person had other support structures (such as family) in place. It is also important to acknowledge the common use of the word 'partner' to describe the person receiving advocacy. The increased adoption of this term has been used to denote parity between the advocate and the service user. However, as Clement (2002) has argued with regard to the term 'empowerment', such language may sometimes be employed to mask power differentials.

³ 'Protective services' was the term coined in the United States during the 1960s to refer to 'those services and activities which are undertaken by an individual or agency on behalf of other individuals who are not fully able to act for themselves' (Helsel, 1973). These included guardianship, outreach, counselling and legal intervention. The primary role of a protective services agency was to ensure that people received appropriate services throughout their lives, and thus acted as procurers and coordinators of services. On occasions a protective services agency would become the service provider if alternative resources were not available. Although protective services collaborated with private voluntary agencies, the agencies were statutorily authorised (Helsel, 1973).

In the UK, citizen advocacy took hold in 1981 with the formation of the Advocacy Alliance, a coalition of five national charities: Mencap, MIND, The Spastics Society, The Leonard Cheshire Foundation, and One-to-One (Butler et al, 1988). This alliance set up a pilot project to introduce citizen advocates to residents of three long-stay learning disability hospitals in south-west London (Atkinson, 1999). In 1984 a similar scheme was developed in Sheffield, although this time the project brought together advocates and local people with learning difficulties including those who lived in hospitals, at home with their families, and in local homes and hostels (Butler et al, 1988). These schemes demonstrate a clear link between the growth of citizen advocacy in the UK and the development of community care services, which gained momentum in the 1980s (Welshman and Walmsley, 2006).

Although the principles of citizen advocacy will be outlined in more detail in section 2, it is worth reflecting here on the vision put forward for this new initiative in the early days of its development. Building on the work of Wolfensberger (1973), and his own contribution to the principles of advocacy (O'Brien and Wolfensberger, 1979) John O'Brien, a leading figure of citizen advocacy in the US, summarised the concept as this:

a valued citizen who is unpaid and independent of human services creates a relationship with a person who is at risk of social exclusion and chooses one or several of many ways to understand, respond to and represent that person's interests as if they were the advocate's own, thus bringing their partner's gifts and concerns into the circles of ordinary community life (O'Brien, 1987: 3).

This vision has been subjected to criticisms from members of the disabled people's movement, some of whom have objected to the potential for citizen advocacy to

perpetuate power imbalances which arise from non-disabled people taking responsibility for disabled people's needs (Tyne, 1994). Tyne argues that amongst those involved in delivering advocacy a debate has arisen around who should receive advocacy. If advocacy is *not* about assuming control over someone with a learning difficulty, then is it right for an advocate to be assigned to somebody who has no means of expressing their wishes? Extended to its logical conclusion, this argument implies that those people who have the greatest need for their interests to be protected could be denied an advocate.

Despite these challenges, advocacy in the UK has grown from its citizen advocacy roots to accommodate a range of organisations, all working towards improving the lives of people with learning difficulties. It has been suggested that there are somewhere between 150-200 one-to-one advocacy schemes alone in the UK (Buchanan, 2004) – some of which constitute the 'pure' citizen advocacy model, with many more facilitating short-term partnerships dealing with specific issues, and longer-term partnerships based upon principles that may not wholly reflect those espoused by the earliest citizen advocacy pioneers. This suggests the phenomenon is a dynamic one, capable of adapting to changing environments (Henderson and Pochin, 2001).

However, developments in advocacy throughout the 1990s also highlight the need for more research into the specific ways in which this diversification has occurred. It begs the question of *why* such diversification has taken place. For example, have specific geographical contexts affected the development of particular groups (local historical, political, and economic factors?) Have key players within advocacy groups been influenced by particular ideas, theories, government policies, or personal experiences? Lastly, it is necessary to consider how the diversification of the past fifteen years has

affected the practice of advocacy on the ground. These questions have not been addressed in the literature to date, and will be discussed in this thesis.

1.3 Self-advocacy

As life history work with people with learning difficulties demonstrates, people were 'speaking up for themselves' long before the 'official' self-advocacy history begins (Taylor, 2003; Hreinsdottir et al, 2006). Accounts by self-advocates given at a conference at the Open University in May 2004 indicated that people with learning difficulties living in long-stay hospitals and community group homes developed various means of resisting the prescribed routines and life patterns assigned to them years before they joined self-advocacy organisations (Tilley, 2004).

However, the history of formalised self-advocacy (speaking up for yourself) – like that of citizen advocacy – begins in Scandinavia and the US. The origins of 'self-advocacy' lie in the leisure club networks of Sweden in the 1960s. Although Britain was also developing such activities through the work of local Mencap branches (Rolph, 2002), the Swedish examples were unique because people with learning difficulties were beginning to organise and manage these groups themselves (Williams and Shultz, 1982: 51). Supporters began to develop courses to 'teach' people with learning difficulties about the skills needed to take on such roles. This eventually led to a national conference in which ideas about these courses and leisure clubs were shared. In 1970 a second conference was held in Sweden, this time attracting international attention, including that of Ann Shearer, a British journalist who had founded the Campaign for the Mentally Handicapped (see below) (Hersov, 1996).

One of the first self-advocacy developments in the US is thought to be Project Two, a self-help group founded, organised and led by Ray Loomis in the mid-1970s, following his deinstitutionalisation in 1968 from one of Nebraska's long-stay hospitals (Williams and Shultz, 1982). Running parallel to this was the development of similar 'support' groups for people in Oregon who had also been discharged from institutions around the same period. It was at one of these meetings that the committee penned the name 'People First'. Following on from a convention organised by the groups in 1974, the first state-wide People First organisation was founded – which went on to inspire the foundation of a number of other People First organisations across the US in the 1970s. However, as Williams and Shultz have pointed out, the People First phenomenon was only part of the wider 'self-advocacy' picture: 'It is an extraordinary fact that during the 1970s a whole network of similar groups sprang up in America, many of them starting as independent local initiatives whose participants only later came to learn that they were part of a "self-advocacy movement"' (Williams and Shultz, 1982: 56). In this respect, the history of People First groups was not unlike the parents' movement.

Although many of the developments in UK self-advocacy took place in the 1980s, some pioneering work was undertaken by the Campaign for Mentally Handicapped People (CMH) in the early 1970s (Hersov, 1996: 130). CMH (now Values into Action) was a pressure group aimed at improving services for people with learning difficulties. In 1972 and 1973, the CMH organised a number of 'participation events', in which issues such as choice, independence and relationships were discussed by people with learning difficulties. At one workshop, the notion of involving people with learning difficulties in the planning and running of services was also raised. As Hersov (1996) points out, it was the CMH which fostered links with the US at this time, notably by supporting Paul Williams's study tour of America in 1979.

Alongside these developments, a number of other self-advocacy initiatives were beginning to take shape; many of them based in Adult Training Centres (Crawley, 1988). Others however, were not based in specific services, with some receiving support from the CMH. Despite initially viewing the participation of people with learning difficulties in self-advocacy activities as the responsibility of service providers, by the mid-1980s CMH was actively encouraging people to set up their own self-advocacy groups, and claim ownership of them (Barnes, 1997: 56). In 1981 Mencap provided both the funding and the administrative base for one of the earliest self-advocacy groups in the UK, which had the aim of representing a number of these smaller local self-advocacy committees at a national level. The ‘participation forum’, as it was known, was set up by Mencap’s London divisional office, although it was not a formally constituted self-advocacy body and lacked an organised representative structure (Shearer, 1986: 187). However, the group did develop its own identity through the production and distribution of films about self-advocacy, and through its hosting of conferences in the early 1980s (Hersov, 1996: 131). The participation forum tackled a range of personal and social issues concerning learning disability in the 1980s, and acted in an advisory role to other fledgling self-advocacy groups. However, its expansion was limited by the moderate funds it received, which in 1986, still did not permit the employment of a full-time advisor (Shearer, 1986).

Representatives from these various self-advocacy projects came together in 1984 in a trip to the first international self-advocacy conference, held in Tacoma, USA. This was made possible by the pooling of funds from a range of organisations such as CMH, Mencap, the King’s Fund and City Lit. Returning from this conference, the delegates decided to form the first British People First organisation – People First of London and

Thames – with John Hersov and Andrea Whittaker as volunteer advisors. One role of this group was to travel throughout the country, explaining self-advocacy to people with learning difficulties and staff in a range of settings, and suggesting the ways in which people could establish their own group. The group also began work on the second international People First conference, which was held in London in 1988. Over 300 delegates attended this conference, and a number of other People First groups subsequently sprang up across the UK. In 1989, People First London secured the first significant piece of funding for an independent self-advocacy group (a three year grant from the Joseph Rowntree Foundation, the Mental Health Foundation and the King's Fund). This funding enabled the group to rent office space and employ a paid advisor, and continue to send newsletters and other information to individuals and groups across the country (Hersov, 1996).

Hersov (1996) acknowledged that a primary cause for concern in these early years was the relationship between self-advocates and those who were 'advising' or 'supporting' them. Both the self-advocates and individuals such as Hersov and Whittaker were aware of the potential tension between needing to teach people the skills to take control for themselves, whilst inadvertently retaining a powerful position in the relationship. This was also borne out at an organisational level. Whilst People First London and Thames were appreciative (and indeed, dependent) upon the administrative support offered by organisations such as the CMH, the King's Fund and Mencap, they wanted to run their own meetings, and have a greater say in their organisation's development (Hersov, 1996: 132). These concerns are still prevalent, and the relationship between supporters and self-advocates continues to be understood in a range of different – and sometimes contradictory – ways (Chapman, 2005). However, it is important to recognise that the origins of self-advocacy in the UK lie in the coming together of a range of stakeholders

– including service users, carers and non-disabled support workers. The different stakeholders in these groups were not mutually exclusive – indeed, the early years of self-advocacy are evidence of a successful process of reciprocal facilitation and learning on all sides (Tilley, 2006).

The history of self-advocacy in the UK is arguably better documented in the literature than that of citizen advocacy and its later manifestations. One possible reason for this might be the publication of papers written by some of those who were instrumental ‘allies’ in the growth of British self-advocacy in the early 1980s (Williams, 1982; Shearer 1986; Whittaker, 1996; Hersov, 1996). By documenting his own experiences as well as the experiences of other friends and colleagues, Hersov – like Williams and Shearer before him - offers researchers interested in the history of self-advocacy a wonderfully rich account of the people, places and events that made self-advocacy a reality in Britain. Likewise, the work undertaken by the Social History of Learning Disability research group at the Open University has also contributed to the unfolding story of self-advocacy in the UK. By charting the direct experiences of self-advocates and non-disabled ‘allies’ in print (for example, Goodley 2000b, and a special edition of the *British Journal of Learning Disabilities*, Issue 3, 2006) the group has encouraged a closer inspection of the ‘rise’ of self-advocacy in the UK, drawing comparisons with international developments. However, these ‘insider’ contributions to the historiography on self-advocacy (updated recently by Buchanan and Walmsley, 2006) may be reflective of a more important development. It has been argued by Bersani Jr (1998) that one indication that a phenomenon has become a ‘social movement’ (capable of initiating ideological change and new dimensions of identity) is when it begins to write its own history. The texts cited above are certainly an indication of such a development,

although as Chapman (2005) has pointed out, the involvement of people with learning difficulties in this process is a relatively recent one and arguably remains marginal.

1.4 Themes raised by the history

A number of themes relevant to this thesis were raised through an historical appraisal of the rise of advocacy. For example, the issue of alliances is a crucial one. Alliances in advocacy have taken place on an individual and group basis, through the relationships between non-disabled people and people with learning difficulties in one-to-one advocacy partnerships, and less formally in their links through self-advocacy. Alliances have also taken place between organisations. The supporting role of a parent-group in the UK (Mencap) reflects wider international developments (see Bylov, 2006, on Denmark, and Tsuda, 2006, on Japan), although it has been argued that the idea of self-representation for people with learning difficulties in England has been greeted by parents with greater hostility than in some other countries (Buchanan and Walmsley, 2006). International alliances have also been integral in the spread of ideas about advocacy and in facilitating mutual learning among people with learning difficulties and their supporters (Ledger and Tilley, 2006).

Whilst alliances between people with learning difficulties and non-disabled allies have clearly reaped a number of benefits for the development of advocacy, they have also created challenges and tensions. From the earliest stages of self-advocacy in the UK, allies have debated the extent to which their role facilitates or inhibits the empowerment of people with learning difficulties. Many of the 'leaders' that emerged within the history of advocacy were people without learning difficulties. As Chapman argued (2005: 30) 'the impetus for the development of self-advocacy came from champions and

allies, because they had the networks to do so, and ways of getting hidden voices heard’.

A review of the literature (Atkinson, 1999; Butler et al, 1988; Flynn and Ward, 1991; Hersov, 1996) demonstrates a number of compatible aims between the twin arms of advocacy throughout their historical development. Those individuals and organisations driving both citizen and self-advocacy all claimed that they were *promoting the interests* of people with learning difficulties. In both cases, inclusion of the *voices of people with learning difficulties* was viewed as integral. Where the proponents of citizen and self-advocacy seemed to diverge was in the extent to which they viewed people with learning difficulties *taking control for themselves*; by its very nature, citizen advocacy was affording a more prominent role for non-disabled advocates in the promotion of disabled people’s interests. However, as discussed above, the role of non-disabled allies in the growth of self-advocacy has also been a site of contestation, with the boundaries of support presenting challenges for both advisors and self-advocates. It is also clear that historically, the purpose of citizen advocacy was to support people purely on an *individual* basis – whereas the historical roots of self-advocacy lie in the activities of people with learning difficulties coming together in *groups* and dealing with issues (such as labelling and employment) that affect them *collectively*. Nevertheless, as a review of the 1988 international People First conference report demonstrates, a focus on individuals (personal stories; skills; and experiences of intellectual impairment) has been of historic importance to those involved in self-advocacy (Wertheimer, 1988).

The history of both citizen and self-advocacy in the UK also demonstrates that these parallel developments have both experienced a certain degree of fragmentation as they

have grown, which may explain why there is still no national organisation for either citizen or self-advocacy in England (Buchanan and Walmsley, 2006). A review of the literature also indicates that there appears to be a close association between the development of community care services and the growth of advocacy (Bramley and Elkins, 1988). A recent international collection of papers on the history of self-advocacy points towards deinstitutionalisation as a significant catalyst in the expansion of advocacy in countries such as Japan, the Czech Republic, and Denmark (Ledger and Tilley, 2006). The nature of this apparent historical link between advocacy and the growth of community-based services for people with learning difficulties in England requires further examination and will be considered in this thesis.

These themes have arisen within the context of national and international developments in advocacy, and all require further exploration based on empirical evidence. It is apparent that advocacy in England remains a localised phenomenon, although in-depth local studies are largely absent in the literature. The first research question of this thesis has been developed in the light of such issues:

What factors influence the development of advocacy in a local context?

2. Values, principles and theories in advocacy

This section reviews the literature on the values, principles and theories that underpin the practice of advocacy. It also draws upon conjectures found in organisation theory that can provide a deeper understanding of the philosophies that drive advocacy groups and shape their work. This can help to explain why a number of tensions have emerged

within the advocacy 'movement', despite a supposed consensus around values (see section 3). It has been argued that the practice of advocacy organisations has rarely been subjected to stringent critical analysis (Clement, 2003; Walmsley and Johnson, 2003). The organisation theory that is reviewed here provides a useful basis for addressing some of the shortcomings within existing research.

2.1 Developing the analytical tools from organisation theory

In the 1980s, Edgar Shein developed his influential theory of organisational culture, in which he broke organisations down to three levels: on the surface, there are organisational artefacts – visible but often undecipherable; beneath these lie values and norms; and at the core of the organisation lies its assumptions and beliefs (Schein, 1984, 1997; Hatch, 1997). This thesis, unlike Clement's (2003) is not a study in organisational culture. Nevertheless, developments in organisation theory – particularly those articulated by Schein – can provide a useful set of tools with which to explore some of the claims made about advocacy in the literature.

Drawing upon Schein's work, Mary Jo Hatch describes values as:

...the social principles, goals and standards held within a culture to have intrinsic worth. They define what the members of an organisation care about... Values constitute the basis for making judgments about what is right and what is wrong, which is why they are also referred to as a moral or ethical code (Hatch, 1997: 214).

It has been suggested that values are what motivate organisations to do the work they do and they encourage members of organisations to behave in ways that exemplify those values (Hatch, 1997). In doing so, they produce a set of organisational 'norms' which people involved in the organisation are expected to abide by (Schein, 1984). However, researchers in organisation theory who have adopted post-modernist positions, question the assertion made by Schein that organisational cultures are consistent entities in which all involved faithfully adhere to a prescribed set of values and norms (Meyerson and Martin, 1987; Martin, 1992). In the learning disability field, Clement (2002, 2003) has drawn upon some of these organisation theory arguments in order to question the assumed solidarity around values among different stakeholders in advocacy organisations and found that a coherent set of values was not agreed upon by all organisational members, leading to a lack of formalisation and organisational ambiguity.

In their review of organisational culture theory, Martin and Meyerson describe Schein's model as the 'integration' perspective, where culture is assumed to be consensual at the organisation-wide level. They refer to the sub-culture model as the 'differentiation' perspective, which describes organisational culture as being subject to fracture by separate, although stable, mini-cultures within the larger organisational context. Lastly they explain the 'fragmentation' perspective, which looks for ambiguity and inconsistency within organisations. This post-modern position argues that because organisations consist of numerous actors – with their own complex personal identities – it is impossible to assume anything but a multiplicity of changing perspectives operating within organisational culture at any one time (Martin and Frost, 1996).

In trying to understand what drives and motivates advocacy organisations, it is important to consider these three perspectives, and how they have informed the literature to date. Few studies have specifically discussed or ‘looked for’ the instabilities and uncertainties highlighted in the fragmentation perspective, and much research on the subject seems dominated by the integration perspective. As Clement (2003) has argued, this may be a result of an implicit desire by researchers in the field to raise the value of advocacy by ‘talking up’. It may also relate to Walmsley and Johnson’s (2003) contention that a failure to use a wide range of research methodologies in the learning disability advocacy field has constrained in-depth and critical appraisals. Furthermore, the integration perspective – whether used consciously or otherwise – serves a broader political purpose. By highlighting a unity of values and consistency in approaches, the integration perspective strengthens the claims made by those working in the field that advocacy is a force for positive change that deserves more formal recognition (Simons, 1992, 1993). It also supports the argument that advocacy should become a legal right, so that disabled people can access an independent advocate when they so desire (Atkinson, 1999).

This is not to say that examples of the other two perspectives are absent from the literature. Personal commentaries have illustrated the different personal backgrounds of self-advocates, and how issues of gender, race and sexuality have impacted upon their experience of self-advocacy and self-advocacy organisations (Walmsley and Downer, 1997; Walmsley, 2002; Goodley, 2000a). Henderson and Pochin (2001) highlighted the historical and continuing tensions that have both infused and hindered different types of one-to-one advocacy. Clement and Chapman have made significant strides in uncovering the complexities and multiple perspectives that exist on a range of subjects within one organisation (Clement, 2003) and between different organisations (Chapman

2005). Both of these studies focus on People First self-advocacy organisations. A gap remains in knowledge regarding the nature of self-advocacy organisations that do not call themselves 'People First', as well as other types of advocacy, such as citizen or situation-based advocacy. As section 1 indicated, my thesis will address this gap.

As Clement (2003) has argued, an approach which combines all three theoretical perspectives in its evaluation of organisational culture (see Martin 1992, 1995, 2002), can be used to explore the different ways in which advocacy groups construct, articulate and practise their organisational values. Combining perspectives provides researchers with a useful set of tools from which to think about the theoretical and philosophical underpinnings of advocacy (the beliefs and assumptions in Schein's model) as well as the more visible goals and principles of an organisation. Martin's 'meta-theory' also highlights these elements whilst questioning how they have been arrived at (and by whom), and the extent to which they are accepted by different organisational members at different times.

Values indicate what is important to an organisation, and provide the organisation with a sense of purpose, and a set of aims. Section 2.2 is concerned with the ways in which the values of advocacy have been narrated in the literature, and thus deals with what might be described as the 'rhetoric' of advocacy. It explores the debates concerning what advocacy *ought* to be about, whilst considering how 'integrated' this rhetoric really is. It has been pointed out that organisations as entities do not have values; people within organisations have values which may be shared by others and reflected in the organisation's official literature (Clement, 2002: 56, citing Stackman et al, 2000). As Stackman et al (2000) have argued, values are attributed to organisations

metaphorically. Consequently, section 3 of this chapter will review the literature which examines how these narrated values are borne out in practice.

2.2 Values in advocacy

A review of the literature suggests that there are a number of values which are shared amongst those involved in both self-advocacy and different types of one-to-one advocacy. The two most significant are:

1. All human beings have equal value

An underpinning principle of advocacy is frequently asserted to be its belief in the equal value of all human beings as a starting point from which to redress social injustice (Brandon, 1995; Georgia Advocacy Office website, 2006; Roets et al, 2006; Thomas and Woods, 2003). Simons argues that ‘rather than stigmatise people on the basis of their ‘difference’ we should relate to them as *people*, with abilities and gifts as well as needs’ (Simons, 1993: 17). Gray and Jackson (2002: 9) contend that this is particularly important for individuals who have been historically devalued by society, as has often been the case for people with learning difficulties.

2. People with learning difficulties should have the same rights as all other citizens, including the right to ‘speak up’

Another value driving the advocacy agenda is that people with learning difficulties deserve the same legal and human rights as everyone else:

The significance of advocacy lies in the recognition that a person's own skills may not include the ability to speak for him or herself, for intellectual, social, emotional, developmental or physical reasons. The recognition of an individual's right to a hearing despite any or all of these difficulties places advocacy within the context of human rights' (Garner and Sandow, 1995: 1).

Garner and Sandow cite this as part of broader historical developments over the past century in which there has been a 'gradual acceptance of an increasing range of individual differences, and the concomitant expansion of human rights' (1995: 3).

However Thomas and Wood (2003) have argued that despite the anti-discriminatory legislation enacted for disabled people in 1995 (Disability Discrimination Act) and the focus on individual rights brought about by the Human Rights Act 1998, people with learning difficulties have often been excluded from exercising their rights through legislative loopholes. Therefore it is essential for those involved in advocacy to retain a focus on rights as a principal value (People First London website, 2006).

Turning values into goals through advocacy

Advocacy is seen as being one method through which all of these values can be exercised. It is a process which can facilitate the fulfilment of these ambitious (although not extraordinary) values. As such, advocacy aims to lead to the realisation of four main goals, neatly summarised by Atkinson (1999):

1. Empowerment

Advocacy has been described as a means by which people can become empowered to make both every-day and life-changing decisions (Atkinson, 1999). Advocacy is viewed by some as being the process through which people gain the knowledge and/or skills to enable them to have more power within the structures and systems (both formal and informal) which affect their lives. This not only means being heard, but having one's views *listened to* and *acted upon* (Simons, 1995). It also involves meaningful ways to participate in decisions that affect oneself – both in proactive and reactive ways (Simons, 1992, 1993, 1995, 1998). Aspis (2002) also views the facilitation of change as an integral goal of self-advocacy for people with learning difficulties. However, she argues that to date 'when groups do successfully advocate for change, it is usually a minor one, and there is no shift of power between people with learning disabilities and the authorities' (2002: 3). Aspis contends that self-advocacy groups have a responsibility to broaden their remits and pose more uncomfortable questions about the status quo if true empowerment is to be achieved.

2. Autonomy

Although autonomy for people with learning difficulties is more commonly linked to people's involvement in self-advocacy, it has also been argued that one-to-one advocacy has the potential to help people take more control in their lives (Simons, 1993), and that this can be at least partially achieved through a process of self-actualisation (Brechin and Swain, 1989: 45; Flynn and Ward, 1991). The views of people with learning difficulties, collected by Ken Simons, clearly illustrate that self-expression and self-confidence were significant reasons for people retaining an involvement in self-

advocacy groups (Simons, 1992: 18-19). Goodley summarised this assumed goal of advocacy: 'It means deciding what's best for you and taking charge of getting it' (2000a: 7).

3. Citizenship

Safeguarding the rights of people with learning difficulties is viewed as an important goal of advocacy organisations. Central England People First outline this as one of their core aims:

To make sure that people with learning difficulties know about their rights, can get their rights, have the same rights as everybody else.

(www.peoplefirst.org.uk/aims)

Similarly, Action4Advocacy state that:

Advocacy is taking action to help people say what they want, *secure their rights*, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. *Advocacy promotes social inclusion, equality and social justice.*

(www.advocacyacrosslondon.org.uk)

Henderson and Pochin have argued that justice – the full realisation of a person's rights, and redress for any wrongs inflicted upon them – 'lies at the heart of advocacy' (2001: 72). A central tenet of one-to-one advocacy is the important role that an advocate plays in defending a person's rights (Brandon, 1995; Wertheimer, 1998). Goodley contends that self-advocacy can be seen as 'a counter-movement to state paternalism, wherein

people with the label of learning difficulties conspicuously support one another to speak out against some of the most appalling examples of discrimination in contemporary British culture' (Goodley, 2000a: 3). Recent research into the views of People First members also highlights the strong focus on rights and equality among self-advocates (Chapman, 2005). These examples demonstrate the perceived power of the advocacy process to act as a pathway to citizenship. However, Aspis (2002) argues that one aim of self-advocacy should be to clarify and pursue the rights that people with learning difficulties have within the law, whilst campaigning to increase the number of rights that fall within the legislative framework.

4. Inclusion

It's to help people with learning difficulties get out into the community (Simons, 1993: 19).

This quote by a People First self-advocate crystallises a goal that has been inextricably bound up with advocacy from its earliest days. The remit of advocacy has been historically linked to the wider movement of deinstitutionalisation and community living for people with learning difficulties. Advocacy is heralded as important in making integration a meaningful reality for people with learning difficulties: living in the community, rather than merely existing on its fringes (Pochin, 2002, writing on citizen advocacy; Simons, 1993 and Tsuda, 2006, writing on self-advocacy). Despite claims that the equality and inclusion agendas may sometimes be in tension (Wolfensberger, 2002), many of those involved in advocacy see them as complementary features that work in tandem (Simons, 1995). The life stories of 'top' self-advocates presented by Goodley demonstrate that despite some tensions and challenges,

involvement in self-advocacy groups impacted upon the narrators' experiences of community life by providing support and friendship, daily routines and a sense of purpose. Goodley reflected that 'regardless of normalisation procedures, self-advocacy groups provide emotional (expressive) gains and serve a number of practical (instrumental) needs of narrators' (2000a: 122). Many of these 'gains' and 'needs' related directly to people's experiences of feeling included in the communities in which they live.

Despite the critique of paternalism sometimes levelled at citizen advocacy (see Pochin, 2002), the development of these schemes in the 1980s has also been described as a 'radical social initiative' due to the way they sought to address the social exclusion of people with learning difficulties through community voluntarism:

Part of the rationale for the citizen advocacy movement was that people with learning difficulties might otherwise miss this kind of relationship that occurs naturally because of the practice of segregating people in professionally controlled settings (separating them from the social world) (Buchanan, 2004: 1).

The values and goals discussed above are all elements integral to different types of advocacy. The following sub-section reviews how these ideals have been 'operationalised' through advocacy principles.

2.3 Principles in advocacy

If values are understood as the basis for action in advocacy, then principles can be described as the guidelines which help to convert values into realisable outcomes. This

section considers the literature on the principles that emerged with the development of advocacy.

Citizen advocacy

Citizen advocacy arrived in the UK with a set of defined values concerned with protecting the interests of people with learning difficulties and tackling social exclusion through the actions of ‘valued citizens’. Alongside these values came strict procedures that set out the necessary ‘rules’ of implementation, enshrined in handbooks produced by citizen advocacy support organisations (Butler et al, 1988; Wertheimer, 1998).

Citizen advocacy was to be pursued via schemes – involving people and structures. A number of prescribed ‘dos and don’ts’ were put forward, with the aim of facilitating best practice (see *Citizen Advocacy Program Evaluation [CAPE]*, O’Brien and Wolfensberger, 1979). At times, these have been described as the ‘principles’ of advocacy (Butler et al, 1988: 5); others have referred to them as the ‘key elements in successful citizen advocacy’ (Flynn and Ward, 1991: 139). Essentially they are guidelines for advocacy schemes; presented in the literature as the indisputable building blocks of advocacy.

Below are some of the most well-known:

- *Independence*

There should be no conflicting interests which limit the action of advocates and the project (Advocacy 2000 website, 2006).

Independence has historically been a key principle in the delivery of one-to-one advocacy for people with learning difficulties. Independence is two-fold. First, it refers to the advocate, who should be:

- a) independent of the advocacy office (supported by the staff, but not directed by them)
- b) independent of the agencies and settings which provide services to the partner
- c) independent of the partner's family

(Wertheimer, 1998).

Second, the independence of the advocacy office from service providers has been perceived as integral to minimising conflicts of interest, allowing a scheme to define its own goals and helping to maintain a clear identity for citizen advocacy – distinct from ‘services’ (Wolfensberger, 1973). This has implications for funding, office premises and administration – all of which it is suggested ought to be independent of statutory authorities.

- *Loyalty to Partners*

It is an advocate's role to be on the side of the person they are supporting – not to be impartial (Advocacy 2000 website, 2006).

Guidelines for citizen advocacy make clear that the advocate is present to provide a partner with as much information as possible from which to make an informed decision, and then support the partner to announce and enact that decision, regardless of the advocate's own personal view (Wertheimer, 1998). However, as noted earlier, challenges arise when the partner is unable to articulate a decision. This may leave an

advocate in the position of having to make a decision on behalf of their partner, on the basis of what they believe to be in their best interests (Williams, 2000).

- *The establishment of relationships that are freely given and voluntary*

The development of supporting relationships not based on payment or compensation has been an integral aspect of the development of citizen advocacy. Wolfensberger argued in 1973 that:

our society currently appears to be in a phase of reaction to the trends towards centralisation and formalisation of societal processes. While such centralisation will undoubtedly continue in many areas, citizens are seeking a balance to this trend, and readiness to volunteer for civic action appears to be a manifestation of this search (1973: 26).

Whether or not Wolfensberger was correct in his perception of the volunteerism zeitgeist sweeping America in the 1970s, those involved in advocacy have argued powerfully for the utilisation of unpaid advocates in one-to-one relationships. It has been suggested that service users are frequently – if not always – in contact with people who are paid to be with them. Emphasising the voluntary nature of the advocate is seen as being a crucial means of tackling social exclusion (Wolfensberger, no date; Wertheimer, 1998; Monaghan, 2005). It is also perceived as having reciprocal benefits whereby ‘the advocate also learns from the partner and develops as a more active citizen with a deeper appreciation of the diversity of her/his community’ (Monaghan, 2005). In this way, one-to-one advocacy is still framed within the civic duty discourse highlighted

by Wolfensberger, and articulated more recently in New Labour policy directives (HMT, 2002).

- *Positive Imagery and Interactions*

It has been argued that ‘citizen advocacy can be a powerful vehicle for challenging the negative and devaluing images frequently attached to many people with disabilities or those who are otherwise stigmatised or disadvantaged’ (Wertheimer, 1998: 19). CAIT (Citizen Advocacy Information and Training – now renamed the Advocacy Resource Exchange, ARX) has maintained that rectifying historically devaluing processes for people with learning difficulties is a key aim of citizen advocacy. It is said that this can be achieved by using positive and respectful language and encouraging people to become involved in valued and age-appropriate activities; in some instances this may include joining the management committees of advocacy schemes. Literature, publicity material and the office location and design should ‘seek to portray positive images rather than images of charity or pity’ (Wertheimer, 1998:20). This is linked to the theory of valued social roles for people with learning difficulties developed by Wolfensberger (1980, 1983b) discussed further in section 2.4.

However, the extent to which these ‘building blocks’ have been unreservedly adopted by schemes in the UK has been called in question, and as Pochin (2001: 104) has argued: ‘beneath the superficial consensus, the picture is less certain’. Indeed, he attributes the diversification in types of advocacy from the initial citizen advocacy starting point as symptomatic of the difficulties or reluctance that some organisations have faced in putting the CAPE recommendations into practice.

Pochin's analysis is a helpful starting point when reassessing the shape of advocacy in the present day. In contrast to the seemingly strong consensus from the advocacy literature of the 1980s, later writing on the subject has focused more heavily on fragmentation and tensions (Buchanan, 2004; Clement, 2002; Tyne, 1994). Henderson and Pochin (2001) have drawn attention to the lack of clear identity and coherence operating in advocacy, arguing that it has left local schemes lacking the power necessary to issue authoritative guidelines to purchasers in local authorities. Whilst the Advocacy Resource Exchange (ARX) has promoted a Code of Practice and provided national support to local schemes for twenty years, it has tended to isolate those schemes not directly involved in citizen advocacy. On the other hand, it has been argued that for those regional forums that have encompassed a diverse range of advocacy groups, what they gain in inclusivity 'they tend to lose in political force' (Henderson and Pochin, 2001: 14).

Self-advocacy

Self-advocacy has grown in a more ad hoc, and less prescribed way than citizen advocacy. The 'principles' that have dominated citizen advocacy and its later manifestations are simply not a characteristic of self-advocacy. This might be because – by its very nature – self-advocacy has developed through the significant contributions of people with learning difficulties themselves. Unlike the academics and activists who developed the key ideas behind citizen advocacy, many people with learning difficulties involved in self-advocacy (despite support from allies) have not had the traditional sources of knowledge and information at their disposal (Chapman, 2005). Ideas around self-advocacy have occurred in a more experiential manner, as a growing number of people with learning difficulties have learned about self-advocacy from supporters and

peers, and become involved in groups in their local areas. Nevertheless, there are some 'key concepts' within the self-advocacy literature which suggest that self-advocacy is developing its own specific value-system. In one of the most influential studies on self-advocacy, Ken Simons (1992) asked self-advocates what they believed self-advocacy was for. Among the people Ken Simons interviewed, self-advocacy was about:

- Representing or helping other people with a learning difficulty
- Self-expression
- Self-development
- Social life and mutual support
- Integration
- Improving services through participation
- Dealing with personal problems
- Affecting wider change – such as challenging labels.

Many of these principles can still be found in recent literature about the purposes of self-advocacy organisations (People First London website, 2006; Chapman, 2005; Goodley, 2000a; Buchanan and Walmsley, 2006). Another principle is the belief that self-advocacy organisations should be 'user-led' or 'user-controlled' (Simons, 1992). This has become something of a holy grail for self-advocacy groups, evident in both the claims put forward by organisations themselves, and the specifications required for commissioners who are funding them (Clement, 2003; London People First website, 2006). This has important, although often ambiguous, implications for the organising of self-advocacy on the ground and will be discussed further in section 3.

The advocacy literature abounds with so-called ideals but very few studies have examined members' views about such organisational 'truths' or how such values and principles are enacted. This research aims to redress the balance.

2.4 Theories and philosophies underpinning advocacy for people with learning difficulties

So far, this chapter has explored the commonly espoused values of advocacy for people with learning difficulties, and some of the historical processes which have led to the emergence of this value-system. However, as its history shows, advocacy has not developed free of conflict. Indeed, as section 3 will demonstrate, many of these tensions continue to engage different advocacy stakeholders in debates today. Questions around the fundamental purpose of advocacy, and who 'owns' it are particularly pertinent in the current climate of user participation and increased specification of advocacy 'services'. But why do these tensions exist? Turning to organisation theory – in particular Schein's model of organisational culture – it seems that conflict within and between different advocacy groups arises because members hold inherently different assumptions both about advocacy, and about people with learning difficulties.

As Hatch (1997) has pointed out, it is not easy to unpick the underlying beliefs and assumptions held by members of organisations. This is particularly relevant for advocacy organisations, considering how little empirical research exists about the different perspectives of people involved in such groups. Walmsley (1997, 2002) has suggested a way forward. She argues that placing citizen advocacy and self advocacy in the context of the major theoretical movements that have informed the learning disability field over the past thirty years (namely normalisation / social role valorisation

and the social model of disability) might help to trace some of the conflicting positions that have emerged within different types of advocacy, and among different organisations. She writes:

I would argue that there are still differences in the ways disabled people and people with learning difficulties and their allies, analyse the situation they find themselves in and differences emerge therefore in practice (Walmsley, 1997: 4).

Those involved in advocacy may be analysing situations from very specific theoretical positions. They may also, however, be subconsciously drawing on deeply-embedded philosophies which they have acquired through their personal experiences in specific environments. Either way, this section will look more closely at the theories that have been used to understand the lives of people with learning difficulties, considering the ways in which they have influenced the practice of different types of advocacy organisations. This section will review the literature on the principal theoretical developments in learning disability, focusing in particular upon their relevance for advocacy.

2.4.1 Normalisation and Social Role Valorisation (SRV)

Normalisation has been described as a 'family of ideas' (Emerson, 1992). Originating in Scandinavia in the early 1960s with the academic work of Nirje (1969), normalisation has been reformulated and adapted over the years, in order to drive forward change in services for people with learning difficulties across a range of countries and institutions (Wolfensberger, 1972, 1983b; Kings Fund, 1980; Towell, 1988; Brown and Smith, 1992).

The original normalisation concept drew heavily on human rights theories, and aimed to foster equality for people with learning difficulties by:

making available to all mentally retarded people patterns of life and conditions of everyday living as close as possible to the regular circumstances and ways of life of society (Nirje, 1980: 33).

This definition of normalisation became a statement about how services could reflect the basic rights of people with learning difficulties in an egalitarian society; and as such mirrored contemporary trends in Western culture at that time to secure the rights of marginalised groups (Emerson, 1992: 3). However, the Scandinavian version of normalisation operated upon the assumption that such egalitarian ideals for people with learning difficulties could be achieved within segregated settings (Emerson, 1992). Normalisation was the objective, whereas integration and segregation were 'simply working methods' (Bank-Mikkelsen, 1980: 56).

In North America, Wolf Wolfensberger proposed a more elaborate definition of normalisation, which he continued to develop and refine throughout the 1970s and early 1980s (Wolfensberger, 1972, 1980, 1983b). Wolfensberger aimed to move the normalisation principle beyond the rights rhetoric of the Scandinavian version, and develop a more 'scientific' [sic] theory that both explained the situation of many disadvantaged groups (not just people with learning difficulties), whilst offering a systematic mechanism for change. He originally outlined this as being the:

utilisation of means which are as culturally normative as possible, in order to establish, enable or support behaviours, appearances, experiences and interpretations which are as culturally normative as possible (1980: 8).

By 1983 Wolfensberger had renamed his theory 'social role valorisation' (SRV) partly to differentiate it from the Scandinavian normalisation principles, but also to reflect a central tenet of his theory that:

the most explicit and highest goal of normalisation must be the creation, support and defence of *valued social roles* for people who are at risk of social devaluation (Wolfensberger, 1983b: 234, original emphasis).

An important feature of Wolfensberger's formulation developed out of contemporary sociological theories of labelling and deviance. He argued that de-valued groups such as people with learning difficulties were trapped in a cycle of role expectancy and role circularity. This meant that the characteristics and behaviour of members of deviant groups were largely determined by the way in which society responded to them once they had been 'labelled', rather than by any biological or psychological factors that led the individual to acquire the label (Emerson, 1992: 6). As Wolfensberger articulated: 'it is not differentness itself that makes for deviancy in this definition, but *negatively valued differentness*' (1980: 8, original emphasis). SRV was developed in order to address this so-called cycle of stigmatisation, and was concretised in Wolfensberger's complex service evaluation programme PASS (1983c). This involved the creation of valued social roles for disadvantaged people via a number of mechanisms – most controversially through the discouragement of devalued people mixing with one another (working on the assumption that this would lead to greater stigmatisation) and by

encouraging disadvantaged groups to reduce the 'overt signs' of their 'differentness'. Whilst Wolfensberger maintained that SRV was a two-pronged strategy which entailed adjusting the behaviours of individuals to make them more socially acceptable, as well as changing society's perceptions about what could be valued (Wolfensberger, 1983b: 235), it was the former that gained most attention, and formed the bulk of PASS (Wolfensberger, 1983c).

The impact of both versions of normalisation - Wolfensberger's in particular - upon the delivery of services in the UK is well documented, and has been reviewed once again in the light of developments in the 1990s (Walmsley, 2006). However, the normalisation philosophies have not escaped criticism. It has been argued that the ideology 'fails to make explicit the tension between giving value and taking power' (Brown and Smith, 1989: 9) and does not address the 'fundamental re-evaluation' that would be needed of such people in order for society to realistically give them valued social roles (Dalley, 1992: 102). Walmsley makes a similar point when she writes that the:

normalising agenda that we are working to, (is) an agenda which maintains that to take part in society on equal terms, people with learning difficulties must heroically rise above the impairment and join in a conspiracy to deny that their intellectual impairments matter. Or maybe these limitations are not real, maybe they are constructed (Walmsley, 1997: 12).

It has also been suggested that normalisation theories served to minimise the collective consciousness-raising for people with learning difficulties, and maintained the position of non-disabled people to decide what was, or was not socially valued (Sviros, 1992).

2.4.2 Normalisation / SRV and advocacy

So what are the links – if any – between normalisation principles and advocacy?

Normalisation theory has played a considerable role in shaping the policy and practice of services over the last thirty years (Walmsley, 2006), but what has been its impact upon the delivery of advocacy for people with learning difficulties?

Normalisation / SRV and one-to-one advocacy

For Wolfensberger (no date), citizen advocacy had the potential to make an important contribution to social role valorisation. First, the citizen advocate – with their extensive social networks – would be able to introduce the ‘protégé’ into the circles of ordinary community life, and hence enable them to join environments in which they could gain a more valued social role. Secondly, and perhaps more significantly, through developing a relationship with the culturally valued advocate, the advocacy partner would gain social value by association. This rested heavily upon the voluntary nature of the partnership. Wolfensberger contended that by choosing to enter into the relationship without payment or connection to existing service structures, the advocate was making a statement about the partner’s role as a friend – a role that is positively valued by the wider society. The citizen advocate thus had the potential to encourage a positive valuation of the advocacy partner by other people. In this way, for Wolfensberger, citizen advocacy and normalisation / SRV were mutually dependent concepts. Citizen advocacy was one mechanism with which to achieve the goals of SRV - and likewise, many of the key principles of citizen advocacy were embedded within the assumptions of normalisation theory.

Many of the criticisms that have been levelled at normalisation can also be extended to citizen advocacy. Citizen advocacy, like normalisation, implies that a non-disabled person will play an integral, perhaps unassailable position, in the lives of people with learning difficulties. By doing so, it works on the assumption that it is *impairment* that is the source of devaluation, as opposed to questioning the ways in which learning disability might be a socio-cultural phenomenon (Dingham, 1968: 76, cited in Walmsley, 2002). It also perpetuates an image of people with learning difficulties as victims, rather than ‘a holistic picture which portrays them warts and all, even acknowledging that at times they may be misguided, and require a more interventionist stance than the citizen advocacy philosophy permits’ (Walmsley, 2002: 29). Indeed, this is an ongoing tension within citizen advocacy, with some activists arguing that in the real world, boundaries around relationships are flexible, with friends and family sometimes giving advice and taking action, even against an individual’s wishes. Thus a citizen advocate should also be afforded a similar remit with which to exercise their own judgment on behalf of the advocacy partner (Williams, 2000). Clearly, the theoretical origins of citizen advocacy are linked to the normalisation / SRV philosophies that developed at the same time, by many of the same academics and activists.

Normalisation / SRV and self-advocacy

The theoretical origins of self-advocacy are less apparent (Walmsley, 2002), and so it is more difficult to trace the impact that normalisation theories have had upon self-advocacy groups. Certainly, central elements of normalisation / SRV are at odds with the basic principles of self-advocacy, most notably its collective nature, which SRV

would theorise as being potentially stigmatising. In her critique of the limitations of normalisation / SRV for people with learning difficulties, Chappell contends:

Such an argument misunderstands fundamentally the nature of friendship as a voluntary relationship based on mutual respect and affection, which has at its centre, shared experiences and interests...Furthermore, identifying other people with learning difficulties as the problem to be avoided (literally) undermines the possibility of collective political action, based on commonality of experience (1997: 4).

Despite viewing citizen advocacy as a precursor to self-advocacy (Wolfensberger, cited in Williams and Schultz, 1982), Wolfensberger (2002) later developed his own critique of self-advocacy, which he believed had become too influenced by the 'empowerment ideology'. He argued that this ran contrary to SRV, which offered an empirically-orientated means of changing the experiences of marginalised people. The 'religion' of empowerment, argued Wolfensberger, provided no guarantees of life improvement; in fact, its emphasis on rights could be potentially damaging to the very people it purported to defend.

By polarising SRV and empowerment in this way, Wolfensberger's arguments seem to suggest that SRV has no place in the practice of self-advocacy. Dowse (2001: 134) illustrates this point when she argues that 'the terrain open to legitimate intervention and action by many self-advocacy groups has been limited by the dogma of normalisation'. However, as Chapman (2005) has demonstrated, the picture is more complex than Wolfensberger's analysis permits. For example, the history of self-advocacy illustrates that self-advocacy groups are dependent upon support from non-disabled people. This

complicates the relationship that self-advocacy might otherwise have with normalisation principles that seem an anathema to the fundamental values of self-determination, acceptance of difference, and group consciousness that characterise many self-advocacy organisations. Martin (2005) has written: 'issues of participation are not salient in SRV. There are no automatic answers to questions of who should take initiatives in helping people into valued roles, but it is important to ask the questions'. Addressing this issue, Chapman (2005) has shown in her research on the nature of support in self-advocacy, that some support workers have *explicitly* acknowledged SRV as informing their practice; whilst others seemed to implicitly use it as they perceive moving people into valued social roles as an important part of their remit.

Although there is no evidence to suggest that disabled people have themselves adopted normalisation / SRV as a model for change (Chappell, 1997) - indeed some have robustly rejected it (Oliver, 1994, cited in Fulcher, 1996) - it is clear that the central ideas of these philosophies have influenced the development of advocacy for people with learning difficulties, particularly citizen advocacy. However, the ways in which current one-to-one advocacy organisations accept the central tenets of normalisation are ambiguous. This ambiguity may provide at least a partial account for the diversification of advocacy over time; but this needs to be examined more closely through additional research. Similarly, whilst these theories may appear to be in conflict with many of the key values of self-advocacy, Chapman's thesis (2005) indicates that with regard to the role of non-disabled allies, the influence of normalisation / SRV might be greater than one assumes. However, as Chapman's study focused solely on People First self-advocacy groups, further research is needed in order to explore the extent to which normalisation / SRV has shaped other types of self-advocacy organisations. One aim of

this thesis is therefore to build on the existing research in this area, and examine the two gaps highlighted above.

2.4.3 The social model of disability

The second important idea to influence the learning disability field in recent years has been the social model of disability. Unlike normalisation and SRV, the theoretical developments associated with the social model have emerged from the work of disabled academics, and have played an integral role in the disabled people's movement over the past three decades (Campbell and Oliver, 1996; Oliver, 2004). Although the model has been developed and critiqued since Oliver first penned the term in 1983 (Oliver, 1983), its central tenets retain a powerful place in disability studies. Essentially, the social model rests upon the assumption that:

disability stems from the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities *rather* than from the inability of a disabled individual to adapt to the demands of society (Hahn, 1986: 128, cited in Barton, 1996: 8).

The roots of the social model of disability are said to have emerged through the Union of the Physically Impaired Against Segregation (UPIAS), a collective of disabled activists who concluded that disability was a form of social oppression (Oliver, 1996). The early proponents of the social model presented an analysis of the causes of 'disability' through a structural-materialist perspective (Hunt, 1966; Finkelstein, 1980; Oliver, 1990). In this way, their theorising was a major departure from much of the existing sociological literature which attempted to explain the disabled experience

through either the 'sick role' (Parsons, 1951) or through deviancy theory (Goffman, 1963). Along with other 'victim-blaming' theories, normalisation was accused of individualising disability and leaving the 'social and economic structures untouched' (Oliver, 1986: 16).

Although the social model undoubtedly stimulated a powerful drive for social and political change (Thomas, 2004), it has itself been subjected to a host of critiques since its inception. Most notably, challenges have contested the model's utility in understanding the 'collective experience of disablement' (Oliver, 2004: 8). This has arisen with regard to the model's reluctance to deal with the 'reality' of the experience of impairment (Morris, 1991; French, 1993); and from academics who have questioned the robustness of the model to incorporate people's multiple identities, including gender, race and sexuality (Morris, 1991; Begum, 1994; Hill, 1994; Shakespeare et al, 1996). Other powerful critiques of the social model emerged from post-structuralist approaches on how disability has come into being (Thomas, 2004).

The social model and people with learning difficulties

So, what has been the impact of the social model for people with learning difficulties? Unlike normalisation, which was designed and implemented by non-disabled people with significant ramifications for service systems, the social model is an inherently emancipatory project. It aims to bring about structural and cultural shifts in order to ensure that disabled people enjoy the same rights and opportunities as others in society; indeed the nature of the relationship between disability theory and activism has been described as a reciprocal one (Dowse, 2001). However, it has developed predominantly through the theorising and activism of physically disabled people. Whilst it claims to

accommodate difference within the disabled community, concerns have been expressed regarding the extent to which this is relevant for intellectually impaired people (Chappell, 1997; Goodley, 2001, 2004; Walmsley, 1997, 2002). These concerns have also been voiced by one activist with learning difficulties, who has accused physically disabled people of 'using the medical model when dealing with us' (Aspis, quoted in Campbell and Oliver, 1996: 7). It is Aspis's contention that the disability movement has been reluctant to embrace people with learning difficulties for fear of being labelled 'stupid'.

Similarly, critiques of the social model that call for the theorising of impairment have focused on the engagement of disability studies with the sociology of the body (Shakespeare and Watson, 1995; Hughes and Patterson, 1997). As both Chappell (1997) and Dowse (2001) have contended, the construction of a new disability framework along these lines does not address the particular exclusions faced by people with intellectual impairments, any more than the earliest conceptions of the social model did. This is further problematised by the questionable likelihood of people with learning difficulties embracing and debating the social theories of disability and impairment for themselves, particularly when the disabled movement has generally neglected to develop its complex ideas about the nature of oppression in accessible ways, free of jargon and presented in Plain English:

By virtue of the cognitive limitations which constitute their impairments, many people with learning difficulties will struggle with abstract concepts and may not be able to link their stories to this broader framework as others have (Dowse, 2001: 138).

It is important to acknowledge that aside from Simone Aspis, unease about the omission of learning disability from developments within the social model has been raised by non-disabled academic allies such as Chappell, Goodley and Walmsley.

2.4.4 The social model of disability and advocacy

The social model and self-advocacy

Whilst Dowse's (2001) outlook on the social model's efficacy in addressing the exclusion of people with learning difficulties is somewhat pessimistic, in drawing upon Goodley's (2000b) narrative work with self-advocates she sees self-advocacy as the specific mechanism through which people with learning difficulties can develop their own individual identities, whilst also identifying with a collective. Indeed, the website of People First London suggests that the organisation provides a focal point for people's collective experience, in particular that of being *labelled* as having a learning disability:

At People First (Self Advocacy), when we talk about people with learning difficulties, we mean 'people labelled as having a learning difficulty'. This is one of the labels that society puts on us to mark us out as not being able to understand things the same as other people. People First (Self Advocacy) is set up for people labelled as having a learning difficulty (People First London website, 2006).

However, as Walmsley points out, the preference among self-advocates for the term 'learning difficulties' – if any label is to be applied at all – implies that the potential to learn is favoured over the 'permanency of oppression encapsulated in the term 'disabled

people' (2002: 31). This has important ramifications for the extent to which people with the label of learning difficulties are prepared to celebrate the difference that has characterised the disability movement, and suggests quite a significant point of departure. Nevertheless, the People First London website goes on to state its allegiance to the social model, which it manages to condense into accessible language:

People First promotes the social model of disability. This is a way of thinking about disability that says it is society that needs to change to include disabled people. We should not have to change to fit in with society (People First London website, 2006).

Recent research has explored the relationship between the social model of disability and self-advocacy organisations and found that some supporters made explicit links with the social model of disability, although they acknowledged that many members had not yet made such connections themselves (Chapman, 2005). Some supporters were encouraging the group to align with other disability organisations, as a means of radicalising the organisation and helping people to recognise power issues for people with learning difficulties. Chapman also suggested that the social model seemed to have a useful part to play in clarifying the nature of the support role. Whilst no self-advocates made an explicit reference to the social model of disability, Chapman observed that members were often of the opinion that people were disabled by society, and People First could be a movement for change. This may have been because support workers often referred to the 'barriers' facing self-advocates, which Chapman argues is a concept rooted within the social model of disability, although possibly easier for people with learning difficulties to understand.

Clement's (2003) findings led him to cast greater doubt on the pertinence of the social model of disability for people with learning difficulties. His ethnographic study of a People First organisation revealed that whilst 'veterans' of People First Anytown (core members who were political activists, advisors, and non-paid disabled people who shared the 'radical perspective') were in a powerful position to promote the model as the lens through which self-advocates could make sense of their experiences, in essence, it was not adopted by most people with learning difficulties. Although Clement acknowledged the model's use as a way for disabled people to look at their worlds, his experience with People First Anytown led him to conclude that:

for some people, the consequence of having an intellectual impairment cannot be manipulated away, and it does people no favours to marginalise impairment in a way that one reading of the social model suggests, or to deny or try to erase its existence altogether (2003: 429).

The social model and citizen advocacy

In terms of citizen advocacy, very little of the literature has engaged with its possible links to the social model of disability. This may be because citizen advocacy has close historical associations with normalisation and SRV principles. As such, links to the emancipatory theories of social oppression that have been developed by disabled activists appear to be tenuous at best within citizen advocacy circles. However, it is probable that such assumptions have led researchers to unconsciously evade an exploration of the possible connections between the social model and citizen advocacy. This thesis aims to redress the balance in this area.

2.4.5 The People First philosophy

In terms of self-advocates expressing and theorising their position *on their own terms*, Chapman (2005) observed through her interviews that this did occur in some instances, but predominantly among those people who had been involved in self-advocacy for a long time. Running contrary to this, was her key finding that ‘theory was imposed rather than worked through and understood, based on the members’ individual needs and requirements’ (2005: 288). This raised an uncomfortable conflict regarding the extent to which consciousness-raising in self-advocacy groups was being directed, if not controlled, by advocacy workers.

However, Chapman also identified what she termed the ‘People First philosophy’ in her research. This was predominantly voiced by supporters, who regularly talked about a ‘philosophy’ that provided a frame of reference for ways of working within the organisation, although the exact nature of this philosophy was never explicitly stated. Discussing the ‘barriers’ facing people with learning difficulties embedded the sharing of their ideas in *experience*, rather than through abstract concepts like the social model. Although Chapman acknowledges that what might constitute a People First model has emerged from the surmising of support workers rather than members, she perceived these ideas as drawing on the ‘doing’ of self-advocacy in a very direct way. Below is a summary of key facets in a People First philosophy:

- Having the same rights and standing up for them
- Having opportunities and experiences
- Showing respect and dignity
- Breaking down barriers

- Being people-led
- Having information and understanding
- Speaking out and setting the scene for empowerment
- Labelling Jars not People

(from Chapman, 2005).

Although many of these values are comparable to the social model, they also diverge on one critical point. As Chapman argues, whilst labelling is rejected, impairment is accepted as a lived reality in people's lives. Barriers in society are acknowledged; but these are to be faced through a cyclical process of action and process; learning through experience, and 're-inventing the wheel' (2005: 293).

This section has explored the literature regarding the values and principles that are purported to drive advocacy organisations, and considered the ways in which advocacy organisations might be influenced by some of the theoretical developments that have come to the fore in learning disability circles over the past thirty years. My research aims to develop knowledge about the philosophical basis of advocacy organisations and the ideological elements that constitute its foundations, and then consider how these relate to advocacy processes. As such, it will address the second research question posited in the thesis:

What is advocacy in practice?

3. Tensions in advocacy

So far this chapter has considered the values espoused by advocacy organisations, and the main theories that might be informing their work. It has also illustrated the challenges that advocacy organisations face; not just from the ‘outside world’, but also from within the ‘movement’, if it can be described as such. This section will focus on the tensions within advocacy at the present time, and in doing so will raise a number of important themes relevant to this thesis.

3.1 Leading and managing advocacy organisations: issues of user control

The issue of user control in advocacy has been more prominent in discussions about self-advocacy. However, one-to-one advocacy schemes have been critiqued for colluding with an oppressive society, by the very nature of their management and staffing structures (Christie, 1993, cited in Brandon, 1995). Alan Dunning (1993) has accused citizen advocacy groups of being dominated by ‘the unmarginalised: non-disabled, white, middle class people...few have been on the receiving end of services or could be said to have experienced significant disadvantage’ (Dunning, 1993, cited in Brandon, 1995: 99).

Self-advocacy groups have been described as ‘organisations controlled *by* the members, although they often rely to greater or lesser extent on assistance from supporters and advisors’ (Simons, 1992: 10). Although a seemingly straightforward statement, in practice this assertion needs much untangling. Both Mack (2001) and Chapman (2005) revealed the difficulties faced by support workers in self-advocacy organisations, many of whom acknowledge that they are participating in a complex juggling act. On the one

hand they may be trying to implement the values of the social model and allow people with learning difficulties to lead and take control (whilst not imposing these values on the group members). On the other, they are aware that managing an organisation involves making decisions, and achieving day-to-day tasks. Mack (2001) writes 'the line between drawing ideas from people and telling them what to think is thin and hard to locate'. Chapman (2005) reported an incident which crystallises this dilemma. In one People First organisation, the support workers took the joint decision to sack another support worker, who they believed was assuming too much power over members. However, this decision was made unbeknown to the self-advocates – many of whom were upset to see the support worker leave the organisation.

Other self-advocacy organisations are dealing with this issue in a variety of ways. The Speaking Up group in Cambridge is now referred to as an advocacy group – even though in the eyes of many it would appear to be a self-advocacy organisation. Craig Dearden, project manager, argues that this is because whilst most of its leaders have learning difficulties, others do not. He commented that some self-advocacy organisations have been weakened by their determination to be completely user-led, as this attributes a greater importance to process rather than outcome. He goes on:

We believe that a partnership between people with and without learning difficulties is far more effective than a situation in which people with learning difficulties are left to do everything on their own...In my experience, those types of organisations often struggle to deliver, and hit problems in the medium and long term . . . I think that is an incredibly slow approach in a competitive charity environment (Craig Dearden, quoted in Mack, 2001).

This view has been upheld by Clement in his account of a People First organisation, in which he questioned the group's decision to privilege the experiential knowledge of disability over the skills and expertise needed to run an organisation (2003: 342).

Conversely, Chapman (2005) has highlighted the importance of process – learning and making mistakes – as being crucial to the empowerment of people with learning difficulties. Similarly, another recent study found that membership of a self-advocacy organisation significantly changed the 'self-concept' of participants, giving them new roles and responsibilities which afforded them status (Beart et al, 2004).

The issue of user control in advocacy organisations is contested and one aim of the thesis is to address this. Once again, organisation theory may provide useful tools with which to undertake an exploration of how advocacy organisations are governed. For example, leadership is a subject that has, to date, been neglected in advocacy research, and which might be addressed via models in the organisation theory literature. Although leadership in the voluntary sector has come under increasing scrutiny in recent years (Myers and Sacks, 2001), the style of leadership deemed most suitable for the task ahead is by no means an uncontested issue. Researchers in organisation studies have focused on the different characteristics which contribute to transactional, transformational and charismatic forms of leadership (Conger and Kanungo, 1987; Kouzes and Posner, 1987; Bass, 1997). More recently, voluntary sector academics have questioned the theoretical links made between styles of leadership and organisational outcomes such as innovation, arguing that they are rarely grounded in empirical evidence of the voluntary experience and the contexts in which they operate (Jaskyte, 2004; Klausen, 1990, cited in Larsson and Ronnmark, 1996). Developments in 'shared' or 'distributed' leadership – “we are all leaders” - are also impacting upon the way in

which scholars and practitioners understand the leadership construct (Gronn, 2002; Pearce, 2004).

The deconstruction of leadership has been paralleled by a small – but growing – focus on stewardship in the literature. Stewardship has been defined as ‘being in charge of something that is entrusted to you, but not your own possession’ (Mollegen, cited in MacNamara, 2004). Proponents of stewardship suggest that this governance model decentralises power in organisations, moving it away from key individuals and giving more autonomy and control over decision-making processes to *all* organisational members or ‘partners’. Stewardship is viewed as a means of distilling patriarchy and care-taking - governance systems said to be engrained in many of our private, public and voluntary sector institutions (Block, 1993). Block has argued that stewardship is more than just another form of leadership, as its political dimension undermines the very notion of a single ‘leader’:

The alternative to leadership is stewardship...Stewardship asks us to be deeply accountable for the outcomes of an institution, without acting to define purpose for others, control others, or take care of others. Stewardship can be most simply defined as giving order to the dispersion of power (1993:18).

The stewardship model proposes that every organisational member is a potential ‘steward’, with a responsibility to carry the organisation forward. However, practitioners have acknowledged that stewardship often starts with senior executives and board members within organisations (MacNamara, 2004). Block also argues that many organisations still require a ‘partner in charge’ as:

Partnership does not do away with hierarchy...we still need bosses. People at higher levels do have a specialised responsibility, but it is not so much for control, as for clarity (1993: 32).

However, the stewardship model suggests that these 'partners in charge' are entrusted with such positions by members across the organisation, and that they manage to straddle accountability without assuming authority – arguably one of the more challenging aspects of the stewardship concept.

Despite the theoretical and practical challenges posed by these different leadership models, they may still help to shed light upon governance practices in advocacy, and as such, will be drawn upon throughout the thesis.

3.2 Individualism versus collectivism

Another debate within advocacy focuses on its purpose as either an individual or collective endeavour (Buchanan and Walmsley, 2006). One-to-one advocacy in its different manifestations places the individual at the centre of its vision. Whether it is helping the partner with learning difficulties to obtain their rights, learn new skills, develop a sense of self-worth or increase their value in the eyes of others, the citizen advocacy project and its later developments have always placed individuals at the hub of activities. For supporters of citizen advocacy, this has been a way of both protecting and empowering people, and ultimately enabling people to speak for themselves (Ward and Page-Hanify, 1986, cited in Simons, 1993). The views of advocacy partners have also endorsed this perspective. As one partner put it, with an advocate's support: 'I've

learnt to cope with my problems...I have done it myself – it's important to learn to think for yourself as it makes you more independent' (Simons, 1993: 112).

Those involved in self-advocacy have also been preoccupied with whether it is, or should be, an essentially individualistic or group undertaking (Buchanan and Walmsley, 2006). The role that self-advocacy can play in teaching people skills and gaining confidence has been prominent in the literature (Wertheimer, 1988; Simons, 1992). This posits self-advocacy as a partially pedagogical project, in which people can learn practical skills such as answering a telephone and running meetings. This educational framework also extends to facilitating a more complex kind of development, which focuses on understanding self and acquiring a personal identity. Narrating life-stories has been used as an integral tool in this process (Atkinson and Williams, 1990; Goodley, 2000b; Hreinsdottir et al, 2006).

Buchanan and Walmsley have argued 'aspirations for self-advocacy to be a vehicle for people to represent their collective interests have co-existed with the individualised modes' (2006: 135). A number of commentators have pointed out the potential for self-advocacy to achieve greater empowerment for people with learning difficulties through group rather than individual activities (Flynn and Ward, 1991; Simons, 1995). Brandon (1995: 67-68) links this type of self-advocacy with other forms of self-help activity, and lists some of the assumed benefits of this kind of peer action such as the open and permissive communication with people who have experienced the same problem or condition and societal reactions to it.

More specifically, it has been argued that this kind of collective self-advocacy facilitates more effective campaigning and lobbying, and affords people greater power when

dealing with providers over service-based issues (Simons, 1998). However, Nind (2001) has questioned the extent to which people with high support needs can meaningfully be involved in this kind of collective self-advocacy enterprise.

Chapman (2005) has raised an interesting point with relation to the potential conflict between the individual and the collective purposes of self-advocacy. Her research demonstrated that in order to be effective campaigners, people need to learn the necessary skills and develop their confidence. However, this takes time, and requires the passing down of experience by veteran members. Thus whilst the two projects are mutually dependent, this creates a tension for those self-advocacy organisations which are politicised and impatient to bring about more widespread change.

3.3 Representation

The issue of representation has been a hot topic for advocacy organisations for a number of years. In one-to-one schemes, the advocate's role in representing people with learning difficulties has been questioned on different fronts. For example, is an advocate merely speaking on behalf of their partner; only asserting the partner's views when they can be sure about what they are? Or is an advocate representing their partner's *interests*; which may involve making a value judgement on what is 'best' for the person with learning difficulties (Williams, 2000)? The two sit uncomfortably within one-to-one advocacy circles, and advocates have revealed the ways in which these tensions emerge on the ground – particularly when a partner has profound learning difficulties, or if the person lacks the confidence to take decisions for themselves (Jackson, 2005; Simons, 1993). Whilst many advocates have struggled with these kinds of ethical questions, they have also been challenged by some parents, statutory officials and staff who question

the 'right' of the advocate to intervene in what may be very complex cases (Jackson, 2005; Simons 1993).

The issue of representation has also been a cause for concern within self-advocacy. This has arisen primarily in terms of user involvement in service planning and evaluation, and more recently, with regard to the Learning Disability Partnership Boards (Clement, 2003). Organisations have been challenged on whether self-advocates are representing their own interests, or those of the wider community of people with learning difficulties (Simons, 1999). With regard to the latter – questions have been raised over how this has been achieved, and whether self-advocates are managing to incorporate the perspectives of people with a wide range of impairments and life experiences; or indeed, if they should be expected to (Clement, 2003). This is further complicated by the need for people to adopt a 'learning disabled role' in order to be deemed representative, which within People First circles at least, is at odds with their 'label jars not people' ethos (Clement, 2003: 520). The issue of whether self-advocates are *representing*, or *representative of* other people with learning difficulties has afflicted self-advocacy groups since the earliest days. In particular, criticisms have come from parents who have challenged the appropriateness of self-advocates (who they perceive as having 'mild' or 'moderate' learning difficulties) to speak on behalf of their sons and daughters with high support needs (Mack, 2001). A more cynical critique has also questioned whether statutory bodies – in order to tick boxes that relate to public participation – 'use' self-advocates as the learning disability 'voice' as a means of evading the wider involvement of users in service development (Clement, 2003).

The question of representation is ongoing, and more research is needed to explore the ways in which advocacy organisations themselves perceive and manage the issues

raised above. However, it is also worth stepping back in order to examine the current preoccupation with representation; particularly with regard to self-advocacy. It has been pointed out that double standards exist with regard to who we interrogate about their so-called 'representativeness' – with providers and statutory officials rarely challenged to justify their right to speak on behalf of others (Keay, 1993). This implies a value judgement about where and to whom democratic principles are applied – something that will be considered in this thesis.

3.4 Society versus impairment as a 'disabling' factor: perspectives within advocacy

As we have seen in the previous section, one-to-one advocacy can trace its roots to the normalisation theories that ran parallel to the early citizen advocacy groups. Similarly, self-advocacy – at least in principle – has been influenced by important tenets of the social model of disability. This might suggest a crude binary between the organisations that view individual impairment as the disabling issue for people with learning difficulties (one-to-one advocacy schemes) as opposed to organisations that place an outcome of disability at the door of society (self-advocacy groups).

But how is this dichotomy borne out in practice? One-to-one advocacy schemes have tended to be quiet on this issue – being more concerned with outcomes (improving the lives of people with learning difficulties), rather than questioning why such interventions are necessary in the first place (i.e. because of impairment, or an oppressive society). Mike Pochin highlights these complexities in response to accusations from some quarters that, by its very nature, citizen advocacy perpetuates the power relations between disabled and non-disabled people, resulting in a cycle of dependence for people with learning difficulties:

On the theoretical side, both self-advocates and the wider disability movement have sometimes been suspicious of a form of advocacy which seems to assume that people with learning difficulties need the intervention of able-bodied advocates if their needs and wishes are to be taken seriously. Is this not simply reinforcing the devalued status of the partners and perpetuating images of dependency?

(2002: 107).

Whilst one-to-one advocacy may have skipped over the impairment versus society debate, self-advocacy groups can be seen to be engaging with these issues more extensively (Chapman, 2005; People First London, 2006). In her article on self-advocacy, journalist Tara Mack (2001) was impressed at the efforts of self-advocates to lobby and campaign on political issues, whilst also questioning the assumptions that society holds about people with learning difficulties. However, she also drew attention to what she observed as the very real limitations to the project that arose from people's intrinsic impairments. Similarly, in a recent ethnographic study of a self-advocacy group in which a 'Parliament' meeting was video recorded, Redley and Weinberg (forthcoming) argue that the empowerment of people with learning difficulties was not limited by exclusionary public policies, nor other macro structural barriers, but from the interaction difficulties that occurred at the micro level – a consequence of the 'MPs'' inability to take and hold the floor. As Mack (2001) has suggested, the implications of impairment for the growing self-advocacy 'movement' certainly draws attention to the role of the support worker. She also contends that it might involve the wider society 'changing the yardstick' regarding what is viewed as empowerment and progress for traditionally marginalised people.

The perspectives of advocacy organisations on the impairment / society debate, arguably requires more attention. The extent to which a particular position informs the practice of advocacy, and an analysis of how the 'macro' and 'micro' elements affect the disablement / empowerment of people with learning difficulties in advocacy organisations remains a pertinent issue, and will be addressed in this thesis.

The issues raised in this section are framed within the third research question:

What are the tensions and challenges that arise in the practice of advocacy?

4. The wider advocacy project: service tool or political force?

Advocacy organisations – often charitable companies limited by guarantee – also occupy a space within the voluntary sector, and therefore form part of the broader discussion about the role of non-statutory / non-profit-making bodies in learning disability policy and practice. Self-advocacy organisations can also be viewed as contributing to the evolving user movement – identified as a phenomenon that gained momentum in the 1990s with the growing interest in using consumer and citizen involvement as a means of improving service quality and enlarging public participation in decision-making processes (Barnes, 1997). This raises questions about the nature of the relationships between such groups and the state, as well the relations that these organisations cultivate with their own constituents. Ultimately it is a consideration of both the ways in which advocacy groups (as voluntary associations) act as *agents* for change, as well as the extent to which they are engaged in an ongoing circular process

of *responding* and *adapting* to wider societal changes (Crossley, 1998). But as Baggott et al (2004) have argued, assessing the influence of user groups remains a problematical undertaking:

Policy is the product of a complex interaction of circumstances, agendas and policy actors. It is difficult, if not impossible, to establish which element has been decisive in any particular instance and there are problems of access to data. Decisions may be taken in secret and may reflect hidden, submerged or informal factors (2004: 327).

The literature suggests that political engagement has been emphasised by some commentators as an important aim of advocacy organisations (Brandon, 1995: 5). But how far has advocacy come in moving towards greater political involvement? A glance at developments abroad may help to provide a useful benchmark. In Denmark, for example, there is now a national self-advocacy organisation, which lobbies government on a range of issues via a variety of political institutions. Bylov (2006) argues that by fostering links with parent groups, self-advocates have enhanced their strategic influence and raised their stake in Danish political life. Without such a strategically placed organisation in England, have self-advocates managed to become a political force?

Certainly, since *Valuing People* set up local partnership boards and the national forum, people with learning difficulties have come closer to acquiring 'a place at the table' (Simons, 1999). For many years, academics and other non-disabled 'allies' have pressed for greater participation by people with learning difficulties in service planning – and have seen self-advocacy as a means of facilitating such developments (Flynn and Ward,

1991; Simons, 1992; Simons, 1998). This has been viewed as a way to both enhance services and make them compatible with people's needs, but also as a means to re-conceptualise the traditional professional / service user relationship, based on the assumed knowledge of the former, and passivity of the latter (Flynn and Ward, 1991; Simons, 1999). In recent years, people with learning difficulties have made great strides in the extent to which they participate in such structures – and self-advocacy organisations have frequently facilitated this (Dearden-Phillips and Fountain, 2005). This has occurred in work relating directly to services; but they have also been increasingly involved in the broader research agenda – often in partnership with universities, a significant example being the National Survey; a project co-researched by Central England People First with Lancaster University (Emerson, 2005).

Whilst these developments are laudable, some commentators have commented upon the risk they pose to the wider advocacy project. Simone Aspis (1997, 2002) in particular has suggested that self-advocacy is becoming a tool with which service commissioners and providers legitimise what *they* want, rather than listening to the needs and aspirations of people with learning difficulties. She has criticised self-advocacy groups for focusing too much on how people *feel* about subjects, rather than acting upon those feelings to achieve outcomes. Similarly, Brandon (1995: 77) writes 'what use is self-advocacy if nothing changes? Oppressed people get dispirited if no one listens or responds'. Walmsley (2002) has also highlighted how the potential radicalism of advocacy might be curtailed if services become the focus of groups' attention, rather than the bigger questions of citizenship or liberation.

Whether to focus on issues that are close to home (services) or wider concerns around oppression, attitudes, labelling and the like, continues to be a dilemma facing those

involved in self-advocacy. However, it might be worth noting that Bylov (2006) analysed the development of self-advocacy in Denmark through ‘generational’ stages. He argues that the contemporary politicised face of the national self-advocacy organisation in Denmark has come about over a number of years, and through various political and cultural developments for people with learning difficulties. Self-advocacy in England may only just be moving into Bylov’s ‘third generation – a movement of political empowerment’.

The funding of advocacy

Advocacy organisations are also linked to statutory authorities through their funding streams (see Chapter 1). Issues around statutory funding for advocacy have long been discussed in terms of the short-term nature of that funding, and the potential conflicts of interest that may arise if an individual advocate or an advocacy organisation challenges the grant-giver on matters of service delivery (Atkinson, 1999; Flynn and Ward; 1991, Wertheimer, 1998). The challenges facing advocacy organisations that are funded through local authorities in the peculiarities of the current climate have also been acknowledged by a small, though growing body of literature (Henderson and Pochin, 2001; Jackson, 2005). It is important to acknowledge that the context today is markedly different from that of the early advocacy schemes – many of which initially considered it a realistic prospect to seek funds that were not tied to statutory bodies. Henderson and Pochin acknowledge:

It is a paradoxical but inescapable fact that advocacy is as well established as it is in the UK because of the resources it has received from service provider and service purchaser organisations; in other words, from local authorities and the

NHS. Were these resources to be withdrawn tomorrow, advocacy activity in the UK would be decimated... (2001: 99).

As explained in Chapter 1, the aim of New Labour's Best Value policy was to improve accountability, clarify the expectations of commissioners and develop a pragmatic approach around what can reasonably be delivered by providers of 'services' – including advocacy. However, the complexities that result from the ways in which advocacy organisations are funded at the present time need to be re-evaluated in relation to this changing context, and will be addressed in this thesis.

In-depth research into the nature of the relationships that advocacy groups have developed with external stakeholders (in particular, statutory bodies) remains marginal in the literature. This gap in existing research has led to the final research question:

How do relationships with external stakeholders impact upon organisations that practise advocacy?

This question will look at how such relations have developed in the light of New Labour policy and practice, and will explore the specific issues arising from this particular historical and political context.

Conclusion

Formal advocacy was established as an antidote to the particular forms of historical oppression and exclusion faced by people with learning difficulties, and has expanded to support many other marginalised groups – many of whom use health and social care services (Atkinson, 1999). Over time it has led to numerous examples of positive change in the lives of people with learning difficulties – either individually, or in groups (Ward, 1998). Advocacy is rooted in the belief that all people have the same fundamental needs, wishes and rights. Whilst it may be difficult to ‘strip away the misconceptions of the past, to see people with learning difficulties as people like ourselves’ (Dowson, 1997: 101), the literature demonstrates how members of different types of advocacy organisations have attempted to redress the power dynamics between those who use services, and those who do not. And although the health and social care industry has made progress in supporting people to have more choice and autonomy over their everyday lives, the wider picture suggests that many individuals remain on the margins of society, experiencing deficiencies in services, but powerless to mount strong challenges (Dowson, 1997; Gray and Jackson, 2002). In this context, the need for advocacy as an important support mechanism and potential movement for change continues.

This review has highlighted a number of key issues for research into advocacy. It explored how advocacy’s history has helped to shape its present practice, and has emphasised the values and theories which appear to be underpinning the work that advocacy organisations do. A number of tensions (both within the groups’ boundaries and beyond) were discussed, illustrating that many unresolved issues face advocacy organisations in the current climate.

The thesis builds upon the existing conjectures outlined in this chapter, whilst generating insights into areas that have been overlooked in previous research. The literature review has demonstrated that existing critiques of advocacy have, in the main, focused upon particular types of advocacy groups – most notably pure citizen advocacy schemes and People First self-advocacy organisations. This thesis redresses the balance by analysing the activities of two different types of advocacy organisations.

In the next chapter I explore the methodological literature that informed my choice of research methods, and my personal experience of the research process.

Chapter 3: The research process: methods and methodology

The following chapter explores the unfolding of my research into the development of advocacy organisations for people with learning difficulties. I developed a multi-method research design, with an emphasis on semi-structured interviews in order to gather data for my thesis. Part 1 is a review of the methodological literature which theoretically and practically informed the decisions behind my choice of methods. Part 2 tells the story of my research. It outlines how I ‘got in, got on and got out’ of the field (Buchanan et al, 1988). It explores the collection and analysis of the empirical data, and discusses the issues that surfaced as a result of my particular choice of methods. Inspired by authors who have provided detailed accounts of the unexpected challenges and ‘messiness’ arising from the qualitative research process (Whyte, 1993; Bosk, 1979; Bryman, 1988) Part 2 also reflects upon my experience of conducting research into small voluntary organisations.

Part 1: A review of the methodological literature

Introduction: creating a montage

Miller has observed that ‘different qualitative methods provide researchers with different possibilities for ‘knowing’ the social settings that they describe and analyse’ (Miller, 1997: 1). I have only truly come to appreciate this sentiment in the latter stages of my PhD, as I have undertaken the processes of analysing and writing up the data that emerged through the different methods pursued during the course of this study. The aim of Part 1 is to outline the rationale behind my choice of research methods, and the

broader methodological 'approach' I adopted throughout the study (Silverman, 2000). My research design needed to suit my research questions as well as reflect my own epistemological, political and ethical position with regards to the nature of social research, and more specifically, the phenomenon under investigation (advocacy organisations for people with learning difficulties).

However, it would be misleading to suggest that this chapter accurately represents all the 'twists and turns' that have occurred in my thinking over the last three years. I have undergone an iterative process of reading the literature, undertaking the data collection, revisiting the literature, analysing my data, and a final reading of both familiar and 'new' texts prior to and during the writing up phase. This chapter would have been much easier to compile had my positions on 'reality', 'objectivity', 'validity', and 'partisanship' remained consistent throughout my PhD. In fact, this was not the case.

The sheer wealth of literature available on the philosophical, methodological and practical issues involved in undertaking qualitative research (see collections by Denzin and Lincoln, 2003; Miller and Dingwall, 1997; Seale, 2004; and Silverman, 2004, for an introduction to some of the key themes), has resulted in an ongoing endeavour to reflect upon my own role within the research process, as well as a continual appraisal of how to produce the final narrative of my research findings. Nevertheless, the journey has been a stimulating one, providing ample opportunity for self-reflection and a questioning of many of my own previously-held assumptions.

Despite these intellectual challenges, I have remained committed to one overarching principle throughout the research process. This has been to create what Tuchman (1994) - drawing upon the work of feminist historian Joan Scott - describes as a 'montage' of the research findings. This involves assembling a 'credible story' through an

engagement with different methodological approaches and methods, in order to present what Rolph refers to as 'multiple discourses and constructions, the official view as well as the personal experience' (1999: 58). Whilst my starting position at the outset of this study was something approaching that of a critical realist, I find myself less convinced by the position after undertaking such a long and detailed piece of research. As I explain below, I am now more comfortable with the notion of multiple constructed realities, ambiguity, and the complexity of social life, and I continue to question the extent to which I can author a final interpretation of those realities (Czarniawska, 1998; Schwandt, 2003). And whilst I accept the challenge to any approach which seeks to reveal participants' 'experiences' (see Silverman, 2004, drawing on the work of Harvey Sacks), I have preferred to use such critiques as a way of tempering an over-enthusiasm on my part to 'get into the minds' of my respondents. In the light of my aim throughout the thesis to 'produce knowledge', I have been particularly drawn towards the views of Miller and Glassner (2004) - in particular their defence of using the interview as a sociological method. These authors offer a convincing argument that justifies the undertaking of qualitative research, despite the philosophical and methodological complexities raised throughout its 'seven historical moments' (Denzin and Lincoln, 2003):

Research cannot provide the mirror reflection of the social world that positivists strive for, but it may provide access to the meanings people attribute to their social world. While the interview is itself a symbolic interaction, this does not discount the possibility that knowledge of the social world beyond the interaction can be obtained (Miller and Glassner, 2004: 126).

More broadly, my research design was informed by methodological literature situated within a number of disciplines. Most notably these were qualitative social science, historical sociology and organisation studies. Occasionally I found an inspiring piece of research which seemed to cross some, if not all of these disciplinary boundaries, providing significant insight for the development of my own work (Clement, 2003; Dunkerly, 1988). As my research questions related to organisations undertaking advocacy, I also drew upon a number of studies that had a ‘learning disability slant’ – particularly developments within participatory research (Rolph, 1999; Chapman, 2005) and (auto) biographical methods (Atkinson, 1998; Hreinsdottir et al, 2006). Whilst I eventually concluded that a participatory or emancipatory framework did not lend itself to this study (discussed below), the literature raised a number of ethical and political considerations that were central for the specific nature of my research sites.

In the light of my review of the literature, this chapter will be structured under the following headings:

1. The qualitative paradigm: issues and reflections
2. Organisation studies and the narrative inquiry
3. The role of history in the social sciences
4. Reviewing my choice of methods: the multi-method research model
5. The political and ethical context of my research

1. The qualitative paradigm: issues and reflections

Research is all about seeing the world in fresh ways...In qualitative research we are particularly interested in how others see and experience the world...The excitement resides not so much in reaching the destination, for we can never completely enter the world of another, but in the voyage, and what might be found on the way (Darlington and Scott, 2002: 20).

Qualitative research, as a method of data collection and analysis, and more broadly as a way of 'knowing' the world, is said to have derived from the *Verstehen* (empathy) tradition (Schwandt, 2003). Max Weber argued that social scientists – in contrast to those studying the natural sciences – needed to understand both the historical dimension of human behaviour and the subjective aspects of human experience (Frankfort-Nachmias and Nachmias, 1992).

The epistemology of such 'interpretive understanding', the extent to which human behaviour is 'meaningful', and indeed, whether such intentions could be 'revealed' by researchers, became a site of contestation within the field of qualitative inquiry (Schwandt, 2003). Nevertheless, many researchers within the social sciences remain committed to the qualitative endeavour, accepting its diversity in terms of philosophies and methods. Scholars claim that in contrast to quantitative research, qualitative approaches aim to explore meanings and perceptions, as opposed to trying to explain social phenomena causally (Ziebland, 2005). Researchers have argued that qualitative approaches have permitted them to generate rich and detailed data, revealing contradictions and deviances, and inviting an exploration of both *what* is being said, and *how* it is said (Darlington and Scott, 2002). Although Silverman (1997) has exposed

some of the problematic assumptions behind the supposed 'conflict' between quantitative and qualitative approaches, and Filmer et al (2004) have argued that there are many instances in which the two approaches have been used effectively alongside one another, generally there is agreement regarding some of their inherent differences. Whilst quantitative research is viewed as the means of confirming or rejecting existing theories, qualitative research (highly influenced by the work by Glaser and Strauss, 1967) is depicted as providing an emphasis on the unfamiliar – a means of generating new theories (Bryman, 1988). Theory may arise – but through an immersion in one's (frequently unregulated) data (Turner, 1988).

The embracing of unregulated data is perceived by exponents of qualitative research as an integral element of the research process (Patton, 1990; Turner, 1988). Ziebland (2005) has suggested that researchers involved in qualitative inquiry must be prepared to 'represent' the world in all its confusion and complexity.

My own background as a historian with a particular interest in oral history, afforded me previous experience in managing ambiguity and complexity within the research process. I viewed the 'piecing together' of a story from data which was often conflicting, as an enjoyable – if sometimes frustrating – part of the historical endeavour. My desire to undertake a study that explored the contemporary nature of advocacy organisations thus guided me readily towards the qualitative social scientific literature.

2. Organisation studies and the narrative inquiry

A study about advocacy organisations also warranted, I felt, a review of the organisation theory literature. Out of an abundance of management tracts, I focused upon a number of highly reflective studies, many of which had clearly been inspired by developments in qualitative social science, anthropology, literary theory and occasionally, history (Bryman, 1988; Gabriel, 2000; Gellner and Hirsch, 2001; Hatch, 1997; Weick, 1995).

In particular, my attention was drawn toward the ways in which phenomenology, social constructionism, post-structuralism and the work of literary theorists had impacted upon the ways in which researchers went into, and interpreted, the organisational 'field' (Filmer et al, 2004; Schwandt, 2003). This led me to a number of studies which drew upon the narrative 'device' as a means of generating and analysing organisational data (Boje, 1991; Czarniawska, 1998; O'Connor, 2000; Weick, 1995).

2.1 The cultural 'turn'

Developments in linguistics and cultural studies from the 1960s onwards, helped to instigate a significant paradigm shift in the social sciences, posing important questions regarding the 'nature of the knower', and critiquing the so-called neutrality of science (Hollway, 2005). Lucey (2005) has argued that feminist research made some of the most significant challenges to the notion of an 'objective' researcher (Gluck and Patai, 1991; Oakley, 1981). Scholars located within disability studies have continued to elaborate upon such debates, at times questioning whether non-disabled researchers have any legitimacy in the field at all (Barnes and Mercer, 1997). Many of these positions were informed by the conjectures of post-structuralists such as Michel Foucault (1980), who exposed the issue of power in the production of knowledge.

Closely tied to such developments around the nature of objectivity and subjectivity has been the increasing interest in the role of narratives as modes of knowing and communicating (Andrews et al, 2003; Bruner, 1991; Reissman, 1993). White and Epston (1990: 13) argue that 'persons give meaning to their lives and relationships by *storying* their experience'. Scholars within narrative inquiry have deliberated over whether narratives represent or constitute reality, and whether they can best be understood as modes of *thought* or *discourse* (Bruner, 1991). Bruner contends that:

once the 'cognitive revolution' in the human sciences brought to the fore the issue of how 'reality' is represented in the act of knowing, it became apparent that it did not suffice to equate representations with images, with propositions, with lexical networks or even with temporally extended vehicles such as sentences...At that point cognitively inclined psychologists and anthropologists began to discover that their colleagues in literary theory and historiography were deeply immersed in asking comparable questions about textually situated narrative (1991: 5).

Such theoretical developments on the role of narratives have continued to inform the positions of a number of qualitative researchers in the social sciences such as Melia, (1997) and Silverman (2001).

2.2 Narratives in organisations

As Czarniaswska (1998) demonstrates, the narrative approach has also begun to enrich the field of organisation studies. Drawing upon the work of Schutz (1973), she argues

that if we are to understand human conduct by exploring its intentions, then we need to consider those intentions in the light of the settings in which they take place.

Organisations, she argues – like other forms of institutions, or sets of practices – have been created by humans and have histories and narratives worthy of explication.

Researchers such as Boje (1991), Gabriel (2000) and Weick (1995), informed by such thinking, have emphasised the role of storytelling as the ‘never ending construction of meaning in organisations’ (Czarniaswska (1998: 15).

Narrative research in organisation studies is commonly used as a means of exploring organisations at a point of change (Dunford and Jones, 2000). O’Connor’s study (2000) – which adopted an ethnographic approach – also looked for stories among organisational members, and highlighted the ways in which narrators use the past to invent the future and to re-narrate organisational life. Drawing upon the ‘expansion’ work of Cicourel (1980) she also used individual narratives as ‘mirror’ texts, to reflect the broader socio-historic narratives in which they are embedded (2000: 175).

In more traditional mimetic approaches to narrative research (in which the researcher is looking for *what* the stories tell us), the researcher attempts (or assumes) objectivity; a distancing of themselves from their subject. However, in arguing that all narratives are spontaneous acts of meaning-making which are ‘relationally responsive’, Cunliffe et al (2004) suggest that it is not possible for the researcher to write themselves ‘out’ of the research: indeed, the researcher is a *co-constructor* of the narrative. In their approach to organisational research, Cunliffe et al propose a more diegetic approach to narrative inquiry (*how* stories are told), which displays a sensitivity to the subjective experience of time, and a consideration of narrative construction as performance. Alongside some scholars in qualitative social scientific research (Holstein and Gubrium, 2004) these

researchers call for greater reflexivity by the researcher with regard to their role in the meaning-making process.

2.3 Reflexive narrative work in learning disability

It seems that such a 'reflexive' approach is already underway in narrative research with people with learning difficulties. Commonly, this research has taken the form of life stories or life histories, and a range of techniques have been adopted by researchers in the final presentation of the research (Meininger, 2006; Hreinsdottir et al, 2006). In some cases, narratives have been presented with little analysis on the part of the researchers: the stories are left to speak for themselves, and the reception they receive depends upon the reader (and may be re-interpreted by the reader upon each re-reading). In *Know Me as I Am* (Atkinson and Williams, 1990) it could be argued, drawing upon Bal (1997), that the narratives are present through a range of media – prose, poetry and art. It could be further argued that the decision to leave those narrative texts (linguistic and otherwise) free of analytical interpretation was empowering for the creators of those texts, and in turn fed into the growing profile of self-advocacy in the 1990s and the development of a participatory paradigm in learning disability research (Goodley, 2000b; Kiernan, 1999). Within this life history work there has been a consciousness among a number of researchers to reflect with participants upon the narratives they have produced, and an awareness of how the researcher is heavily implicated in this process (Rolph, 1998; Walmsley and Johnson, 2003; Chapman and McNulty, 2004).

Interestingly, despite this strong body of literature in learning disability research which has used narratives in the context of life histories and life stories, there have been fewer attempts to extend it into the realm of organisations for people with learning disabilities.

If the conjectures of the organisational studies authors referenced above are accepted - that organisations provide an ongoing site of meaning-making through narrative exchanges - then this approach might provide a useful strategy for deepening an awareness of what it means to practise self-advocacy, and knowledge of how people use narrative devices to make sense of their experiences within a user-led organisational setting.

3. The role of historical data in the social sciences

Many of the approaches and debates that arise within the field of qualitative research mirror the discussions that can be found in the literature on historical methodologies. My background in historical research encouraged me to pursue some of these links – particularly as I was keen from the outset to include an historical dimension to the thesis. In doing so, I discovered an interesting body of literature generally referred to as ‘historical sociology’. This literature includes discussions about the purpose of using historical data in social scientific research, and some of the challenges that may emerge from an approach that combines the methodologies of two different disciplines within the same study (Bonnell, 1980; Hall, 1992; Tuchman, 1994).

As Bryant has commented, historical methods have come under fire from two competing epistemological camps in the social sciences:

Critics of the interdisciplinary enterprise of historical sociology commonly contend that the narrational accounts of past social phenomena provided by historians are inadequate to the task of theory-building and testing. In support of

this negative assessment, opponents will adduce informational deficiencies in the available data (the standard positivist appraisal of historical evidence), or cite the interpretive anarchy that seemingly prevails at the narrative phase of emplotment (the sceptical, postmodernist contention that historiographic texts ‘construct’ rather than veridically represent the events they artfully contrive to signify) (2000: 489).

Such critiques are not uncommon, and indeed, reflect many of the debates within historical circles (Burke, 2001; Evans, 1997; White, 1978). Bryant however, remains convinced that historical social science has the capacity to be a wholly legitimate venture, capable of ‘veridical reconstructions of the past’, through the ‘reflexive interpretive protocols of source criticism’ and the ‘sociology of knowledge’, which can help researchers to mediate between a number of competing theories and narratives. Tuchman takes up a similar position when she outlines her own methodological and epistemological approach to the research process: ‘...adequate social science includes a theoretical use of historical information. Any social phenomenon must be understood in its historical context’ (1994: 306). With reference to the construction of meaning, Giddens too advocates an appraisal of the past:

Social meanings are recursive. The past continues to speak to the present. All that we take for granted as ‘natural’ is a product of both historical and contemporary processes (Giddens, 1984, cited in Tuchman, 1994: 310).

This supports the beliefs of some narrative researchers in organisation studies outlined earlier; the past is seen as inextricably entwined with phenomena in their present form. Other scholars in organisation studies have also come to advocate the role that historical

data can play in our understanding of organisational life. Dunkerly – one of the principal exponents of such a view – argues that despite the significant managerial emphasis in the field, the cultural turn of the 1960s enabled researchers to question the ‘organisation’ concept thus highlighting the need for greater historical sensitivity to the phenomenon under observation:

By problematising the concept of organisation, by recognising that ‘organisation’ cannot be a taken-for-granted phenomenon, by questioning the empirical reality of organisation, this move towards greater historical understanding became more and more necessary...organisation structure is a reflection and expression of particular modes of rationality. Such modes can only be identified through an understanding of historical processes (Dunkerly, 1988: 84-85).

Dunkerly argues that whilst providing a description of what has gone before in organisational research is often helpful to both the researcher and the reader, scholars should be considering in more depth how the past can be used as a means of elucidating the phenomenon in its current form. He suggests that a careful exploration of process and change is integral to gaining a richer understanding of organisational life. This can also be seen in some recent studies into voluntary organisations for people with learning difficulties (Rolph, 2002, 2005). Bylov’s (2006) work on ‘generational movements’ in self-advocacy also draws upon an historical approach, using, as he does, a number of oral, written and visual sources to chart the development of self-advocacy groups in Denmark.

4. Reviewing my choice of methods: the multi-method research model

This section outlines the research methods and methodological approach that I adopted after reviewing the literature. I decided to develop a multi-method research design, with an emphasis on semi-structured interviews. Alongside this method I chose to undertake some observation and document analysis. I will discuss the literature regarding these methods in turn, and will also use this section to raise issues of triangulation, and the political and ethical context of my research.

4.1 Interviews

The expanded use of interviews in qualitative research in recent years has been subjected to various critiques, some of which are discussed below. However, a number of researchers remain committed to the interview method (structured, unstructured, or semi-structured) as a means of generating data about people's recollections, experiences and perspectives on a range of issues. Darlington and Scott (2002) have also argued that the method is useful in situations when the observation of 'naturally occurring' data is either impossible, or unethical. They view the interview as a legitimate means of 'finding out how people think or feel in relation to a given topic' (2002: 50). Darlington and Scott also emphasise the shifting temporality of the interview, which enables participants to reflect upon events and feelings across a wide span of time:

They also enable us to talk with people about events that happened in the past and those that are yet to happen. These retrospective and anticipatory elements open up a world of experience that is not accessible via methods such as observation (Darlington and Scott, 2002: 50).

In the light of one of my research questions, which sought to identify the origins and historical development of advocacy organisations, the interview method (for the reasons outlined above) seemed highly appropriate. My previous experience involving research with small voluntary organisations had alerted me to the possibility that the two groups in my study may not have organised an archive of their documents, and indeed, may have disposed of many written records (Tilley, 2001). This is likely to be the case for a number of small voluntary organisations which lack the resources for such archiving activities, and may help to explain the lack of existing in-depth studies of advocacy, as discussed in Chapter 1. Such a situation also raises important questions regarding the extent to which future researchers will be able to undertake detailed explorations of the history of advocacy. Therefore, I identified face-to-face interviews as useful means of recovering different stakeholder perspectives about the past as well as people's current experiences.

Whilst Silverman (2001) has cautioned researchers about the 'romantic' impulse which seeks to identify 'experience' with 'authenticity', Miller and Glassner have argued that interviews can provide useful opportunities to 'collect and rigorously examine narrative accounts of social worlds' (2004: 137). They also contend that it is possible to find 'realities' in interviews through 'intersubjective depth and mutual understanding' (133). This can be achieved through developing trust and familiarity with participants – a complex, but manageable task. Darlington and Scott (2002) also highlight the importance of rapport-building throughout the research process, although they suggest that:

rapport is not a finite commodity that can be turned on and off with the researcher. It is relational... Like all relationships the researcher-participant relationship is subject to continuing negotiation and re-working (54).

In her life history work with people with learning difficulties, Rolph (1999) also highlighted the importance of trust between herself and the participants in order to build people's confidence. Although it is difficult to assess exactly how, or at what point this trust was achieved, Rolph suggested that spending time explaining the project to participants (often with the aid of visual images), offering small gifts to thank people for their time, and allowing people to telephone her before and after the interviews, all contributed to the development of positive relationships with participants.

Despite the increasing popularity of interviews in qualitative research, Hammersley (2003) points out that in the past decade, the method has also been subjected to rigorous criticism. For example, Murphy et al's (1998) 'radical critique of interviews' focused upon their perception of the over reliance upon interview data in qualitative research, and its use as a 'window on the world' or on the minds of informants. Hammersley suggests that whilst criticisms of interview-based methods are not new, the concerns have shifted over time. At one stage, researchers focused upon whether informants were 'telling the truth' and whether their data were 'complete'. Hammersley refers to these as practical and methodological concerns about 'what different methods could and could not provide' (2003:120). More radical critiques however, question the capacity of interviews to 'provide accurate representations, either of the self or of the world', and argue that they can only be used as sites for 'meaning making'. It is in this vein that scholars such as Atkinson and Coffey (2002) and Holstein and Gubrium (2004) have highlighted the 'performative' element of interviews, suggesting that the interviewer

plays an integral role in shaping the direction of the narrative. If interviews are perceived primarily in terms of being 'contextually situated social interactions' (Murphy et al, 1998: 120), then it is argued that what people say is driven more by presenting themselves in the appropriate way to the interviewer, than by presenting facts about the world or themselves.

Hammersley (2003) notes four ways in which interviews have been used by social scientists. I found this useful when considering which method to choose. Interviews have been used as:

1. A source of witness accounts of the social world. Interviews may be used to supply information about participants' biographies, sets of events, or relevant stable features of situations they are familiar with.
2. A source of self-analysis. Interviewees are asked to reflect upon their behaviour, attitudes, personalities, and these reflections are used as components of explanations for what they – or others – do, or did.
3. An indirect source of evidence about informants' attitudes or perspectives. Here, the analyst uses the data as a means of drawing inferences about their intentions, motives and preoccupations. It is generally assumed that what is detected are seen as stable orientations that generate behaviour in other contexts besides the interview.
4. A source of evidence about the constructional work on the part of the informant (and perhaps the interviewer also). Here, interviews are used as interactional sites for various sorts of discursive practice, which may or may not be seen to operate elsewhere.

(Taken from Hammersley, 2003: 120, with slight adaptations)

I went into the field assuming that I would use interview data for the first two purposes outlined by Hammersley – particularly in light of my aim to elicit information about the history of the two groups in the study, and to find out people’s perspectives on a range of issues facing advocacy organisations today. However, as I became increasingly immersed in the data, it became apparent that I was (almost without realising it at first), drawing inferences from what people said, and using that ‘implied knowledge’ to ponder about ‘hidden’ findings. Using the data at this level was fascinating, but at times problematic, for reasons outlined in Part 2. Whilst I retained a keen interest in narrative and stories throughout the data analysis (in light of the literature outlined in section 2), I did not undertake a close discursive analysis of the interview transcripts, as using the data in this way would have been less suitable for my research questions.

4.2 Interviewing people with learning difficulties

It was always my intention to interview a variety of stakeholders within the groups that I was researching. Within a self-advocacy organisation, this clearly involved interviewing people with learning difficulties. There is now a significant body of literature that has explored the implications of undertaking research with people who have cognitive impairments or difficulties in communicating through speech (Booth and Booth, 1996; Mitchell, 1999; Rolph, 1999; Walmsley, 1995).

As Darlington and Scott (2002) contend, people with learning difficulties have often remained ‘voiceless’ within the research process. They suggest that this is partially because this group of people are perceived as vulnerable, but also as a result of calls for interviewees in qualitative research to be articulate, reflexive, and have the capacity to give full and vivid descriptions (Polkinghorne, 1989). Darlington and Scott (2002:103)

advocate that undertaking research with people with learning difficulties requires at least three elements:

- That we value their experiences
- That we respect their perspectives as valid
- That we find ways to elicit those experiences and voices.

For example, Biklen and Moseley (1988) recommend a period of observation prior to interviewing, both as a means of getting to know something about participants' lives, and to ensure that interviewees are fairly familiar with the researcher. Rolph (1999) also reflected upon the importance of preparation before interviews – to avoid missing terms that relate to key pieces of information about people's lives. Researchers have also highlighted the importance of visual images (such as photographs) as a means of stimulating discussion and helping interviewees to remember details about events, people and places (Booth and Booth, 1994; Rolph, 1999).

4.3 Observation

Although some researchers have privileged participant observation over interviewing as the principal method in qualitative research (Dingwall, 1997), others have seen the value in using the two methods alongside one another. Darlington and Scott explain that observation may provide a useful contrast with what people say in interviews. It can enable the researcher to assess the extent to which people's actions (and interactions) reflect the rhetoric that may arise in interviews:

Interviews allow access to what people say, but not what they do. The only way to find out 'what actually happens' in a given situation is through observation (Darlington and Scott, 2002: 51).

Although a noted proponent of participant observation, Dingwall (1997) problematises the position assumed in the quote above. He argues that observation does not show what is 'real' or what is 'going on inside the heads of the people who are making the world real for each other' (1997:61). However, he argues that observation can help researchers to come closer to understanding the 'production of everyday life' (61). This has been evidenced in a number of studies which used participant observation (often within a broader ethnographic approach) to generate fresh findings, and to destabilise entrenched assumptions and theories within the field (Goffman, 1961, cited in Silverman, 2001; Whyte, 1993). Other scholars such as Clifford Geertz (1973) have shaken some of the foundations of ethnographic methodology, suggesting that the researcher's analysis of the various meanings of an event is a reflexive interpretation of what he / she has witnessed, rather than an objective description (Walsh, 2004).

Participant observation (and ethnographic approaches more broadly) is a tool that has been adopted by a number of researchers in organisation studies (Bryman, 1988; Czarniawska, 1998; Gellner and Hirsch, 2001). It has also been used to elucidate findings about learning disability organisations – in particular, self-advocacy groups (Clement, 2003; Goodley, 2000a). Much of the literature provides guidelines for the 'nuts and bolts' of this method – in terms of accurately recording concrete descriptions of the data and writing analytic memos (Silverman, 2001; Walsh, 2004). A number of scholars have also written about the ethical and practical pitfalls of observation, and have suggested ways in which such issues can be managed (Beynon, 1988; Silverman,

2001). In Part 2, I will discuss how I negotiated such challenges throughout my research.

4.4 Document Analysis

Within a multi-method approach, documents can be used to provide background information, to check details about the phenomena under study that may not arise through interviewing or observation, and to aid the researcher's contextual knowledge, which may be very important before interviewing (Rolph, 1999). Emphasising the importance of exploring documents within the research process, Walsh contends that the records of organisations are 'made and used in accordance with organisational routines' (2004: 234). He argues whilst written documents may be viewed as constructing a 'privileged' reality, because they are sometimes 'treated as the objective documentation of it', researchers should be aware that documents require a rigorous analysis of 'how they are written, how they are read, who writes them, who reads them, for what purposes, with what outcomes' (2004: 234). A similar point has been made by Meininger (2006) in his advocating of the use of life stories for people with learning difficulties.

The interpretive issues in document analysis have been raised in historical and sociological fields alike (Tuchman, 2004 and Silverman, 2001, respectively). And whilst documents are never 'neutral facts' (May, 1996, cited in Rolph, 1999), treated sensitively, they can (and have) be used as a means of helping researchers to better understand processes and events within the social world. This has been particularly true in the field of learning disability history, in which archival work has at times, been used to great effect to reveal important findings about policy and practice (Thomson, 1998;

Walmsley et al, 1999; Welshman, 1999). I chose to undertake some document analysis as part of my multi-method approach. I anticipated this including official records (for example - national and local policy documents; minutes of meetings) and written documents from the organisations (for example - publicity material, Annual Reports).

4.5 Triangulation

Adopting a multi-method approach suggests that the researcher is attempting to 'triangulate' the data. As Silverman (2000) has pointed out, such an approach can be useful, but is also fraught with problems if the researcher has not clearly thought through their theoretical perspective or model. Triangulating data may be used as a means of cross-checking, and verifying findings (Denzin, 1978, cited in Rolph, 1999).

This suggests that the researcher may be attempting to map the 'whole picture' and use data obtained from different methodological tools to fill in gaps and corroborate other sources in order to get closer to 'the truth'. Silverman (2000) also suggests that some people adopt a multi-method approach, but mistakenly use methodologies that arise from different theoretical perspectives (such as discourse analysis and interview data on individual points of view – which have conflicting views about the nature of reality).

However, other researchers – clear about their own epistemological position - have used triangulation to reveal the complexity of social life. Rolph emphasises that she combined oral history, life history and archival methods as a means to 'enrich, broaden and include, as well as to check dates and sequences of policies, in the spirit of constructing a history from many points of view' (1999:78). Triangulation can be used to reveal multiple perspectives and discourses, as well as to check basic information.

Czarniawska also advocates a multi-method approach in organisation studies. Her rationale for doing so matches my own, and is thus worth stating here:

...the material collected via observations and the material collected via interviews complement one another, and ought in turn to be complemented by many other techniques. The attractiveness of all such techniques needs to be measured against the degree to which they permit one to tackle the peculiarities of modern organising: the condensed time, the simultaneity of events taking place in different settings, and the invisibility of a growing part of operations (1998: 31).

5. The political and ethical context of my research

A number of recent studies about people with learning difficulties have used participatory methods during the research process (Chapman, 2005; Rolph, 1999; Williams, 2002). Ward and Simons (1998) have described various ways in which people with learning difficulties have been able to participate in shaping the research agenda, advising and assisting research projects, doing research themselves, and being involved in its dissemination. Walmsley and Johnson (2003) link these developments to a broader shift within qualitative research towards participatory action research, and the more specific influence of feminist scholars and researchers within the disability movement. Whilst Walmsley and Johnson contend that there are differences amongst researchers with regard to how 'inclusive' research is practised, they also suggest that participatory studies are driven by the common principles of a commitment to social change, and the empowerment of participants.

The participatory model has become increasingly common in recent years, culminating in the first national survey of people with learning difficulties being undertaken by service users (Emerson et al, 2005). Inclusive research is contentious, and in many ways, a political hot potato in learning disability research. Whilst voices from the disability movement have on the one hand called for more emancipatory approaches, in which disabled people initiate, design and undertake the research - ultimately retaining full control (Aspis 2000; Zarb, 1992) - others have advocated the need for clearer and more honest accounts of how the research process developed and what people's roles were within it (Walmsley and Johnson, 2003). Clement (2003), who chose not to pursue his research on self-advocacy through a participatory framework, argues:

My initial view of much of the self-advocacy literature was that people were so committed to the cause of self-advocacy, that they were communicating propaganda rather than scientific truths (2003: 106, drawing on Furedi, 2001).

The participatory literature is persuasive, and as somebody committed to both of the principles outlined by Walmsley and Johnson, I considered very carefully the extent to which my methodology would (or should) be driven by a participatory approach. I eventually decided that my research questions did not lend themselves easily to participatory methods. Although I was not attempting to pursue 'scientific truths' like Clement, my questions required a cross section of perspectives, which could not be guaranteed within a participatory model. And indeed, having raised the issue with the self-advocacy group involved in the study, it also seemed highly unlikely that the self-advocates (many of whom were undertaking research activities via the organisation already) would have had the time to participate to the level required for an inclusive

approach. Nevertheless, my research questions *did* lend themselves to hearing the voices of as many respondents within the organisations as possible, and for that reason, it was essential that service users were interviewed throughout the research. The ethics surrounding this issue will be discussed in depth in Part 2.

Conclusion to Part 1

Few methods or methodological approaches are likely to reveal the full complexity of organisational life. Organisations are multifaceted and unstable phenomena, shaped by a range of factors both inside and beyond their organisational boundaries. The overarching aim of this thesis is to consider what some of these factors are within the context of advocacy, and how the impact of events, policies, and people (both in the past and present) are played out within advocacy groups. I felt that the multi-method approach described above would be the model best suited to this task.

Part 1 of this chapter has indicated that my epistemological position within the research process has been influenced by theoretical frameworks such as phenomenology and social constructionism. However, I entered the field with a number of important questions to answer about the nature of advocacy and advocacy organisations, and hoped to avoid a reduction of all my data (despite its complexity) to a set of interpretations that could not be used to say anything about anything. For that reason, I take comfort from Martin Hammersley's words (drawing upon Seale, 1998):

...it is true that if we are to conceptualise what we see or how we feel we must do so in a language that is a social product. But this does not imply that such

conceptualisations have no referents, or that some accounts cannot be more accurate than others. The fact that how such accounts are constructed can be made a sociological topic does not mean that they cannot also be used as a sociological resource (2003: 122).

In the second part of this chapter I discuss the processes which led to the construction of the final account of my data.

Part 2: Research methods: data collection and analysis

Introduction

Part 1 explored the rationale behind my adoption of a multi-method approach to data collection. In the second part of this chapter, I tell the story of my research. This includes an explication of how I gathered and analysed the data, and presents some of the challenges that arose along the way.

My data were collected simultaneously, creating processes in the research that were 'iterative and overlapping' (Turner, 1988: 110). In the spirit of a grounded theory approach, findings that emerged from one method fed into the collection of subsequent data via another method, as I gradually built up a complex picture of organisational life in both advocacy groups. I kept a journal to document the chronology of my unfolding research, and used this as a space to record my thoughts, concerns and initial analysis, as well as specific details about people and places.

Undertaking research into organisations offers the potential for a rich and varied set of data, but the difficulties associated with such research have also been acknowledged (Bryman, 1988; Gellner and Hirsch, 2001). In the second part of this chapter, I raise some of the difficulties that were specific to my research – many of which I suspect will have resonance for other studies on small voluntary organisations. Issues of access and gatekeepers, anonymity and identification, and how the passing of time impacts upon the research process, all contributed to a number of ethical challenges that had to be addressed during - and after – the data collection period. This chapter discusses some of these issues in depth, and explains how I attempted to resolve them.

Part 2 is organised under the following headings:

1. Introducing the case studies: organisations and participants
2. Gaining access to the field
3. Doing the research
4. Analysing the data
5. Managing challenges in the field: gatekeepers, anonymity and ethics

1. Introducing the case studies: organisations and participants

1.1 The organisations

Figure 1: The People's Voices Logo



People's Voices is a one-to-one advocacy organisation that has been in existence since the early 1990s, although, as will be shown in chapter 4, its roots can be traced to a steering group that began meeting in the mid 1980s. People's Voices recruits volunteer advocates from the local area, and matches them with service users who need support on particular issues.

Figure 2: The Talkback Logo



Talkback is Buckinghamshire's only self-advocacy organisation. It emerged from People's Voices, which set up a self-advocacy group in 1996. In 2000, Talkback left People's Voices and established itself as an independent organisation.

1.2 Using case studies

Chapter 1 made the case for using People's Voices and Talkback as case studies through which to explore broader issues relating to advocacy and advocacy organisations, and to shed light on wider questions about the development of the English voluntary sector in health and social care. Chapter 1 also highlighted the absence of other such studies into advocacy framed by the methodological and non-partisan approach of this research.

Whilst the necessity for qualitative researchers to defend the validity and generalisability of their case-study based research is receding (Bryman, 1988; Becker, 1998), Silverman (2000) suggests that it is still important for researchers to explain the rationale behind their specific choice of research site(s). Silverman, drawing upon the conjectures of Mason (1996) believes that case studies can produce findings that have resonance beyond the peculiarity of the particular site in question, but this depends upon an explication of why sites were chosen, and how they relate to pre-existing knowledge about the phenomenon in question.

For example, drawing upon Hammersley (1992), Silverman (2000: 128) suggests that 'quantitative measures may sometimes be used to infer from one case to a larger population'. In order to do this, I obtained information about other advocacy organisations and compared my cases to them. The literature review revealed that in self-advocacy, much of the existing research has been conducted through a focus on People First organisations. This includes two recent PhD theses, which explored such groups in considerable depth (Chapman, 2005; Clement, 2003). Initially, I considered building upon such research, through an exploration of People First organisations in the

South East of England. However, the challenges that I faced in accessing these organisations as potential research sites impacted on the final choice of case studies. First, it was very difficult to make contact with members of People First organisations who were willing to speak to me about the research. Telephone and email messages were frequently not returned, and when I did manage to discuss the project with an organisational member, there was considerable ambiguity concerning with whom the responsibility lay to make a decision on the group's involvement. Some of the groups also informed me that they were busy working on a number of other research projects, and were wary of becoming involved in a project that seemed to lack a strong participatory element, particularly as I am a non-disabled researcher.

These initial access issues prompted me to revisit the self-advocacy literature, focusing upon non People First organisations. I found a paucity of studies which addressed such organisations in depth. I subsequently decided to focus upon a self-advocacy group that was not a People First organisation. This was partly to look for comparisons between the two, but also to investigate a research site which might generate new insights into self-advocacy, and possibly reveal an alternative organisational 'model'. In this way, my decision to study Talkback was an example of purposive sampling. Similarly, People's Voices was an example of the other significant area of advocacy activity frequently discussed in the literature, which has gained increasing attention of late through policy initiatives such as the Independent Mental Capacity Advocacy service set up under the Mental Capacity Act (2005). People's Voices' history (which had spanned the best part of two decades), and its link to Talkback, suggested that it would be a rich and complex site for analysis. Throughout the thesis I reference the literature on other advocacy organisations in order to demonstrate similarities, but also to highlight diversity, and occasionally, fragmentation.

I also thought carefully about the geographical location of my research. As my research questions were designed to find out how the external environment has influenced the development of advocacy, I paid close attention to where the research sites were situated. It was important that both organisations were based within the same geographical area, as I wanted to assess the impact of the local culture (for example, policy, economics, and attitudes) on different types of advocacy groups. As means of providing a contrast to some of the existing advocacy literature, I decided to focus upon organisations based within a predominantly rural area. Buckinghamshire was particularly appealing, as – unlike areas such as Cambridgeshire (Dearden-Phillips and Fountain, 2005; Redley and Weinberg, forthcoming) – it was relatively ‘untouched’ by researchers. It is also known for its political stability, which has witnessed over one hundred years of uninterrupted Conservative control at the local level. I wondered whether such an environment had shaped advocacy in any particular ways.

I contacted Talkback and People’s Voices through emails and telephone calls and both groups agreed to become involved in the research by the end of 2004 – just over a year into the research process. These case studies were therefore chosen as a result of both the politics of researching self-advocacy organisations and from a desire to address a number of gaps in the existing literature.

1.3 The interview participants

Respondents for my study were found through the combined methods of network sampling, in which interviewees were obtained through referrals among people with similar characteristics (Bloch, 2004) and by identifying those individuals who could be

considered 'key informants' (Seale, 2004). My commitment to obtaining multiple perspectives about advocacy – both within and outside the organisations – encouraged me to locate as many participants as possible, until I felt that I was approaching 'saturation' point (Dipex, 2005). I was interested in interviewing individuals who would provide a cross section of views, both at different levels within the advocacy groups, and also within Buckinghamshire social services. This method of locating interviewees was partially reliant on specific 'gatekeepers' who had both the knowledge to suggest suitable respondents, and the wherewithal to facilitate my access to them (see section 2 below). In total I interviewed 20 respondents, outlined in table 1, on the next page. Each interview has been coded, and these codes will be used throughout the thesis to reference quotations. Some interviews were conducted jointly (illustrated by '*' in the table), which is discussed more fully in section 3.

Respondents were interviewed once, with the exception of Jean Rein. I interviewed Jean twice – both at the beginning of the fieldwork, and at the very end. In the spirit of a grounded theory approach, I discussed with Jean the idea of interviewing her for a second time after I had been in the field for a while, and had developed a greater understanding of the issues raised either by other participants, or through document analysis and observation. Jean thought this would be a useful strategy, and agreed to be interviewed at a later stage. With other respondents I developed skills for covering a wider range of topics within a single interview – as I was aware that some interviewees (due to their busy schedules) would be unable to be interviewed for a second time.

Table 1: List of respondents

Respondents from People's Voices (in chronological order of interviews)	Respondents from Talkback (in chronological order of interviews)	Respondents from Buckinghamshire County Council (in chronological order of interviews)
<p>PV1 Barbara Poole (Project Manager) <i>Interviewed on 05/01/2005</i></p> <p>PV2* Anita English (Chair of the Board) <i>Interviewed with Elizabeth Firth on 25/04/2005</i></p> <p>PV2* Elizabeth Firth (Company Secretary) <i>Interviewed with Anita English on 25/04/2005</i></p> <p>PV3 David McCluney (ex Managing Director) <i>Interviewed on 27/04/2005</i></p> <p>PV4 Becky Jones (Advocacy Support Manager) <i>Interviewed on 07/06/2005</i></p> <p>PV5 Brian Drew (Advocate) <i>Interviewed on 21/03/2006</i></p> <p>PV6 Wilma Smith (Advocate) <i>Interviewed on 21/03/2006</i></p>	<p>TB1a Jean Rein (Chief Executive) <i>Interviewed on 22/07/2004</i></p> <p>TB1b Jean Rein, <i>Interviewed on 19/07/2005</i></p> <p>TB2* Jackie Brodie (Self-advocate) <i>Interviewed with Chris Eastwood, on 26/07/2004, supported by Jean Rein</i></p> <p>TB2* Chris Eastwood (Self-advocate) <i>Interviewed with Jackie Brodie, on 26/07/2004, supported by Jean Rein</i></p> <p>TB3 Rob Beattie (Self-advocate) <i>Interviewed on 15/11/2004, supported by Jean Rein</i></p> <p>TB4 Steve Dean (Self-advocate) <i>Interviewed on 15/11/2004, supported by Jean Rein</i></p> <p>TB5 Simon Evans (Project co-ordinator) <i>Interviewed on 11/02/2005</i></p> <p>TB6 Lyn Griffiths (Project coordinator) <i>Interviewed on 11/02/2005</i></p> <p>TB7 Clare Hawes (then Chair of the Board) <i>Interviewed on 02/03/2005</i></p> <p>TB8 Fred Charman (Self-advocate) <i>Interviewed on 21/03/2005</i></p>	<p>BCC1* Jenny Harris (Valuing People Strategy Manager) <i>Interviewed with Stuart Mitchelmore on 10/03/2005</i></p> <p>BCC1* Stuart Mitchelmore (Executive Manager of the Integrated Learning Disability Services) <i>Interviewed with Jenny Harris on 10/03/2005</i></p> <p>BCC2 Peter Loose (Head of Adult Disability and Mental Health Services) <i>Interviewed on 19/04/2005</i></p> <p>BCC3 Chris Flahey (Commissioner for Advocacy) <i>Interviewed on 26/04/2005</i></p>

2. Gaining access to the field

2.1 Getting into the organisations

My route into the organisations was facilitated by Barbara Poole at People's Voices and Jean Rein at Talkback. However, in both organisations, my entry into the field had to be approved by other key members. Barbara Poole took my research proposal to the People's Voices Management Board, who subsequently decided to grant access. At Talkback, Jean Rein invited me along to a Management Group meeting⁴ in order to introduce myself, discuss the nature of my research, and explain how Talkback could become involved. Jean contacted me a few days later to say that the Management Group liked the sound of the project, and were happy for me to spend some time researching Talkback.

2.2 Identifying and accessing interview participants

In both organisations, gatekeepers were integral in facilitating the interviews (Bloch, 2004). At People's Voices, Barbara Poole suggested names for me to contact – which I then followed up. At Talkback, Jean Rein also put forward prospective participants – particularly with regard to potential self-advocate interviewees. Jean's justification for this was that she would be able to identify self-advocates who had been involved in the organisation from its inception, and would thus be able to assist me in charting the organisation's history. Jean was responsible for organising these interviews, at which she was also present (see below, 'doing the research').

⁴ The Management Group is explained fully in a broader discussion of Talkback's organisational structure, in Chapter 5.

As I spent more time in the field, and got to know more people, I identified a few participants who I decided to contact directly. This included two staff members at Talkback (Simon Evans and Lyn Griffiths), the then Chair of the board (Clare Hawes) and one self-advocate (Fred Charman). I also approached the representatives from Buckinghamshire social services directly. I had already been introduced to Jenny Harris, Peter Loose and Stuart Mitchelmore (by Jean Rein) at a Learning Disability Partnership Board meeting. I then followed up these brief conversations with formal letters, requesting interviews.

2.3 Accessing meetings

I observed a number of meetings throughout my research (see 'doing the research'). These were internal Talkback meetings and Buckinghamshire Learning Disability Partnership Board meetings. For confidentiality reasons it was not possible for me to observe any People's Voices one-to-one advocacy sessions, and the organisation was not forthcoming in granting me access to board meetings. At Talkback, the Management Group approved my attendance at internal meetings, and this was then arranged on subsequent occasions through Jean Rein. Peter Loose was responsible for granting me access to the Learning Disability Partnership Board meetings.

2.4 Accessing documents

I accessed a range of documentary evidence. Much of this was available on the internet, and thus did not require approval by individuals or institutions. This included policy documents, Buckinghamshire Adult Social Care's strategy plans, Buckinghamshire County Council minutes of meetings, information regarding Buckinghamshire's

learning disability services and the Learning Disability Partnership Board. I also regularly read the websites of People's Voices and Talkback, which provided their 'official' organisational perspective.

Jean Rein from Talkback also granted me access over a two day period to read organisational documents, including publicity material, annual reports, and research projects undertaken by the group. I was able to photocopy many of these documents and study them more closely away from the organisation's office. David McCluney, Anita English, Elizabeth Firth and Barbara Poole also came along to the interviews with records and documents from People's Voices that they had photocopied for me.

2.5 Consent

Gaining informed consent from participants was integral to this research. Rolph (1999) has highlighted some concerns over the extent to which participants really understood the nature of her study, and how their words would be used by the researcher. I was also worried about these issues, but drew upon Rolph's recommendations regarding how to maximise the chances of consent being genuinely *informed*.

I designed information and consent forms, which were approved by the Open University's Human Participants and Material Ethics Committee, and sent to all potential interviewees. The information sheet outlined my research aims at the beginning of the study, and was written in an accessible style with visual images (Appendix 1). The consent form was designed to clarify how the interview transcripts were to be used, but also to give respondents the opportunity to make any amendments

that they felt were necessary (Appendix 2). For example, one participant added a clause which is indicated below in italics:

I agree that she (Liz Tilley) may use my comments in publications such as journal articles, book chapters, or in conference papers (*with the proviso that the date the comments were made is indicated, as the situation continues to evolve*).

The consent form also enabled people to withdraw from the research, and to be anonymised if they preferred. No participants requested anonymity. This issue is discussed at a later point in the chapter.

Jean Rein agreed to go through the forms in depth with any service users who did not read. For those service-users who were unable to sign the consent form themselves, I anticipated that a person close to that individual would sign on their behalf, although this issue did not arise in practice. The forms were piloted with the Talkback Management Group at the outset of the research. The group were happy with my design and felt that it would be accessible for people with learning difficulties. However, as Swain et al have noted, projects do have the tendency to change over the course of the research life cycle, and therefore a 'full explanation of the research is not possible at the outset' (1998: 28, cited in Rolph, 1999: 105). To address this issue, I made a point of discussing the progress of my research with participants whenever we met. This was easiest to do with members from Talkback, as I had a number of opportunities to speak with them at the different meetings I attended.

My greatest concern on the issue of informed consent was with regard to the observation element of my research. At the first few Talkback meetings I addressed this

issue by introducing myself, describing the research, and explaining that I was taking notes that would help me to understand what happened at Talkback. People appeared to be happy with what I said, and nobody ever requested that I stopped taking notes. But were people really clear that I was going to present my field notes in an explicit way throughout the thesis? This certainly presented one of the most significant ethical dilemmas during the writing up stage. I have used data from these meetings throughout the thesis – and have made a considered decision on every occasion whether it was appropriate to anonymise the individuals concerned. As a general rule, people have been anonymised if the fieldnotes contained data that was personal, or sensitive in any way. On occasions where the content of the data was more generalised, or if it was necessary to explicate precisely who was making particular points in order to set the context, then people's names have been given.

3. Doing the research

3.1 Interviews

The interviews were semi-structured, and lasted between half an hour and one and a half hours. They were conducted within a range of settings. Most of the interviews with organisational members took place in the offices of People's Voices and Talkback, although I also interviewed some people in their own homes, and met with two of the self-advocates at their local day centres. The interviews with officials from the local authority were conducted at the offices of Buckinghamshire county council. All of the interviews were tape recorded, although I did ask respondents before every interview whether they would prefer for me to take notes only.

I prepared topic sheets for each interview, which I used as prompts, rather than for specific questions. At the end of each interview I would check that all my topics had been covered and asked respondents if there was anything else that they would like to add. I began by asking everybody that I interviewed how they first became involved in their respective organisation, which I found to be a good ice-breaker, whilst also prompting people's memories and inviting them to think about the past. Most of the interviews combined discussions about the present and the past.

With the exception of Fred Charman, all of the self-advocates were supported throughout the interviews by Jean Rein. Jean's rationale for being present at the interviews was that it would assist people to remember past events. Whilst I was concerned at the outset that such support might give rise to Jean's voice dominating the transcripts, in practice, I found that her presence did enable people to open up and start remembering events and experiences from the past. In some interviews, Jean also brought photographs and other documents with her in order to generate discussion. Her own knowledge of developments within the group meant that she was able to prompt self-advocates with specific information that I simply did not have. The passage below is one example in which Jean was able to use specific details to help jog Rob's memory on an event that took place over five years ago:

Jean: Do you remember we went to that workshop thing, at Bucks university, where it was about developing the guidelines for advocacy?

Rob: I remember, I remember going, but I can't remember what it was for.

Jean: Because it was when William brought his frog broolly. (laughs)

Rob: Oh yeah! (laughs)

Jean: William brought his frog brolly. It was pouring with rain, and there we were, the early days of Talkback, gonna be really professional, weren't we?

Rob: (laughs)

Jean: And we got out the car at the university, making our way in, and William gets out and puts up this umbrella, which has frog's eyes, bright green!

Rob: Oh, yeah, that's when John O'Brien was there, as well, weren't it?

(TB3 p.1)

At other points in the interviews, Jean's presence aided the development of a conversation in which memories were shared and expanded:

Jean: At that meeting, when we used to meet at Chalfont, it wasn't just you people from Hillcrest, was it? It was other people.

Chris: All sorts.

Jean: Can you remember who else used to come? From what other sorts of places?

Chris: Endeavour in Chesham.

Jackie: I can't remember.

Jean: And, the Epilepsy Centre?

Chris: Yeah, Chalfont. Nicky Cox.

Jean: Yes! Yes, you're right.

Liz: Who's Nicky Cox?

Chris: An old friend of ours. Yeah, we had, er,

Jean: Andrew?

Chris: Andrew Townsley.

Jackie: That was when we were in Amersham!

Chris: We had Jeffrey from Endeavour.

Jean: That's right.

(TB2 p. 2)

However, at certain points, I was aware that Jean's voice was becoming dominant within the interview. At times I also sensed that she was attempting to steer the conversation in order to make a specific point. One such occasion was during a discussion about Talkback's visit to a day centre in Milton Keynes. Jean appeared to be directing the conversation in order to emphasise the valued social roles undertaken by people with learning difficulties in the Milton Keynes centre, although this point was not 'taken up' by Chris and Jackie. This is discussed further in chapter 5.

Fred Charman was not supported by Jean during his interview, for two reasons. The first was a very practical one. Following a period of participant observation at a Talkback meeting, the team asked whether I would mind dropping Fred home, as it would be on my route back to London. The journey was about half an hour long, and as I had my tape recorder with me, I asked Fred whether he would mind being interviewed in the car, as it had proved very difficult to find a day when he was free to meet. Fred was happy to do this, and I managed to tape record the discussion. Although I did not have my topic sheet to hand, by that stage I had already interviewed a number of people, and held all the questions in my head. Second, Fred is well-known for his (quite extraordinary) memory. I suspect that Jean was aware that he would not need any support in order to help him remember events and experiences.

At the end of every interview, I informed participants that I would be transcribing the interview over the next few days, and asked them whether they would like to see a copy of the transcription or listen to a copy of the tape. This was to give people an

opportunity to check that I had transcribed all of the details from the interviews correctly, and to allow people to amend, add to, or retract any comments they had made. About a third of interviewees chose to read the transcripts, and these came back with only minimum amendments (usually filling in gaps where the tape had been muffled). None of the self-advocates chose to see the transcripts or to listen to their tapes.

3.2 Observation

I observed nine meetings throughout the research process, two of which were for the Buckinghamshire Learning Disability Partnership Board. The others are outlined below⁵:

Talkback meetings:

- Annual General Meetings (x 2)
- Management Group meeting
- Finding Out Group meeting
- Board of Trustees meeting
- Pre co-leads meeting
- Co-leads meeting (with representatives from Buckinghamshire county council)

The Talkback meetings all involved a mix of self-advocates and members of the staff team.

⁵ Details about the groups referred to here can be found in section 1 of Chapter 5.

During every meeting I took detailed notes, trying – where possible – to note down precise quotes. As Silverman (2000: 157) has pointed out, one challenge with field notes is that ‘you are stuck with the form in which you made them at the time, and that your readers will only have access to how you recorded events’. Silverman advocates a number of techniques which can be employed as a partial solution to this issue, all of which I attempted to follow. For example, Silverman recommends paying close attention to what you can see, as well as what you can hear - watching the interactions between different people, and considering how spatial arrangements may differentiate groups of people. As is shown throughout the findings chapters, this issue came to be an important part of my analysis, as I began to consider the implications of where people were situated during meetings.

Following every meeting I immediately developed my notes further, whilst the details were still fresh in my mind. I also maintained a provisional running record of analysis, and used a different coloured pen throughout my notes to indicate to myself where I was beginning to interpret the data. As I began a thorough analysis of the data when the fieldwork was completed, I was pleased to revisit these notes and find how detailed they were.

4. Analysing the data

4.1 Using grounded theory

I drew upon a ‘modification’ of grounded theory, for the collection and analysis of my data throughout the research process (Ziebland, 2005). As Turner (1988) has suggested,

removed of the polemic, Glaser and Strauss's (1967) approach is a highly useful means of going about most forms of non-quantitative inquiry. Although I did enter the field with some prior knowledge of the issues, and with a broad set of research questions, the grounded theory approach enabled flexibility throughout the study, and encouraged the development of an iterative process whereby I would use an initial analysis of the transcripts, field notes and documents to inform how I collected the next set of data. Sometimes this involved asking participants fresh research questions, although where possible, I contacted previous participants (either by telephone or email) and posed these questions to them also.

4.2 Thematic analysis

I analysed the research using a broadly thematic approach. In line with my 'modified' use of grounded theory, some themes were anticipated, but many emerged through the course of the data collection and analysis.

I immersed myself in the data both during and after my time in the field. I read, reflected, and re-read the transcripts, documents and field notes until I had become very familiar with the data. This process also involved constant comparative work – both within my own data, but also with other research in the literature. I was also alert to 'deviant' cases that arose (Locock, 2005). I then began coding the data into broad categories and went on to develop sub-themes that I felt best reflected significant issues arising from the material. I coded the data physically – first by using different coloured pens and symbols to organise it, and then by cutting and pasting the text into Word. In particular, I was exploring the *meanings* attached to these themes by different participants. For example, I contrasted how respondents narrated their experiences with

organisational rhetoric, and discovered a number of tensions between espoused values and practice.

It is also important to acknowledge that the coding process was not a static one; new themes developed and previous themes were revised as I began writing up. For example, I noted at quite an early stage in the analysis that governance in advocacy was a significant (albeit contested) issue for a number of participants. I then identified that within the two organisations, governance could be sub-coded into the areas of user control, decision-making and representation, and leadership. However, some of these sub-codes – particularly the latter, were presenting me with a number of interpretive and ethical challenges. For instance, could I identify certain members as ‘leaders’, if they did not identify themselves as such? And what constituted a ‘leader’ anyway? A subsequent exploration of the literature on stewardship, as a possible antidote to the writings on leadership, proved to be valuable reading. This literature, which was discussed in Chapter 2, had a significant impact on how I re-read and re-interpreted some of the data.

By the end of the analysis stage, I had:

- Made an initial attempt to develop categories that illuminated my data
- Made an attempt to ‘saturate’ those categories with many appropriate cases in order to demonstrate their relevance
- Developed those categories into more general analytic frameworks with relevance outside the setting

(Taken from Silverman, 2000: 179).

4.3 Narrative analysis

I combined the thematic approach to coding data with some narrative analysis of the interview transcripts. The rationale for this was to pay close attention to *how* things were said in the interviews, as well as *what* was said. I focused upon how stories were constructed within the transcripts, and considered why the participant had developed the story in that particular way. Narrative analysis invites the researcher to consider the social context of the text, and to explore power dynamics that the narratives may expose (Ziebland, 2005). This was particularly important when I was analysing the transcripts in which self-advocates had been supported throughout the interview. Narrative analysis also encourages multiple readings and interpretations of the text, and cautioned me against ‘grabbing a quote and running’ (Dipex, 2005). For example, in one key passage, Barbara Poole told a powerful story in order to make an important point about the historic exclusion of people with learning difficulties in the planning of services in Buckinghamshire, and the tension that existed between parents and people like herself who were supporting service users to become more involved:

Barbara: Well, I sat with X in a meeting with Hillcrest – was it about 8 years ago now? – while the parents that were there accused me of briefing X to say that she wanted to be involved in this consultation, and it was obvious that she couldn't get involved, and none of them could get involved, and what could they say, and why was I pushing this, and I got abusive telephone calls at home and all sorts of things. And that was trying to get people with learning difficulties involved.

(PV1, p.3, Barbara's emphasis)

The story culminates in Barbara revealing how this tension became so palpable, that it penetrated beyond public meetings, into the private sphere. The unusually long sentence also creates a narrative drive and sense of urgency, which emphasises Barbara's point further.

Finally, a narrative analysis of interviews involves a consideration of the 'active' role played by different parties in the production of data, and therefore necessitates considerable reflexivity on the part of the researcher. This issue is explored in more depth in the final section of the chapter, below.

5. Managing challenges in the field: gatekeepers, anonymity and ethics

I embarked upon this research with the aim of furthering knowledge about the concept of advocacy for people with learning difficulties, and providing insight into how the concept is understood and enacted within organisational settings. Steven, a long-standing self-advocate at Talkback, suggested in a conversation we had about my research at Talkback's 2006 AGM that my 'distance' from the group meant that I had a useful overview of it:

You're in a good place to see what we're like, because you're outside the organisation. You can be more objective than us.

Throughout this chapter, I have indicated my position with regard to how 'objective' a researcher in the human sciences can be. Whilst I would like to claim that I remained an impartial observer throughout the study, my time spent collecting and analysing

the data highlighted how problematic such a claim would be. Like proponents of narrative analysis, I became increasingly aware of how my own values, biases, and relationships within the field influenced both the production of data, and my reading of it. Despite some initial reservations, I became increasingly interested in such processes and how I could explain their relevance in light of the broader research. As Bosk has argued, relationships are the major methodological tool in qualitative research, and 'how we manage these relationships determines the depth, validity and reliability of the data we collect and the inferences we draw from it' (1979: 202).

This section outlines some of those issues, and describes how I negotiated them at different stages of the research process.

5.1 Gatekeepers in small organisations

A number of scholars have highlighted the powerful role played by gatekeepers in gaining (and maintaining) access within the field (Bloch, 2004; Bosk, 1979; Whyte, 1993). Gatekeepers also have the capacity to deny or restrict access, depending on their view of the research, or the researcher (Walsh, 2004; Beynon, 1988). I became highly aware of gatekeepers in my research at a relatively early stage, although this became more pronounced as the study continued. At People's Voices, Barbara Poole was my point of entry into the field, and was the person responsible for communicating my ideas about the research to other organisational members. Similarly, access into Talkback was highly dependent upon Jean Rein, who, as I have explained, organised my initial meeting with the Management Group, and put forward a number of participants for interview. As I indicated in section 1, these individuals also played a key role in facilitating access to potential interviewees. Whereas my contact with

Barbara tailed off after the first few months, Jean remained a central figure in my association with Talkback. This may have been a result of Jean's role as 'steward' within the organisation, discussed in more depth in chapter 6.

The role of these two individuals in opening a number of doors within the research process was not lost on me. Like Whyte (1993) I also found that in the case of Talkback in particular, I did provide more information about the research to the gatekeeper, than to other members. I was in regular email contact with Jean Rein for two years, and we often spoke on the telephone as new issues emerged that she felt would be of interest to me, or if I required some clarification or illumination about an element of my data.

As Bosk (1979) has pointed out, the 'gift' that such gatekeepers may bestow upon researchers (for example, disclosing information that would otherwise be unavailable; providing access to people and other data that enriches the study; imparting a sense of shared understanding, and perhaps collaboration on the project) also presents two significant challenges. The first he calls 'the danger of over-rapport, so thoroughly merging with the subject's point of view that one cannot achieve the critical distance necessary for analysis' (1979: 204). Whilst much of the qualitative literature focuses on the need to develop a certain level of rapport with respondents, my experience also highlighted the difficulties that can arise when one becomes too close to participants. During the analysis stages I frequently had to reflect upon whether I was being 'captured' by the perspectives of Jean Rein or Barbara Poole. This was further complicated by the status afforded to them by other organisational members (see chapter 6). Mostly I managed to negotiate this issue on my own. On other occasions, I was grateful to my supervisors for pointing out instances in which I appeared to have elevated the perspectives of the gatekeepers above the voices of other members.

The second issue highlighted by Bosk was that of over-indebtedness, 'so thoroughly feeling a sense of diffuse obligation that one can no longer assess what one does and does not properly owe his subjects' (1979: 204). Whilst I was appreciative of some of the 'unofficial' information passed onto me by the gatekeepers, like Bosk, I also reflected on what the boundary was between privileged information and data that could be included in the research. On a number of occasions I learned informally about events and developments that had a significant impact upon my interpretation of the issues facing advocacy organisations. I felt that such knowledge was crucial for developing my arguments and producing a fair account of what I had seen and heard. However, some of this data was clearly sensitive - told to me in confidence on the assumption that I would not use it in my thesis. This clearly posed methodological and ethical dilemmas that were not easily resolved. In some instances I was able to find other ways of making broad points without including specific details (see the section on 'tendering' in chapter 7). On other occasions I felt that the material was simply too contentious, and could not be used without damaging either the organisation in some way, or the trust that I had worked hard to establish between myself and the participants.

Whilst the gatekeeper / researcher relationship in many ways provided the foundation upon which much of the research was based, I also came to realise the importance of disentangling myself (where possible) from these associations, in order to engage in a process of reflexivity with regard to how such connections might be influencing my interpretations.

5.2 Issues around anonymity and the passing of time in organisational research

Some of these dilemmas were arguably intensified by the identification of the organisations and the participants in my research (although as I have explained, interviewees were given the option of anonymity). Whilst some researchers have chosen to name participants and organisations where possible (Beynon, 1988), others argue that anonymity is the preferred option – a means of avoiding ethical challenges, and emphasising the generalised features of the findings (Bosk, 1979; Bulmer, 1988). As Scott and Darlington (2002:31) point out: ‘research has the capacity to harm the legitimate interests of the organisation and the professional and personal reputations of the individuals it employs’. As such, the issue of organisational anonymity was not taken lightly.

I chose to identify the organisations (with their permission) at the outset, as I felt this was appropriate for my research questions. My aim was to explore the impact of the local context (historical and geographical) upon the growth and development of advocacy and this necessitated a detailed explication of the political, economic and historical culture of the local area. My belief was that when writing the findings up, it would be both difficult and counter-productive to anonymise the organisations and their local area. Like Clement (2003), I imagined that this research could act as an historical document, a means of charting the experiences of two unique organisations that also shed light on wider issues about advocacy. As such, I felt that it was important to identify the groups in order to provide specific contextual details for future researchers. I was aware that my research was asking questions about organisations and not individuals, which I believed would raise less personal or sensitive information. Additionally, my initial reason for exploring Talkback and People’s Voices was linked

to my impression that they were working in ways that could be viewed as innovative. This being the case, my belief was that it would be useful to clarify exactly where (and in what context) these organisations were operating. This was discussed with the groups at the beginning of the research in the light of Clement's (2003) experience. Clement's decision to keep the issue of anonymity negotiable throughout the research process led to an unfortunate situation at the final stages in which he and the group had conflicting views with regard to whether the organisation should be identified.

The lack of anonymity did not present any major challenges to the research process, but it did raise some interesting issues. Primarily, it made me aware of how the passing of time in PhD research (two and a half years from my initial introduction to the groups, to the writing up stage) represents a significant period in the life of small (and growing) voluntary groups. Although People's Voices was a more established (and arguably more stable) group than Talkback, neither organisation was static during my time in the field. Talkback in particular expanded significantly – employing four new members for the staff team since I conducted interviews, and developing numerous new projects and 'About Me' groups (discussed in chapter 5). The group also secured a contract to develop self-advocacy in another county, and were extending their influence through a number of local and national partnerships. As a result, Talkback (and the chief executive in particular) became more concerned about what material would be discussed in the thesis, and who the readership might be. Knowing that the organisation would be identified, induced among some members what I perceived to be an increasing anxiety about how the group would be presented, and how this might impact upon the organisation's image and external relationships. This culminated in the withdrawal of one transcript, in which the respondent felt that they had been too revealing. This withdrawn manuscript is not included in the list of interviews in Table 1. Such an action

is understandable within a climate in which advocacy funding is highly precarious and dependent upon the upkeep of smooth relations between different stakeholders.

However, it also presented me with some interesting challenges in how to write about complex issues which I felt were important to the ongoing dialogue about advocacy's future. In order to avoid the difficulties that Clement (2003) faced in the final stages of his research (when the group unexpectedly requested organisational anonymity in his thesis), I endeavoured to discuss such issues with the members from Talkback and People's Voices in order to find ways in which sensitive subjects could be written up without harming the group or its members.

Conclusion to Part 2

Part 2 of this chapter has explicated precisely which methods I adopted in this research, and has told the story of the research process. It has raised a number of methodological and ethical dilemmas which arose throughout the course of the research, and has explained how I attempted to address such issues. Negotiating relations in the field, and recognising the impact that such relations can have on both the production and analysis of the data was a significant lesson learned throughout the research process. The collection and analysis of the data was not the straightforward, ordered process that I had anticipated – although over the course of the study I came to recognise how a number of important findings arose from some of the most challenging moments in the research. In this respect, I found Turner's comments particularly helpful:

...if they (social researchers) are to succeed in qualitative research, they will need to recognise that when social research takes place, there will be an

overlapping and a partial fusing of the horizons of knowledge of at least three parties: the observer, the observed, and the audience (1988: 114).

In the following four chapters, I explore the findings from the research.

Chapter 4: Factors influencing the development of advocacy at the local level

Introduction

This chapter sets out why advocacy developed in Buckinghamshire in the way that it did. It charts the origins and early histories of People's Voices and Talkback, and the geographical and socio-political factors which influenced their development. Human geographers in recent years have highlighted 'the strategic importance of space, place and politics for understanding the development and implications of voluntary activity' (Fyfe and Milligan, 2003: 398). Drawing upon this research, I decided to explore the specific local circumstances in which People's Voices and Talkback have emerged, in order to analyse whether this background can help provide a richer understanding of the current practice of both groups, and to shed light upon wider issues about advocacy organisations for people with learning difficulties.

This chapter will address the first research question:

What factors influence the development of advocacy in a local context?

The findings in this chapter address a number of important issues which are analysed further in the following three chapters. For example, the early histories of the two groups and their geographical location, raise critical questions about the relationships that one-to-one and self-advocacy organisations have developed – both with each other, but also with statutory organisations, carers and service users. Another important theme that emerged through the exploration of these organisations' early histories is the role

played by non-disabled supporters in facilitating the establishment and expansion of advocacy groups. The findings in this chapter also reveal differing perceptions of what advocacy *is*, or *ought* to be – a theme that is developed in chapter 5.

Many of these issues are inter-related. For example, the chapter highlights early tensions between the vision held by non-disabled supporters for the future of self-advocacy, in contrast to the views held by service users. It also illustrates the early attempts made by Talkback to address the challenge of facilitating both individuals and the collective group to practise self-advocacy - particularly in the light of people's varying support needs, differing levels of intellectual and physical impairment, and previous life experiences. Some of these issues were highlighted in the literature review (chapter 2), and so build upon and develop existing knowledge. Others however, illustrate new lines of enquiry. For example, the findings in this chapter also demonstrate that the two organisations experienced various stages in their early histories, shaped by particular individuals, organisational priorities, and external pressures. The current literature on organisational stages within small voluntary groups is modest, and thus these findings represent an emerging theme in the study of advocacy. The notion of organisational stages in advocacy is explored more fully in chapter 6 – specifically with regard to governance issues – in the light of Bylov's (2006) model of 'generational movements'.

The data presented here also reveals the important – albeit complex role – played by advocacy organisations in the wider story of service development for people with learning difficulties in Buckinghamshire in recent years. I argue in this chapter that over the past two decades, Buckinghamshire has been quick to respond in some areas of welfare development (such as the privatisation of services), and relatively slow in others

(such as incorporating the voices of users and carers into service provision). This appears to reflect the political and economic agenda of the council and many of its constituents. This has certainly been borne out in learning disability services, and has shaped broader attitudes towards service users and their families. The emergence of advocacy – particularly self-advocacy - occurs alongside the eruption of unanticipated events in Buckinghamshire, most notably the uncovering of a private care home scandal in 1994 (the Longcare Inquiry) and the agitated response of carers (and subsequently users) to the proposed introduction of eligibility criteria in the mid-1990s. Whilst some of the data from Buckinghamshire County Council officials demonstrates a somewhat ahistorical explanation of the current trend within learning disability services to include the user voice in service design and delivery (for example, highlighting recent governance reforms and the role of current managers as the major causes of change), the broader picture emerging from the data indicates that this process has been more complex. I suggest that the emergence of the user voice – most notably through the mechanism of advocacy - was the result of an historical interaction of policy (national and local), practice (both positive and negative), and grassroots action throughout the past two decades.

This chapter is organised under the following headings:

1. Buckinghamshire's learning disability services: 'evolution not revolution'
2. The origins and early history of People's Voices
3. The origins and early history of Talkback

1. Buckinghamshire's learning disability services: 'evolution not revolution'

I entitled this section 'evolution not revolution' after noticing its appearance in two pieces of data – twenty years apart. The first can be found in a longer statement describing the first wave of community care in Buckinghamshire made in 1986, by Dr Julian Candy, chairman of the division of psychiatry at St John's Hospital, in Stone (Buckinghamshire County Council, 1986: 7). The second time this quote appeared was in an interview that I conducted with Peter Loose, Head of Adult Disability Services and Mental Health in Buckinghamshire, in 2005 (BCC2, p.2). He used these words to describe the modernisation of day services in Buckinghamshire from the late 1990s onwards. The quote seems to be an eloquent depiction of service development in Buckinghamshire over the past twenty years, reflecting the broader picture of political conservatism and a local council which has shown a continued reluctance to pay for more innovative services.

Nevertheless, ruptures throughout the 1990s – in particular the Longcare Inquiry and the direct action of carers over cuts to services – created opportunities and pressures for change. As Peter Loose commented:

There are a couple of significant chapters in our history that have really shaped the future.

(BCC2, p.3)

Moreover, changing directives from national government have forced Buckinghamshire County Council to reassess the priority it affords social services – including those for

people with learning difficulties. It is under these circumstances that advocacy has developed in Buckinghamshire. The emergence of self-advocacy (see below, section 3) has also coincided with the wider changes in Buckinghamshire Council's governance structures. These political changes were brought about to increase transparency in the running of local government, and to generate new ways for local constituents and service users to contribute to the planning of service provision. Chapter 7 will consider how the development of self-advocacy has interacted with these broader political aims.

As the remainder of this chapter demonstrates, advocacy organisations were an integral element of this unfolding story. This first section will consider the specific development of community care in Buckinghamshire from the 1980s onwards, and will focus on the events that have impacted upon services for people with learning difficulties over the past twenty years. It will consider how various social, political and economic factors have come together in Buckinghamshire to create the context in which advocacy has grown and developed.

1.1 Buckinghamshire

Buckinghamshire has a population of approximately 475,000, with a mixed urban and rural composition. Within its boundaries lie the four district councils of Wycombe, Aylesbury Vale, Chiltern and South Buckinghamshire. The county council has been in existence for 120 years, and has been Conservative controlled throughout its entire history. This places Buckinghamshire amongst a small number of local authorities who retained a Conservative-led council throughout the 1990s, in a period renowned for the marginalisation of local Conservatism (Game and Leach, 1996; Atkinson and Wilks-Heeg, 2000).

In 1997, Milton Keynes (formerly covered by the county council) became a unitary authority in its own right as part of Local Government Reorganisation, and as a result the council reduced in size by about one third. This also involved the transfer of approximately 30% of Buckinghamshire Council's services to Milton Keynes Council, leading to the loss of many experienced staff and managers. The downsizing of some services meant they were no longer sustainable due to lack of economies of scale. In conjunction with a host of other difficulties, including the publication of the Longcare Report in 1998 and the hostility emerging from the proposed introduction of eligibility criteria for people with learning difficulties (see below), the decade between 1990 and 2000 has been described by council officers in social services as 'turbulent' (Buckinghamshire County Council, 2001a). The early 1990s also witnessed the transfer of large sections of learning disability residential services in Buckinghamshire to the Fremantle Trust, evidence of the council's swiftness in developing a mixed economy of care (Atkinson, 1994).

Political context – 'modernisation' in Buckinghamshire

The old management style of the (social services) department had been experienced by many as secretive, paternalistic and defensive. This began to change significantly in 1998 and has continued.

(Buckinghamshire County Council, Joint Review Position Statement, 2001a: 6)

Buckinghamshire Council has undergone a significant internal re-organisation over the last few years in response to the Local Government Act, 2000. The new system of governance has entailed a move away from strong departmentalism, to a more corporate

emphasis on leadership and strategic management – the ‘Leader and Cabinet’ model. This change in political and management structure brought an end to the traditional social services department in Buckinghamshire. Instead, it has been divided into two ‘portfolios’ – one for Children and Young People, and another for Adult Social Care. The advocacy schemes researched for this thesis fall under the funding remit of the latter.

Adult Social Care has experienced a number of organisational changes in recent years. This includes the establishment in 2002 of a new integrated body to oversee learning disability services. The Integrated Learning Disability Services require joint working between health and social care – with the latter taking overarching responsibility. Each of the Buckinghamshire County Council managers who I interviewed for this thesis emphasised the significant challenges involved in negotiating this new way of working.

The aim of this massive internal re-organisation has been to create ‘a management style and culture for social services which sets out to be open, honest, listening and non-defensive’ (Buckinghamshire County Council, 2001a). In the quote below, Jenny Harris (Valuing People Strategy Manager) identifies these governance reforms as an important stimulus for change in learning disability services, as the new Cabinet style ensures that the decisions made by councillors are more likely to be contested and held to account by a wider group of local politicians:

I think one of the things we (in learning disability services) have benefited from – and it’s a double-edged sword - is the involvement of cabinet members, or our elected members. We’ve had the change from the social services committee to the cabinet arrangements, and it’s quite significantly changed the way that has operated, from the

members being a cohesive band of people supporting one another in the development of social care, to the cabinet style, where the opposition members have much more of a critical approach to it now.

(BCC1, p. 4-5)

As this chapter demonstrates, governance reforms are only one factor in the wider story of service development for people with learning difficulties in Buckinghamshire.

However, it is within this changing political climate that advocacy – in particular self-advocacy – has expanded and raised its profile. Chapter 7 will consider the extent to which this wider context has provided advocacy with a space to engage in political action, and assert the user voice in the planning and evaluation of services for people with learning difficulties, as championed by writers such as Ken Simons (1998, 1999).

Economic context

Buckinghamshire is an economically prosperous county, with very low levels of unemployment. However, it has been acknowledged that this relative prosperity tends to mask pockets of deprivation and acute need (SSI/Audit Commission, 2002).

Nevertheless, the local council's spending levels have been partially driven by political concerns – particularly a desire to maintain modest local taxation levels

(Buckinghamshire County Council, 2001a).

Education has traditionally been a high political priority in Buckinghamshire, possibly to the detriment of social services (Buckinghamshire County Council, 2001a).

Throughout the 1990s, social services struggled to implement the NHS and Community Care Act (1990) against a backdrop of limited financial resources. Budget guidelines

from the council represented a consistent challenge for the department as resources could not keep up with the increased demands on services, and led to conflicts between carers and users of services, and the department. However, it has been claimed that the change in political structure in recent years has fostered a more effective relationship between council members and social care managers, with the former having a greater involvement in social services – including lobbying for more resources (Buckinghamshire County Council, 2001a). This has apparently led to a long-awaited increase in spending for social services, although funding pressures remain an important issue in the commissioning and delivery of services (BCC2).

1.2 Developments in community care for people with learning difficulties in Buckinghamshire

Buckinghamshire provided its first learning disability-specific services in 1926, with the purchasing of Manor House in Aylesbury. Institutional care for people with learning difficulties grew with the building of Borocourt in Berkshire in 1933, which had an agreement to house a number of residents from Buckinghamshire. Manor House itself was developed in order to admit greater numbers of children and adults – many of whom spent their whole lives there, despite its supposed ‘temporary’ purpose (Oxford Health, PR, 2002). Manor House’s most significant expansion occurred in the 1970s, as large numbers of people were transferred from generic hospital care in Aylesbury and Winslow, to services designed specifically for people with learning difficulties. This was comparatively late as deinstitutionalisation was anticipated to advance in the 1970s following the publication of the 1971 white paper, *Better Services for the Mentally Handicapped* (Welshman and Walmsley, 2006).

The process of deinstitutionalisation by Buckinghamshire County Council began in the mid-1980s, with the closing of St John's 'mental' hospital in Stone (Buckinghamshire County Council, 1986; Crammer, 1990). Community care for people with learning difficulties followed on from the closing of St John's, albeit slowly. The rundown of Tindal, Winslow and Borocourt hospitals in the 1970s and 1980s meant that Manor House hospital was admitting record numbers of people with learning difficulties who were perceived to be in greatest need. Although 72 residents were transferred to community-based accommodation between 1985 and 1992, nobody was moved out in the following seven years. The final push to transfer the remaining 96 residents came in the late 1990s, with the last resident moving out in 2002 (Oxford Health PR, 2002). Respondents from social services suggested that this transfer created a number of financial and operational difficulties, as the windfall afforded to the health economy when people died in institutional care throughout the late 1990s was not re-invested into the provision of future social care services. Peter Loose also argued that the hurried transfer of the remaining Manor House residents occurred without due consideration of the level of support these individuals would need in the community. He said:

I think we were blighted at that stage by some idealism.

(BCC2, p.4)

Aylesbury Vale Advocates (AVA) were invited to offer advocacy to people leaving Manor House, when it became apparent that they had not been adequately prepared for life in the community. AVA have continued to provide support to a number of these individuals (BCC3).

Developing a mixed economy of care

Alongside the closure of the large learning disability and mental health hospitals, Buckinghamshire also transferred its residential homes to independent providers (Buckinghamshire County Council, 2001a). Between 1992 and 1993, eighteen homes for people with learning difficulties, housing up to 200 residents in total, were assigned to the Fremantle Trust (The Fremantle Trust, no date). It is interesting to note that the transfer of these homes opened up a significant space in which one-to-one advocacy and self-advocacy could develop and reach people with learning difficulties. Following on from the recommendations made by Atkinson et al (1993), advocacy by People's Voices and Talkback became an important and ongoing aspect of life in the Fremantle homes:

Elizabeth: The advocacy side of that was quite important, wasn't it? Because people needed advocates during the transfers and things ...And they've been very scarred. They're so institutionalised that the advocates can't really always help them - very difficult to get through to some of them... We've just opened our first supported living unit in Aylesbury – with Fremantle – and of course the advocacy service has been very involved in that, because it's a new world for them all, and they have a lot of issues and concerns.

(PV2, p.8)

2002 marked the end of formal institutionalised care for people with learning difficulties in Buckinghamshire – comparatively late in relation to other counties (Oxford Health PR, 2002).

1.3 Ruptures

Despite a history of political stability and conservative service development for people with learning difficulties throughout the twentieth century, the events of the 1990s forced some significant changes upon the social services department in Buckinghamshire. These events are described below.

The Longcare Inquiry and calls for advocacy

Peter Loose: About 12 years ago the Longcare scandal took place, at Stoke Place, and it's ours. Essentially a man called Gordon Rowe abused a significant number of clients – physically, sexually and financially – and he escaped detection for far too long, largely because we didn't have a robust enough inspection team. And that was big news, which blighted our services for a decade.

(BCC2, p.3)

In 1994, an internal report of Buckinghamshire County Council's Social Services Inspection Unit was leaked to the *Independent* newspaper (Waterhouse, 16/09/1994). This report outlined the initial findings of the inspection unit into allegations of abuse at the private care homes in Stoke Poges, Buckinghamshire, run by Longcare Ltd. However, despite uncovering numerous incidences of physical, sexual and emotional abuse at the homes, the council delayed their closure, arguing that it did not have the legal powers to make such a decision (Buckinghamshire County Council, 1994). As public interest in the case grew, central government applied pressure on Buckinghamshire to act. The police authorities soon became involved, and Gordon

Rowe (one of the home owners) committed suicide the day before he was due to be charged with raping one of the residents (BBC News, 23/06/98).

In 1997, an inquiry into the events at Longcare was commissioned by the Department of Health. The publication of Tom Burgner's report in 1998 highlighted the deficiencies within Buckinghamshire social services that had enabled the system of abuse at Longcare to go undetected for so long. Despite the mounting evidence, Burgner argued, council inspection teams did not act to withdraw the homes' registration. This was in spite of police investigations into previous allegations of abuse made against Rowe, and numerous concerns raised by the families of Longcare residents. This is substantiated by Anita English who remembers that:

The relatives had tried to point out that they thought something was wrong to the social services. But a lot of it was ignored.

(PV2, p.7)

A number of people that I interviewed highlighted the tragic importance of Longcare in Buckinghamshire's recent history. On more than one occasion it was described as a 'scandal' and a 'disaster', from which the county is only starting to recover. Longcare also led to the county's social services being specially monitored by central government, in order to help it develop effective inspection and enforcement teams (DoH, 2000b). However, as with previous scandals in learning disability services (Donges, 1982), the result of Longcare provoked a change in the broader service culture and attitudes towards service users and their families:

Jenny: Undeniably that has had huge impacts on Buckinghamshire. First of all for them getting through the trauma of being this awful county where this happened, to actually – I hate to say the benefits of it, because that feels really crass – but it's about what we've learnt from it, and what actual difference that has made to services for people with learning disabilities in Buckinghamshire, because it raised the profile of the needs of people with a learning disability. And the County Council did something about it.

(BCC1, p. 5-6)

The social services directorate changed soon after the publication of the Longcare Inquiry, and new leaders were employed, in order to initiate the processes that would help to avoid a recurrence of the catalogue of errors which characterised the Longcare case. Barbara Poole argued that paying greater attention to the voices of service users was a significant part of this new approach:

Well that (Longcare) was a major driver for change in Buckinghamshire...So there was a move afoot to recognise that something like that shouldn't happen. And one of the reasons it had happened was because there was no way for people to hear the voices of people with learning difficulties. So the Longcare report itself does talk a lot about those areas, about access to people with learning difficulties.

(PV1, p.3)

Increasing access to the voices of people with learning difficulties came in different forms, such as trying to include more users in consultation groups (see below, section 3). However advocacy was also highlighted as a key element of this new strategy, and People's Voices became involved in providing one-to-one advocacy to some of the former residents of Longcare (PV2, p.7-8).

Cuts to services and the direct action of carers

Between 1993 and 1996, Buckinghamshire's social services began implementing the NHS and Community Care Act, 1990. Buckinghamshire Council documentation states that 'this was a major step for the department, but was against the background of limited financial resources' (Buckinghamshire County Council, 2001a: 40). Like a number of other councils, Buckinghamshire decided to tackle this issue by introducing eligibility criteria for service users, and cutting the day services available to people with learning difficulties (Means et al, 2003). This provoked an unanticipated local response, particularly among the carers of people with learning difficulties. Peter Loose explains his understanding of those difficult months between 1995 and 1996:

We decided to take large chunks of money out of our day services. I wasn't here, but as I understand it we decided to take something like half of our day services money out, and that was front page news of the local newspapers for quite some while. The clients of some of the day services camped out on the steps of county hall, it was an evening news item fairly regularly, and it's the first time that the carers in Bucks really got their act together. And it was very much in a 'the local authority has to stop closing our services down' mode.

(BCC2, p.3)

The campaigning of carers in the mid-1990s was an atypical response for an interest group in Buckinghamshire, and as such attracted media attention, and considerably raised the profile of learning disability. As Barbara Poole explained, the carers' protests also led to direct results – notably, the decision to drop the eligibility criteria for people with learning difficulties:

And part of it was not so much at that stage because of the voice of people with learning difficulties, but because the parents were so bloody-minded.

(PV1, p.4)

As Jenny Harris recalls, this period was characterised by ‘daggers drawn’ (BCC1, p.2). Peter Loose has described it as a ‘battle’ (BCC2, p.3). This was the emergence of grass-roots action within Buckinghamshire social services – what I have described elsewhere as the rise of the ‘insider’ voice (service users and their families) (Tilley, 2006).

Initially, people with learning difficulties were excluded from this process – particularly in the formal participatory structures that were developed in response to the campaign (see section 3 below). However, the lobbying of parents undoubtedly created an opportunity through which service users also became increasingly involved in the development of services in Buckinghamshire, prior to the requirements of *Valuing People*. Jean Rein explained how the campaigns around cuts to services and eligibility criteria in the mid-1990s necessitated the development of some form of self-advocacy, as it became increasingly apparent to service providers and other concerned allies that people with learning difficulties were being marginalised in discussions:

It was a very scary time for people with a learning disability, with threats of services being closed. And the whole idea of the user voice was growing, so service providers would then say ‘so if you don’t want services to close down, what do you want to do?’ And it was really hard for people to say what they wanted to do - some had no idea what the choices were. So of course, that’s when the whole thing about the building of the self-advocacy voice to feed into service providers began.

(TB1a, p.4)

This passage also helps to explain Talkback's current focus on skills-building, and 'learning how to look'. As can be seen in Chapter 5, teaching service users how to assess their different options through the development of information gathering and questioning is a key element of the practice of self-advocacy at Talkback. This can be traced back directly to the earliest activities in the organisation's history.

Beyond the development of self-advocacy, the campaigns in the mid-1990s created long-lasting tensions between carers and the local authority, which have only begun to subside recently. Peter Loose explained how trying to resolve these tensions through open dialogue has been one of his most challenging tasks since taking on the role of Head of Adult Disability Services in 2004:

And certainly I've had to talk quite hard with carers on the Partnership Board about, 'this is actually a partnership, and we're here to jointly champion people with a learning disability'. And whilst a part of my job is to secure as much resources as possible, the other part of my job is to make sure that whatever resources we either provide ourselves, or take from elsewhere, achieves the maximum impact for the client group. And in that respect, we're on the same side.

(BCC2, p.3)

These tensions have also impacted upon advocacy over the past ten years. This is explored in section 3 of this chapter, and will be developed further in chapter 7.

1.4 Buckinghamshire social services: national directives and the impetus for change

Naming and shaming Buckinghamshire

As was discussed above, the Longcare Inquiry led to Buckinghamshire's social services being placed on special monitoring measures, along with a small number of other local authorities. Although Buckinghamshire was removed from this list in 2000 (DoH, 2000b), Cabinet Member Minutes reveal that Alan Milburn (then Secretary of State for Health) named Buckinghamshire as one of the fourteen worst performing social services authorities at the Annual Social Services Conference in October, 2001 (Buckinghamshire County Council, 2001b, Cabinet Minutes, 22/11/01: G4). Milburn reached his conclusion on the basis of three years of low-scoring performance indicators in Buckinghamshire, although the Cabinet Member for Adult Social Care attributed this to Buckinghamshire's inadequate level of central government funding, combined with high unit costs (Buckinghamshire County Council, 2001b, Cabinet Minutes, 22/11/01: G6). Alongside this came the Joint Review of Buckinghamshire's social services, published in 2002. Whilst this review acknowledged the impact of Buckinghamshire's turbulent history on service development throughout the 1990s, it highlighted a number of deficiencies that continued to exist at the turn of the twenty-first century.

However, Peter Loose argues that these national critiques have begun to initiate a change in approach to how social services operate in Buckinghamshire:

I think it was a little bit of a wake-up call. Social services had tended to be seen in the county as a bit of a blight that absorbed large sums of money, without really benefiting a large proportion of the population. So that had to be rethought.

(BCC2, p.3-4)

Whilst these national directives for change in Buckinghamshire have led to some positive outcomes, it has also caused friction, low morale among staff, and a general sense of instability with social services. However, there is a sense that this is beginning to change with the present ongoing tenure of Peter Loose, and the consistency of learning disability managers such as Jenny Harris and Stuart Mitchelmore. As Jenny explains:

We've had a lot of change in senior management in Adult Social Care, and I think we can't deny the impact that has had...People do come in and get scapegoated – but also everybody comes in with new ideas, not a lot of understanding about where we've started from, and because we've had such a massive change at the top, we've got nobody with any history...I mean we had five heads of services in two years...And we have got a level of stability now, which is starting to feel comfortable.

(BCC1, p. 10)

This quote exemplifies the point raised about 'presentist' data in the introduction to this chapter. Jenny Harris acknowledged the lack of collective memory among current Bucks officials – arising from a high turnover of staff in recent years. An analysis of the changes in learning disability services in Buckinghamshire, and the factors which influenced the development of advocacy in the area, is deepened by the more

historically conscious accounts provided by members of the advocacy organisations in sections 2 and 3.

National policies and local priorities: managing implementation

Another pressure facing Buckinghamshire social services as it has struggled to come to terms with a turbulent decade has been the necessity to manage competing local and national agendas. Whilst the broader restructuring of the Council and the social services department was taking place, a learning disability strategy was being developed in Buckinghamshire which would see the development of an integrated learning disability service, led by the local authority. As Stuart Mitchelmore indicates below, this created a number of difficulties for staff working in learning disability services, some of whom found it difficult to adapt to the new joint-working arrangements between health and social care:

I think initially when we started there was 'us and them' in terms of health and social care, and we've worked hard at breaking down those barriers. And now the next stage really is moving on... it's almost like moving from rhetoric into reality. We've set the basis, people know what the issues are, so it's a case of addressing them now, rather than just talking about them.

(BCC1, p.2)

The number of times that the new joint working arrangements of the learning disability service were raised in interviews with representatives from Buckinghamshire County Council, demonstrated the extent to which it has occupied the department's attention in the past three years. Nevertheless, alongside this huge internal re-organisation, the

learning disability team have also been responding to the government's white paper, *Valuing People* (DoH, 2001). The instructions directed at local government from this policy document included the setting up of learning disability partnership boards – designed to oversee the implementation of the white paper's recommendations and direct local strategy, whilst simultaneously providing a mandatory mechanism through which service users and carers could be consulted and involved in decision-making processes. The Buckinghamshire Learning Disability Partnership Board was not formally constituted until January 2003, which Cs wider research findings that discovered how some authorities had struggled to implement elements of *Valuing People* within the recommended time-frame (Fyson and Simons, 2003).

Impact for people with learning difficulties

It is apparent how these competing local and national agendas have affected staff within Buckinghamshire's learning disability teams – but how have they impacted upon service users? One clear example is the move (across the whole council) towards more accessible information. Jenny Harris explained how this has helped to increase the levels of service user participation in local government processes, whilst symbolising a broader sea-change in the way that the local council presents itself to an ever-widening group of 'recognised' constituents (including people with learning difficulties):

I mean just simple things like the county council changing the font style of its general information. The fact that we're using symbols and pictures... There is a much more open attitude.

(BCC1, p.5)

This changing attitude within Buckinghamshire council has also led councillors to make greater efforts to include people with learning difficulties in decisions that affect their lives. For example, members of the overview and scrutiny committee began consulting with service users at venues that suited people with learning difficulties, and producing accessible versions of their reports (BB1, p.5).

Whilst it is difficult to assess *exactly* why this change of approach has occurred, it seems to have arisen from a combination of factors that include the broader political changes at council level (emerging from the wider modernisation of local government), as well as national policy directives specific to learning disability. I would argue that it has also come about as a result of the motivation of staff in social services, keen to eradicate and work through the failures of the past ten years.

The changes have not gone unnoticed by those working 'on the ground'. Simon Evans, a project worker at Talkback, acknowledged that a culture shift has taken place in recent years, although he suggests that the process remains an on-going one:

Yes, there are changes, yes there are advantages. The biggest change I think that's been noticeable, is there's a much more transparent management system. The senior managers, those people who work in the ivory towers in the council offices in Aylesbury, were to everybody, unknown. And now they are visible. When you say 'Stuart Mitchelmore', people know who you mean – members of staff, and people with a learning disability feel they are able to contact these people with their concerns, they are able to raise them... There's certainly better communication, but not perfect.

(TB5, p.2)

Peter Loose also suggested that despite tackling a number of difficult issues in recent years, progress in learning disability services in Buckinghamshire had been made. He conceded that stakeholder relations had been strained in recent years – and this had been exacerbated by struggles in social services to obtain the funding needed to provide the necessary resources for its client group. He commented:

So our legacy from history has a fair bit of conflict in it, not a lot of money, and as a consequence of the conflict, the people who should be our partners, have been our opponents. When I arrived in February last year, we were at war with health over the small staffed homes, the carers saw us as the targets that they had to do battle with, and there were a lot of tensions between service users and carers, in terms of service users wanting to have their say, and carers not quite understanding why they should have their say.

(BCC2, p.4)

However, Peter Loose insisted that despite these pressures ‘the impact on service users is quite good’ (BCC2, p.2). Chapter 7 will critically examine Peter Loose’s supposition in more depth, by considering how these recent changes have impacted on service users through the interface between services and advocacy.

This section has set the scene for the two advocacy organisations, presenting important contextual information about the local context which helps to situate their growth. It has also communicated the perspectives of Buckinghamshire officials on particular events and policies. The following two sections explore the specific experiences of the two advocacy organisations within these developments.

2. The origins and early history of People's Voices

The purpose of this origins section is to explore the reasons why People's Voices was founded, whilst considering exactly when and how this happened. An analysis of the origins of People's Voices contributes to the small but growing literature on the history of advocacy, and raises a number of interesting issues which will inform other themes that arise throughout the data chapters. First, it seems that the concept of advocacy for people with learning difficulties in Buckinghamshire was fostered in a climate of constructive voluntary-statutory relations. These relationships were achieved through mechanisms such as the joint consultative committee and the joint advisory boards, at which prominent voluntary sector representatives such as Anita English (Chair of People's Voices at the time of writing) were present. The committees enabled a dialogue to develop between members of different sectors which facilitated the founding of the original steering group.

Second, this section demonstrates that contrary to typical citizen advocacy principles, People's Voices emerged from the commitment of individuals from both the statutory and voluntary sectors. These people worked in close alliance to improve the quality of life for people with learning difficulties, although it is clear that service users themselves were not involved in the early stages of the organisation's growth.

The history also illustrates that the organisation experienced a number of 'stages'. These stages were characterised primarily by the individuals who assumed leadership roles throughout them (Sheila Fairbrother, David McCluney and Barbara Poole).

Finally, this section indicates that the origins of People's Voices lie in the citizen advocacy phenomenon, although from the earliest stages the group was focusing upon

fostering instrumental (case-work / situation-based) advocacy, rather than expressive (socially involved) partnerships more typical of the citizen advocacy model.

The research also reveals which people were integral in bringing advocacy to South Buckinghamshire, and what motivated them to do so. Sheila Fairbrother - the initial driving force behind the original steering group – died before I conducted my interviews, and so in trying to unravel why she first had the idea to set up an advocacy project, I am reliant upon the words of others who worked alongside her in those early years. This includes Anita English, who has been involved in the organisation from a very early stage, and David McCluney, who acted as Managing Director of the organisation from the early 1990s until his resignation in 2000.

2.1 Stage one: innovation

The beginning of community care in Buckinghamshire:

partnership working between the voluntary and statutory sectors

Anita: The push (for advocacy) was people coming out into the community.

Elizabeth: Yes, the closing of these big mental wards. The institutions.

(PV2, p.9)

The interviews that I conducted revealed that the first signs of advocacy in Buckinghamshire coincided with the policy of deinstitutionalisation in the county. This mirrored the contexts of earlier advocacy projects in the US (Wolfensberger, 1973), and later UK-based schemes, such as The Sheffield Advocacy Project (Flynn and Ward,

1991). As was seen in section 1, in the mid to late 1980s an increasing amount of community-based service provision was being made available for a variety of service users in Buckinghamshire, including those with learning difficulties and mental health problems (Buckinghamshire County Council, July 1986).

According to respondents, the voluntary sector in Buckinghamshire worked alongside the statutory sector in order to identify what services would be needed for people leaving local institutions. Through formal mechanisms such as the joint consultative committee (JCC) and the joint advisory groups (JAGs) a number of key local stakeholders decided how joint funding – from health and social services - would be spent in order to support people moving into the community. As Anita English explains below, a lot of the monies made available in the 1980s in Buckinghamshire were used to fund a variety of voluntary-led projects:

There were lots of projects being set up to support what was happening in the voluntary sector. The advocacy part of it happened round about this sort of time, around '86.

(PV2, p.1)

As the voluntary representative on the JCC at this time, Anita English had a good vantage point from which to observe the developing community care agenda in Buckinghamshire during the 1980s. She was the conduit between statutory officials and a number of voluntary organisations throughout the county, and built up an extensive network of key players involved in the changing health and social care climate of the period. She noted that whilst documentary evidence may not highlight the full extent of the voluntary sector's involvement in the development of community-based services in the 1980s, her experience was one of significant partnership working between different

agencies and stakeholders, which led to a number of new, innovative projects. This illustrates the findings of a number of researchers who explored the 'opening up' of local government in the 1970s and 1980s, and the growing diversity of voluntary organisations resulting from the increased interaction between the two sectors (Kendall and Knapp, 1996; Stoker, 1991; Unell, 1989; Wistow et al, 1994). The enthusiasm of individuals wanting to develop new community-based services was reinforced by joint funding, which earmarked monies for exactly this sort of work, and provided the context in which an advocacy project could be established. Anita explained:

...we all talked together, we worked very much together then, the voluntary sector and the statutory sector, setting up new things. They would have ideas, we would have ideas. And a lot of it was through this joint funding, because it enabled you to actually set up projects that people had identified. Innovative projects. And that was a source of money that was set aside: it couldn't be used for anything else.

(PV2, p.2)

Public sector professionals and the push for advocacy

A guiding principle of much of the early citizen advocacy literature stresses the importance of project independence from state structures and personnel (Wolfensberger, 1983a; Butler et al, 1988). However, the respondents revealed that whilst people from a range of agencies formed the original People's Voices steering group, the initial driving force came from an individual based within the statutory sector. Sheila Fairbrother was a Director of Nursing who had worked in hospital-based services for people with learning difficulties for a number of years. Sheila was concerned that the implementation of community care policies in Buckinghamshire could lead to the

marginalisation of individuals leaving institutions, if adequate support was not in place to help smooth their transition to community living. It seems that such a view was not unusual at this time:

Anita: A lot of people in statutory authorities had spent all their working life caring for very vulnerable people, in places like St John's and Manor House. And although we know now that it wasn't the ideal way – people were in locked wards and all sorts of things - these people were the only people that some of them knew that cared for them. And they were very devoted. And a lot of them were concerned that when they came out into the community, who was going to fight for them? Who was going to make sure that they were looked after? And it (advocacy) did come a lot from some of the 'care' professional people.

(PV2, p.2)

This was further demonstrated by David McCluney who recalled that the original steering group:

...were all leading members of voluntary and statutory organisations, who felt there was a need – who perceived a need... They were all professionals.

(PV3, p. 11)

It was not possible to find out how Sheila Fairborthor came to hear about advocacy, and whether she was committed to developing a service along a particular set of theoretical or philosophical lines. However, she clearly perceived a link between the need for a new type of service that would advocate for the needs of those people leaving institutions and moving into the community. There is some confusion today as to whether the

original steering group formed by Sheila Fairbrother initially envisioned the project having a learning disability focus, or whether it was intended to be a generic scheme for all service users. It was suggested that Sheila had begun to develop a vision for an advocacy project in Buckinghamshire, although it was difficult for interviewees to provide specific details:

David: Sheila had got the advocacy bug and knew what she wanted to do.

(PV3, p.1)

Interviewees had difficulty recalling the exact chronology for this early period, but it seems that for at least three years (c.1987-90) no action was taken to implement any kind of advocacy activity, with the steering group engaged in continuous discussions about where the project was heading. Throughout this period the steering group expanded and encompassed individuals from a range of backgrounds (social work, hospital staff, the Citizens Advice Bureau, the Bucks Association for Mental Health, the Red Cross) who were keen to develop advocacy as a service separate from those they already provided – but who may not have had the time to engage with the development of an advocacy-specific agenda. As David McCluney pointed out, there were issues around this broad-based group lacking a shared understanding of the nature of advocacy and how such a project could be implemented:

The discussion when I joined the meeting was ‘Could lady someone-or-other be asked to be president?’ And I thought ‘well this is super they are obviously well advanced’ so I kept quiet ‘til any other business. Then foolishly, I responded to Sheila saying ‘Have you got any questions David?’ And I said ‘Yes. What is advocacy?’ And the meeting was clueless – utterly clueless – they could not explain to me what advocacy was. They

all had their own concept, but there was no common understanding of the subject, no definition of what advocacy was.

(PV3, p.2)

A range of publications on advocacy had been published by the late 1980s (Butler et al, 1988; O'Brien, 1982, 1987; Sang and O'Brien, 1984) and so it is unsurprising that those working in social services and the voluntary sector in Buckinghamshire had learned about developments in this relatively young field. However, David McCluney's statement above indicates that whilst the ideas of advocacy may have been circulating during the 1980s across different sectors, there continued to be a lack of understanding about the essential nature of advocacy, what it was for, and how it might be implemented within a specific local context – an issue that Henderson and Pochin (2001) highlight as symptomatic of the problems that continue to face advocacy organisations today.

2.2 Stage two: formalisation - setting up and bedding down the organisation

New members, new principles?

Whilst the earliest stages of a small voluntary initiative may be defined by a common grievance, or a broad vision for change, the implementation of such ideas in practice involves a certain level of bureaucratisation that may involve bringing in stakeholders who have less attachment to the original cause (Wallcraft, 1994). As such, David McCluney was first invited to the Buckinghamshire advocacy steering group meeting in 1990. Anita's networks with the local voluntary sector meant that she was able to access David through the Council for Voluntary Services (CVS) in Chesham, a local

committee which they both sat upon. David had worked on one of the CVS's subgroups that focused specifically on the practicalities of getting new voluntary groups off the ground, which included issues such as start-up funding. Anita felt at this point that the advocacy steering group was flailing somewhat, and needed input from an individual who could introduce a new perspective, and create some momentum for action. She explained:

And this was of course the main thing: that you had to have some sort of funding to help. A voluntary organisation can get going and can keep rolling for a little while, but then it needs some form of staff. You know, whether it's just a few hours a week or whatever, to sort of keep it coordinated. And David had a great deal of business background.

(PV2, p. 2)

Introducing David McCluney into the organisation began a period of professionalisation in which the vision of Sheila Fairbrother and her colleagues was turned into realistic goals and organisational tasks (Wallcraft, 1994; Dartington, 1996). A key part of David's role was helping the steering group to develop a set of principles which they all understood, and which could be grasped by other stakeholders, including advocates, advocacy partners and funders. The dissemination of principles has been identified as an integral variable in the eventual success or failure of a fledgling organisation (Wilson, 1986). Developing a workable concept for advocacy in Buckinghamshire was also crucial for the recruitment of a suitable advocacy manager. As David explained:

...we were in a situation where a job spec was needed, but we didn't know what we were looking for. So I said 'alright, I will help write a job spec' and I spent...well, it

must have taken until 1992, and I used to pop into Sheila's office in Booker and say 'look, I still don't understand'. And eventually we came to a definition of what I call 'The 4As', which is just so helpful to me. If you're going to help somebody as an advocate, you want to help them gain 'Access' to the right person; help them 'Articulate' – that is not saying something for them, but help them say what they want to say; help them carry through the 'Argument' (I usually use this word and then explain that I mean discussion); and get an 'Action'.

(PV3, p. 2, David's emphasis)

These principles are orientated towards a more instrumental version of advocacy (see Wertheimer, 1998, for an overview of the differences between 'instrumental' and 'expressive' forms of advocacy), and will be examined more thoroughly in chapter 5 within an analysis of the current values and principles guiding the work of People's Voices. The '4As' placed an emphasis on developing the networks and resources that were necessary in order for an advocacy partner to secure a successful outcome regarding a particular situation. This was a divergence from the citizen advocacy literature that was circulating at the time, which stressed the importance of enduring relationships, based upon a model of friendship and long-term commitment (Harris, 1987 and Carle, 1984 – cited in Flynn and Ward, 1991). The '4As' may have emerged because Sheila Fairbrother and her colleagues perceived a specific need amongst Buckinghamshire service users for short-term partnerships that revolved around the specific life circumstances of home transition. Alternatively, another reading of the early shaping of People's Voices' principles might place greater attention on the role played by David McCluney and the perspective he brought to the steering group coming from his background in the private sector. This will be pursued further in chapter 6.

Becoming a charity and employing staff

David McCluney directed the steering group to take the steps needed to transform it into a viable, working scheme. First, the steering group had to come up with a name which reflected both its proposed remit and its geographical sphere of activity, and would be focused enough to appeal to funders. It was known to the group that another advocacy project had been founded in the north of the county (Aylesbury Vale Advocates), and so the group focused its attention on serving the needs of service users in South Buckinghamshire. The group called itself 'The South Bucks Advocacy Association' (SBAA), and established itself as a legal entity:

David: And so we registered as a charity and gathered together some of the people from the original steering group, and then began to build the organisation.

(PV3, p.2)

This involved receiving an £11,000 grant from joint funding, which enabled the group to employ staff. Over the next two years the steering group held a succession of strategic planning meetings that were facilitated by David, in which they deliberated which type of service they actually wanted to develop. With a clearer understanding of the group's remit (by using the '4As'), David McCluney felt confident that he would be able to design a job specification to attract a candidate with the ability to implement the steering group's vision. He explained how this proved to be a successful strategy, as Barbara Poole applied for the role:

...we were obviously hitting the button, in that we hired Barbara. Barbara was a consultant / freelance trainer. She was training people to speak up for themselves, and

training service provider personnel in a range of skills. She knew what she was talking about, and she knew what we were talking about.

(PV3, p. 2)

Barbara Poole secured the role as the Training and Development Officer in 1994. Forthcoming chapters will demonstrate the ways in which she impacted upon how the group defined its purpose and its activities. Barbara had previously been employed by MIND in their training and education department. MIND was one of five organisations that formed the Citizen Advocacy Alliance, which had piloted the first UK citizen advocacy scheme in the early 1980s (Butler et al, 1988). Barbara attended presentations delivered by Sally Carr of Citizen Advocacy Information and Training (CAIT) as a MIND employee, and developed an extensive knowledge base around the principles and practice of citizen advocacy. Whilst SBAA / People's Voices has never officially labelled itself as a 'citizen advocacy' scheme (see chapter 5 for a discussion on this), it is clear that its roots lie in the citizen advocacy movement. As we have seen, the aim of the original steering group was not to facilitate the growth of self-advocacy, but rather to cultivate advocacy in which members of the community (who were not service users) would work alongside vulnerable individuals as they made the transition to community life. Soon after Barbara was employed with the remit of training advocates and managing the organisation's developing programme, an advocacy manager was employed to match partners and support the advocates on a day-to-day basis. The first advocacy partnership took place at the beginning of 1995.

3. The origins and early history of Talkback

Talkback self-advocacy was created under the umbrella of People's Voices. It began life as a small group of people with learning difficulties in Buckinghamshire who were supported by Barbara Poole to develop their 'own voice' within the county. The two principal advocacy organisations in Buckinghamshire (People's Voices and Aylesbury Vale Advocates) had been assisting people with learning difficulties to take more control over particular issues affecting their own individual lives, through the provision of independent advocates. However, there were fewer examples of people with learning difficulties taking control over their lives on their own or by their own initiative. Nor were there many examples of people with learning difficulties working together collectively to influence attitudes in order to make more widespread changes to the way that services were planned and delivered. Talkback was established in order to redress the apparent lack of self-advocacy occurring among people with learning difficulties in Buckinghamshire. Talkback would complement the existing practices of one-to-one advocacy, by facilitating those who could, to start representing themselves and other people with a learning difficulty.

This section tells the story of Talkback's origins, and its early history. In doing so, it raises a number of critical questions about the wider development of self-advocacy. The key role played by non-disabled support staff in the group's origins and subsequent growth is an important finding, and one which can be at least partially explained by the organisation's founding links with an existing advocacy group. The important (and perhaps dominant) position held by non-disabled people in the early years is also apparent in the fragmentation that occurred when Jean Rein began to adopt a more influential role in the group. The tensions that existed prior to Talkback's separation

from People's Voices were characterised primarily by differences of opinion held by the supporters of the group. In contrast to organisations such as Central England People First (Spencer and Walmsley, 2006), no people with learning difficulties emerge as prominent players in the early history of Talkback. This issue is followed up in the light of current practices at Talkback in chapter 6.

Like People's Voices, an analysis of Talkback's history demonstrates the significant – and often supportive – impact of statutory staff in the development of independent self-advocacy in Buckinghamshire. Unlike the dominant historical narrative, this section highlights how for many people with learning difficulties, support from social services staff was integral in facilitating their transport to self-advocacy meetings that were held at an independent venue.

The data also indicates that Talkback faced a number of practical challenges such as finding accessible venues for people with physical impairments, and organising transport to ensure a wide range of individuals had the opportunity to be involved. More complex challenges involved developing self-advocacy meetings in order to meet the needs of individuals with different levels of intellectual impairment and varying expectations of their contact with Talkback. This section demonstrates how Talkback attempted to meet these challenges by diffusing the initial group, and setting up smaller groups to suit people's needs.

This section also shows that the tensions and challenges that Talkback experienced with other influential stakeholders in its early years (most notably, carers) profoundly affected its development. By necessity, the organisation adopted strategies of non-confrontational negotiation which continue to characterise their relations with others

today (see chapter 7). Similarly, a set of turbulent events set the scene for greater inclusion of people with learning difficulties through the mechanism of self-advocacy. Arguably, this was partially achieved in the light of their previous exclusion. The findings of the Longcare Inquiry, cuts to services, and the actions of parents, emphasised how marginalised and passive people with learning difficulties in Buckinghamshire were in the mid-1990s. With support from allies, service users utilised this opportunity to start 'talking back' through formal and informal channels.

3.1 Stage one: a new People's Voices' project

Setting the agenda: the role of non-disabled people in the establishment of self-advocacy in Buckinghamshire

According to the South Bucks Advocacy Association / People's Voices' AGM minutes from 1996, Barbara Poole was approached in 1995:

...by a group of people from Hillcrest, Micklefield and Endeavour (day) centres to establish some form of self-advocacy initiative.

(SBAA / PV Minutes of the AGM, 1996)

In contrast to wider developments, it seems that self-advocacy in Buckinghamshire developed comparatively late. Whilst historical detail for other groups is slim (as discussed in chapter 1), a glance at Ken Simons' 1992 publication '*Sticking up for yourself*' demonstrates that a number of independent organisations had been active since the late 1980s.

The 'people' who had made this initial request for self-advocacy to be developed in Buckinghamshire were staff within the services, who were considering running groups within their workplaces, and approached Barbara for advice. The role of statutory employees in helping to prompt some form of self-advocacy in Buckinghamshire not only mirrors the origins of People's Voices, but also reflects the growth of a number of service-based self-advocacy groups that emerged in the 1980s and 1990s (Crawley, 1988; Goodley, 2000a). However, concerned that this would compromise the autonomy of people with learning difficulties who were members of such groups, Barbara decided to facilitate a few meetings herself, as a person independent of services:

... originally, staff in Buckinghamshire wanted to set up a self-advocacy group, which is a contradiction in terms, and so I set up a couple of meetings to give people an opportunity to think about what sort of self-advocacy group they wanted.

(PV1, p.1)

David McCluney recalled a different motivation for the development of self-advocacy. He suggested that the funders of People's Voices encouraged the organisation to expand its services in order to provide some more specialist advocacy for people with learning difficulties, because the learning disability context was undergoing such rapid change in the mid-1990s. In fact, as David remembers, there was a demand on People's Voices to introduce some kind of self-advocacy activity for people with learning difficulties:

As you probably know, getting money is usually tied to particular targets, and social services were very keen that we should actually help people with learning difficulties - perhaps because the learning difficulties scene was changing very rapidly...And all those conflicts with all those different people involved in that change, meant there was a

lot of demand for advocacy, and indeed self-advocacy. So some of our funding had to be spent in that area.

(PV3, p.4)

In both versions of events, the push for self-advocacy in Buckinghamshire came from non-disabled people. Self-advocacy in Buckinghamshire is not evidence of the authentic bottom-up, grassroots phenomenon indicated in some of the learning disability literature (Bersani, 1998). Unlike some other self-help, user-based groups (Baggott et al, 2004; Barnes et al, 1999), Talkback was not instigated by people with learning difficulties. Instead, the idea emerged from non-disabled people who supported the principle of people with learning difficulties being able to speak for themselves. However, Barbara's decision to manage the initial development of self-advocacy at the early stages removed the control from service providers. Whilst service-based self-advocacy groups can be seen as part of a broader 1980s and 1990s policy agenda around user participation and choice, they have also been accused of potentially institutionalising people's experiences and thus leading to 'the fragmentation of political action through the colonisation of the "voices" of people with learning difficulties' (Armstrong, 2002). The voluntary sector has been perceived to provide a more sensitive and empowering space in which service users can seize greater control for themselves (Bylov, 2006), although as Chapman (2005) has pointed out, this rarely involves a considered analysis of the role of non-disabled supporters in such voluntary groups.

Developing relationships and networks

The first 'self-advocacy' meeting took place in January 1996, and included service users from the three day centres mentioned in the SBAA AGM minutes. In these first few

weeks, Barbara was also keen to raise the profile of the group, and therefore introduced members to other people in the county who were influential in making decisions that affected their lives. The passage below indicates the role played by Barbara in helping the group to become both noticed, and more widely connected:

David: Barbara convinced the helpers (in services), to support us in bringing together some meetings at the end of a normal day, or during the afternoon. We used a village hall and Barbara got groups of learning difficulties people together, I remember there being about 30. Barbara first of all invited people that were important to this group – like local politicians and social services managers, to actually come and talk. She competently organised for them to have their own chair and their own secretary – to organise the meetings themselves. (PV3, p.4)

Jean Rein, who joined the organisation as a supporter a few months later (see below) commented that the development of the group at this early time was also dependent upon the commitment to self-advocacy by social services staff. Commitment from staff to the self-advocacy concept had important practical implications regarding whether or not service users were able to consistently attend Talkback meetings:

Well, there were a couple of members of staff within one or two of the day centres, who, when we first started to talk to them, were really keen. They believed in self-advocacy and they were happy to support us, in trying to get this off the ground. And they were very supportive in coordinating their end, you know, making sure that people remembered it was the meeting, and so they'd get the right bus, those sorts of things.

(TB1a, p.2)

For a few months, there was a consistent group of individuals attending the Chalfont leisure centre for the monthly Talkback meetings. These people were mostly service users in some of south Buckinghamshire's day services. Jean was also making contact with staff in more day centres, and as a result, the numbers of people present at Talkback meetings grew. Jean strove to achieve good relationships with staff and other stakeholders, as she viewed that as an important means of widening the scope of people that Talkback reached:

And we used to always invite service providers and councillors (to conferences and events) to start a dialogue between people with disabilities and people who provide services. And it was a super way of getting people together from different parts of the county, people with learning disabilities learning about one another's experiences.

(TB1a, p.2)

The negotiation of relationships with different stakeholders has remained an important organisational strategy for Talkback as it has grown. The implications for self-advocacy of such negotiations will be discussed further in chapter 7.

External pressures and the growing voice of people with learning difficulties in the conceptualisation of self-advocacy in Buckinghamshire

The group – supported by Barbara – began to organise itself within the first few weeks of 1996. Barbara supported the service users to think about what type of group they wanted to develop, and what it should be called. To help facilitate this process, she invited representatives from other self-advocacy and user-led organisations to meet the Buckinghamshire group, and discuss the various options and 'models' for self-advocacy

organisations. This included Hillingdon People First (a user-led organisation for people with learning difficulties), and POhWER in Hertfordshire, which consisted of people with learning difficulties, mental health problems, older people and people with physical and sensory disabilities.

However, before the group had come to a decision on the ‘type’ of self-advocacy organisation they wanted to be, following their meetings with other disability groups, Buckinghamshire County Council announced that it was making cuts to learning disability services, which quickly caught the attention of the service users. The anxieties that surrounded these proposed cuts not only preoccupied the group for the following few months, it also led to its ‘naming’. Barbara explained how at the earliest incarnation of Buckinghamshire self-advocacy, she had to put her own preferences for the group to one side, in order to allow the individuals in that group to come to their own decision regarding the future of self-advocacy. As will be seen in chapter 5, this is reflective of a central tenet of one-to-one advocacy at People’s Voices, whereby the advocate has a duty to support the decisions made by the partner – regardless of the advocate’s personal view. The quote also reveals the circumstances under which self-advocacy in Buckinghamshire was initially formed:

Barbara: And my not so hidden agenda was the hope that they’d go more broad-based because I thought it was an interesting idea, but of course, it wasn’t my decision to make, obviously. So, I had a meeting that was supposed to be about people with learning difficulties getting together to talk about what sort of self-advocacy organisation they wanted, and what they wanted to do was talk about their day service, because it was going to be taken away. And so, one of the people with learning

difficulties actually came up with the name Talkback, because they said 'we want to talk back to them, because they're telling us what we want'. (PV1, p.2)

The proposed cuts to services for people with learning difficulties that were announced in 1996 had a significant impact on the development of Talkback. First, it established the group firmly as self-advocacy for people with learning difficulties only. Second, the group's remit was formed in response to service-based issues, which has had a lasting impact on the aims and objectives of the organisation as it has grown over the years.

Whilst Aspis (1997) believes this is a phenomenon which has constrained the political power of self-advocacy, the data indicates that concrete, practical concerns may have been a more mobilising force than a focus on abstract ideas for the self-advocates in Buckinghamshire.

Organisational roles for self-advocates

At this time, Barbara also suggested that the group elect officers, and develop roles as chairs and secretaries. By supporting such elections in the first few meetings, Barbara was facilitating the group to start thinking about organisational processes, and was encouraging them to behave in congruence with other types of user organisations which democratically vote people into particular roles (Barnes et al, 1999). However, Barbara contended that supporting the group to elect officers in this way was problematic, as the group were not experienced enough to make the process meaningful:

...but it was too early to do that, because people hadn't had any background in being representative in the way that the core group is now. (PV1, p.2)

Barbara suggested that such difficulties nearly stalled the group's development.

However, the philosophical and pragmatic issues around the actual 'running' of the group (what they wanted to *be*) were overshadowed by events which spurred the group into action (what they needed to *do*):

... the external pressure got the group over that, because they were so concerned about what was going to happen to their day services. (PV1, p.2)

Barbara accepted that in the first few months people might not yet have reached the stage whereby a representative self-advocacy organisation had real meaning for them. However, members of the group were asserting their citizenship in other, less formal ways (Armstrong, 2002). By asserting their desire to deal with cuts to services rather than what 'type' of organisation they were going to be, the Talkback self-advocates demonstrated both their aspirations and abilities to tackle issues on their own terms.

Negotiating tensions with other stakeholders

One of the first tasks facing Talkback was to negotiate a role at the social services Consultation Group. This group was set up by the then director of social services, in response to the direct action of carers following the introduction of eligibility criteria, and the proposed cuts to services. This was an important step forward in terms of the greater involvement of carers in the planning of services. Initially however, service users were not invited to join the group as active members. They could attend as public observers, but were not entitled to contribute. Jean Rein acknowledged that representatives from Buckinghamshire social services were not hostile to involving

people with learning difficulties, but carers were vociferous in their opposition. Barbara Poole recalled some tense moments when the Consultation Group first began:

I went along with some people with learning difficulties to try and get them involved, but the parents got very angry...and I got abusive telephone calls at home and all sorts of things.

(PV1, p.3, the full quote can be seen in Chapter 3, p.136)

Steve Dean, a Talkback self-advocate, also remembers how uncomfortable people with learning difficulties were made to feel at those early meetings:

Oh, yes, because we were not, because we were a disabled person, we weren't allowed to speak. We were allowed to listen, but not speak...But I don't know what would have happened if we'd've spoken then.

(TB4, p.5)

However, within a few months, the situation began to change, and eventually the Talkback self-advocates became full participatory members of the Consultation Group. One reason for this seems to have been the commitment from the director of social services at the time, to encourage and support greater involvement of service users in consultation processes:

Barbara: The then acting director of social services John Beckerleg, was very, very committed, once he realised what was going on. And they did have one particularly nasty session in these consultations where I think John swept up all the users and Jean afterwards, and took them all to the pub because it had been such an unpleasant

session. So, you do need some sort of lead from the top and then, subsequent directors, or assistant directors with an interest in and responsibility for learning difficulties care have been very proactive and supportive.

(PV1, p. 4)

Jean also acknowledged that members of social services became increasingly supportive of greater user involvement. However, she primarily attributes Talkback's success in acquiring equal membership status at the group, to the way in which the self-advocates quietly asserted their role at meetings in a professional, non-confrontational way:

Because everyone there was so professional, they just eeked their way in.

(TB4, p.5)

Acceptance by carers of Talkback's right to participate in service planning also came about through a process of dialogue and negotiation on both sides, which happened over a longer period of time:

Jean: After we were involved in different pieces of work, we got chatting with a couple of carers, and they actually said 'why are we fighting, this is really not on, we're all on the same side really, you know, this is all supposed to be about improving people's quality of life'. So we had a couple of meetings, with us sitting down with the carers, discussing why should there be differences, you know, it's not about one group or the other. And that's been enormously helpful.

(TB1a, p.9)

As will be demonstrated in chapter 7, negotiation – as opposed to confrontation – continues to be the main strategy adopted by Talkback for dealing with challenges from other stakeholders.

3.2 Stage two: ‘growing up and leaving home’

Fragmentation

The group continued to be supported by Barbara for another year. In 1997, People’s Voices made a successful grant application to the National Lottery, which funded Talkback as a start-up project for three years. People’s Voices was then able to advertise for a part-time employee to work alongside Barbara in order to support Talkback to expand. The comments that were made by interviewees with regard to the employment of Jean Rein in many ways match the sense of triumph that the Board members seemed to have felt on ‘finding’ Barbara in 1994. As David McCluney recalled:

So we did a job spec and a person spec, and advertised, and about three people were interviewed. But we nearly fell over when Jean came in – I mean, she was just perfect. She lived locally, she’s done her MSc focusing on learning difficulties, she’d had a child with learning difficulties, and she was just so moved by the whole idea. So we employed Jean and she started working alongside Barbara. (PV3, p.4/5)

Over the next few months Jean’s role developed into a full-time position. But as Jean began to have a greater input into Talkback, tensions arose regarding organisational ownership. As will be seen below, under Jean Rein, Talkback made huge strides in expanding beyond the initial group of self-advocates who met at the Chalfont leisure

centre. However, this was achieved with Talkback still working under the auspices of the People's Voices board of trustees and management structure. Jean had concerns that self-advocates would not gain the opportunities for organisational participation under People's Voices that both she and they were starting to envisage. As a result of this concern, Talkback established itself as a separate organisation in 2000, at the end of the Lottery funding period:

Jean: We moved away from People's Voices towards the end of the lottery funding, as the core group developed and people were more involved in the sort of things that we do. So for example, anything that came in to Talkback we would take to the core group, and say 'this has come in, do we want to get involved in this? We've got a bit of funding there, do we want to go for that?' All of those sorts of things, and that was absolutely fine. It was brilliant – people with a learning disability, as far as Talkback was concerned, were completely included. But they weren't included in the overall, overarching (People's Voices) service. They didn't have a real voice there, the (People's Voice) Board was very separate. People said that they wanted more input, their own organisation. If it was user-led, then that's what it needed to be. And so we moved towards what we called: 'we grew up and left home'. We're now a company limited by guarantee, and a registered charity, which has enabled people to be really involved.

(TB1a, p.5)

This passage raises a number of interesting issues. First, it suggests that the decision to leave People's Voices happened in a rather ad hoc way, whereas this quote from Barbara Poole offers a different version of events:

You know, that was always the intention, which was in the lottery application, that it should become an independent organisation. (PV1, p.4)

David McCluney's comments on the decision taken by Talkback to set up as an independent organisation, presented a third scenario. He suggested that the split came about as a result of Jean and the People's Voices' board visualising different ways of developing Talkback which eventually became difficult to reconcile:

My message to Jean was 'you take Talkback and make what you want of it. What I want is People's Voices' ethics, culture, protocol to be the base of that business'. Jean and Barbara just went off in two different directions...Talkback, after a very short while, felt limited by Barbara being there – and in the end I had to say 'you should just get on with it'. (PV3, p.8)

It was not possible to obtain the original Lottery application that was made by People's Voices to fund the Talkback project. Therefore it is difficult to assess whether People's Voices did anticipate the Talkback project breaking off and becoming a separate organisation – which would be contrary to the recollection of David McCluney in the above quote. However, it is clear that Jean Rein invested a significant amount of her own time and energy in expanding the group, and was passionate that on principle people with learning difficulties needed to be more involved in the steering and management of the organisation – for example, through governance structures like the management group⁶. By 1998, it seems that the issue of inclusion (*'if it was user led then that's what it needed to be'*) was becoming an increasing preoccupation for Jean Rein, and something which Talkback's affiliation with People's Voices was unlikely to

⁶ The different groups within Talkback are explained in section 1, Chapter 5.

promote. As none of the people with learning difficulties who were interviewed discussed this issue, it is difficult to assess how they felt about Talkback 'leaving home', and the extent of their involvement when the decision was made. However, an interesting finding is that the fragmentation that occurred between the two types of advocacy organisations in Buckinghamshire came about principally because of differences of opinion between non-disabled support workers. This is in contrast to some People First groups, where organisational tensions have emerged between self-advocates themselves (Bramley and Elkins, 1988; Spencer and Walmsley, 2006).

Developing the Talkback 'model'

As will be seen in chapter 5, Talkback developed an organisational structure which is not mirrored by other self-advocacy groups that have been explored in the existing self-advocacy literature (Crawley, 1988; Goodley, 2000a; Clement, 2003; Chapman, 2005). How and why did such a unique structure develop? By conducting interviews with some of the people who were involved in the earliest days of the Talkback group, I was able to trace the roots of this organisational 'model' to a number of factors which Jean Rein and the group identified and acted upon throughout 1997 and 1998.

Initial concerns about accessibility

As noted above, Jean and Barbara were coordinating with staff from the different day services to organise transport for service users to the Talkback meetings, which by 1997 were taking place in a leisure centre in Chalfont. Although the meetings at Chalfont were helping people to develop the individual skills associated with self-advocacy (Simons, 1992), they were also impeding more people from joining Talkback. Although

having meetings at the Chalfont leisure centre had certain advantages – namely its lack of association from service-settings and its social atmosphere – it was not an accessible place for people with mobility problems. Additionally, as Jean continued to make contact with service users a bit further afield, it was becoming increasingly difficult for the organisation and day service staff to coordinate people’s transport to the meetings. This has also been highlighted as an issue restricting the growth of other self-advocacy organisations – notably Avon People First (Simons, 1992).

Aside from such practical disadvantages, Jean was also becoming increasingly aware that some individuals in the group were ‘doing’ self-advocacy very successfully during the meetings, and were confidently asserting themselves and taking on more responsibilities. However, she also observed that others were not flourishing in quite the same way. Jean explained the reasons behind Talkback’s eventual change of format:

But the most critical part was that there were some people who had ‘a voice’ – they were comfortable talking in a big group, so it didn’t matter to them. There were other people who had very different starting points, and so, as Talkback was developing, it was clear that we needed to work in another way, both for cost reasons, because money was being spent on few people by having to use so many means of transport, and there were lots of people who couldn’t get there, and because people within the group had different starting points, and had very different life experiences, which then made it difficult for people who didn’t have such a broader knowledge of life to get involved. And so that made us change how we did these meetings.

(TB1a, p.1)

The observation that Jean made so early on in Talkback's development highlights an ongoing tension in the history of self-advocacy. Many organisations practising self-advocacy, as well as scholars writing about it, have struggled to reconcile the inherent conflict between meeting the needs of the group (collective self-advocacy) and meeting the needs of individuals within that group (Buchanan and Walmsley, 2006; Chapman, 2005). Jean came to the conclusion that this tension could not be reconciled in the Talkback group as it existed in 1998, particularly as for many service users in Buckinghamshire this was their first experience of self-advocacy.

Expanding and diffusing the group to meet the needs of individuals

In order to reach more service users and to heighten people's experience of self-advocacy and develop their skills in more depth, Jean and the 'Chalfont' group made the decision to end their large group meetings. Instead, smaller self-advocacy groups were formed in particular service-settings (mostly different day centres or 'resource' centres around Buckinghamshire), facilitated by Jean. The challenge of operating a self-advocacy organisation in which people's life experiences and impairments often lead to self-advocates being at very different 'stages', has been highlighted in research on People First organisations (Chapman, 2005). Talkback, like some other self-advocacy organisations, decided to adapt its organisational structure in order to address this challenge, although this manifested itself in a different way to the federated structure adopted by Central England People First, for example (Spencer and Walmsley, 2006). Without having observed these discussions as they took place, nor having located sufficient documentary evidence that might help to illuminate them, it is difficult to assess the precise role that either Jean or the self-advocates played in making the decision to develop a new organisational model.

As the number of self-advocacy groups increased, another support worker was employed. As well as being more practical, Jean also believed that holding the meetings in places that were familiar to people would help service users to feel more confident and relaxed. She explained:

...we started talking to the different resource centres to see if they would be ok with us holding meetings in the resource centres, so that we were going to where people were, so we travelled to them, which cut down on the hassle factor. But more importantly, at that stage, they were in an environment that they knew well, and could talk quite easily. And so it enabled people to develop the skills of self-advocacy in a natural environment.

(TB1a, p.2)

Holding self-advocacy meetings in service-based settings is reminiscent of the 'service-system' group model identified by Goodley (2000a). However, the groups differed from this model as they were still technically independent of services in terms of support. The services quite literally provided a meeting place for Jean and the other Talkback support worker to facilitate self-advocacy. Having observed one of these service-based self-advocacy groups in 2004 (now called 'About Me' groups), it was apparent that the people attending that meeting clearly framed it as a 'Talkback' meeting, and not just another day centre activity. This will be considered further in chapter 5.

Developing the inclusion of people with learning difficulties in the running of Talkback through the 'core group'

Another facet of Talkback's early history also distinguished it from the traditional service-based self-advocacy group, and brought it closer in line with the People First - or Goodley's 'autonomous' - model. This was the development of what Talkback termed its 'core' group. Jean explains:

At the same time there were a core group of people, even at that stage, who maybe didn't use the day centres or maybe didn't use the day centres on the days that we went there - there were all of those sorts of things - who were really interested in Talkback as an organisation, and because we were very keen that people with a learning disability were right at the core of what was happening, that was when we started what we then called the 'core group'. That group of people were more involved in the development of where we are, what we should do, what we should take on. (TB1a, p.2)

This group would meet regularly to discuss the progress of Talkback, and where its future priorities should lie. Some of the people who were in this core group as it first emerged in a formalised way had been involved with Talkback from the earliest days in 1996, and continued to operate at the central hub of Talkback during the fieldwork. Chris Eastwood and Jackie Brodie are two such people, and in a group interview with them (supported by Jean) they described one of their roles as members of the Talkback 'core' group:

Jean: You made a video.

Jackie: Oh yeah, we did - a video, yeah!

Jean: Because do you remember you made a video of what the meetings were like, and where it was held,

Chris: And I used to tell them to get the chairs out, 'cause that were most important.

Jean: And so what was the theme of the video – who made the video, what happened?

Chris: Didn't we, I think we went on TV.

Jean: We did show it on TV, you're quite right. And we invited everyone from the centre to come and find out about what we were doing at Talkback.

(TB2, p.10/11)

As the core group developed, they began to work more closely alongside Jean in attracting new members to Talkback, and explaining the concept of self-advocacy to service users, and what it might mean for them. The core group were the visible 'user' presence at the hub of Talkback – an organisational feature that Jean was very keen to foster for two reasons. First, it demonstrated that people with learning difficulties were capable of developing roles and responsibilities within an organisation so long as the appropriate support was available to them. Second, Jean believed that the core group's presence helped to cultivate a sense of 'ownership' of Talkback among people with learning difficulties. As Clement (2003) has demonstrated, the realisation of such goals in practice is often difficult to achieve. Chapter 6 will consider the extent to which such organisational structures have truly enabled people with learning difficulties to participate in the running of Talkback.

Conclusion

This chapter has presented the groups' organisational histories, in order to trace how and why the organisations have developed their particular forms of advocacy. This feeds in to the wider purpose of the chapter, which was to explore the factors that have influenced the development of advocacy at the local level. The findings presented here demonstrate that a combination of change-inducing local events, a new social services directorate, and the opening up of the 'insider voice' through carers' campaigns, provided an opportunity for advocacy to grow and gain legitimacy in Buckinghamshire. This has been supported by a number of 'top-down' directives – notably the *Valuing People* white paper, and recommendations by the Department of Health that Buckinghamshire social services develop a more open and participatory system for its service users.

The chapter has also demonstrated that the development of advocacy at the local level in Buckinghamshire has been heavily influenced by the role of non-disabled allies. This includes key supporters such as Barbara Poole and Jean Rein, but also staff in statutory services. People with learning difficulties themselves were not involved in the development of one-to-one advocacy, and non-disabled supporters also dominated the early history of self-advocacy, although there is evidence that this picture was beginning to change by the late 1990s. The growth of advocacy organisations was also influenced by the groups' external relationships and networks. For example, one important finding is that the origins of advocacy in Buckinghamshire lie in the extensive partnership working between the voluntary and statutory sectors in the late 1980s.

This chapter has set the scene for the other three data chapters which follow. Chapter 5 begins with an analysis of how members of advocacy groups articulated the concept of advocacy in the interviews - and addresses the issue of what advocacy is in practice.

Chapter 5: The relationship between values, principles, theory and practice in advocacy

Introduction

This chapter presents my findings on the values, principles and theories underpinning advocacy organisations, and considers how they are borne out in practice. The chapter sheds light on the diversity in advocacy and presents new insights about how members of different types of advocacy organisations understand and narrate the work they do. The literature review demonstrated a number of conflicts and tensions that exist in the day-to-day practice of advocacy organisations for people with learning difficulties. An awareness of these tensions encouraged me to look more closely at the internal factors that might be influencing practice at People's Voices and Talkback. This involved an appraisal of the groups' respective value-systems, an analysis of how these value-systems have been constructed, and an exploration into how values are (or are not) enacted by organisational members.

In doing so, it addresses the second research question:

What is advocacy in practice?

Identifying and analysing the themes

In order to address the research question, I considered how particular discourses were constituted within the advocacy organisations, and for what purposes. This approach paid particular attention to the narratives and stories produced by organisational

members in interviews, as well as written documentation and website pages. The second level of analysis critiqued these discourses in light of ‘resistant’ or ‘counter’ narratives (Andrews et al, 2003) found in the interview transcripts, and through my own observations. The rationale for this approach is that as a person not ‘socialized in the same systems of meaning’ as other members of the groups (Czarniawska, 1998: 30) my reading of events and practices is a ‘novel’ one, and can thus contribute new insights to an understanding of the advocacy phenomenon (De Vault, 1990). Through my interpretation of a range of narratives, this chapter presents findings which demonstrate the complex and diverse understandings of advocacy among group members. I have drawn upon organisation theory and the literature on user groups (discussed fully in the literature review, chapter 2) in order to identify and analyse the data presented here. Some of the findings discussed in this chapter will be explored in more depth in chapter 6 ‘*Tensions and challenges in the practice of advocacy*’.

Models for practice

In order to try and understand what happens ‘on the ground’ at People’s Voices and Talkback, I believe that a review of what ‘drives’ the organisations is both an interesting, and necessary undertaking. As Clark (1991: 2) has argued, ‘the existence and purpose of voluntary social welfare organisations is typically justified in essentially ideological terms’. I was interested in *who* narrated the ideologies of the respective organisations, and whether members’ accounts conflicted in any way.

I have drawn upon Clark’s (1991) ‘model for practice’ in order to address such issues.

In the context of this thesis, a ‘model for practice’ refers to the values, goals and

theories which underpin and shape the activity of People's Voices and Talkback. Clark has posited four categories of ideas, which impact upon practice:

- **Epistemology:**
What do people count as true and relevant knowledge and valid inference?
- **Moral and political values**
What do people consider to be the essential components that contribute to a better world? How does this impact upon people's work?
- **Substantive social science knowledge**
What body of social science knowledge (if any) do people have at their disposal?
- **Conceptions of social phenomena**
How do people conceptualise issues that impact upon their practice?

(Adapted from Clark, 1991: 9-10)

Although Clark's model relates to individual practitioners in the voluntary field, I argue that it has wider application for our understanding of how voluntary *organisations* work. Using this model to address the question, 'what is advocacy in practice?', the findings from this chapter demonstrate that at the time of writing, the advocacy practised by People's Voices and Talkback was an activity driven by the goals of improving the quality of lives for people with learning difficulties, and enabling them to 'have a voice'. Advocacy was an activity based upon an identifiable set of values,

although these were not necessarily articulated by all organisational members.

Sometimes these values were held in tension as a result of the enactment of particular organisational principles. Whilst both groups ‘operationalised’ their values through distinct organisational principles, there was evidence of some principles being difficult to follow in practice. The findings also reveal some discrepancy between how different members of People’s Voices narrated the advocate role, and how self-advocacy was conceptualised in quite different ways by the staff and self-advocates at Talkback. The chapter illustrates that advocacy was an activity underpinned by wider theoretical perspectives such as the social model and social role valorisation, although these theories were referred to implicitly – and perhaps more interestingly - interchangeably.

In the light of these issues, this chapter is organised under the following headings:

1. Overview of the two organisations
2. Values and principles in advocacy
3. Constructing the value-systems in advocacy

1. Overview of the two organisations

This section presents an overview of the two organisations that formed the basis of the research. It outlines some of the key individuals in the two groups, and describes the main activities undertaken by the organisations at the present time. This section

provides a reference point for a number of these organisational activities that will be discussed in the forthcoming analysis.

1.1 People's Voices

Who's who at People's Voices

People's Voices became a registered charity in 1994, and a company limited by guarantee in 1996. Since then it has gone on to expand its remit and undertake a range of activities in both South Buckinghamshire and Milton Keynes. This thesis is particularly concerned with the People's Voices one-to-one advocacy scheme for people with learning and physical disabilities in Buckinghamshire.

One result of the organisation's growth has been the employment of more paid staff. This included Barbara Poole (project manager), two one-to-one advocacy support managers (Becky Jones and Sam Marshall), a paid mental health advocacy worker (Colin Le Guillou), and four Direct Payment advisors. However, the majority of people who 'work' with People's Voices continue to be volunteer advocates. The South Buckinghamshire office had 37 advocates on its books at the time of writing.

The Board

The Board had eight members, one of whom was a (mental health) service user, and some of whom were People's Voices advocates. The recruitment of new trustees was decided upon by current Board members. Whilst People's Voices is officially a membership organisation – free and open to anyone living in the area that supports the

objectives of the group – at the time of writing the membership consisted only of the volunteer advocates, and a few other affiliated groups. Only Board members had voting rights within People’s Voices.

Management

In 2003 it was agreed that the running of People’s Voices would be dispersed through a series of committees, all of which would feed into the main Board. In the following months, committees for Operations, Human Resources and Risk Management were appointed, made up of existing Board members, employed staff, and in the case of Human Resources and Risk Management, at least one advocate. Members of these committees now take responsibility for particular areas of organisational activity (much of which was previously dealt with by Barbara Poole) and each committee has become accountable for their area of practice.

Organisational Activities

The original one-to-one advocacy scheme for people with learning and physical disabilities at People’s Voices has continued to expand, and now operates a second branch in Milton Keynes. People’s Voices was also awarded a contract in Buckinghamshire in 1999 to provide support for people who are interested in using Direct Payments. In Buckinghamshire, uptake of Direct Payments has been concentrated among people with physical disabilities, although a small number of people with learning difficulties were beginning to use this service. The activities of the organisation are summarised below:

Table 2: Organisational activities at People's Voices

Activity	Description	Key players
One-to-one advocacy	<p>People's Voices provides one-to-one 'situation-based' advocacy to people with learning difficulties and physical disabilities in Chiltern and South Buckinghamshire. Some service users also have additional mental health issues.</p> <p>The advocates interviewed for this research undertake advocacy work with service users in Buckinghamshire who have learning difficulties and / or physical disabilities.</p> <p>At the time of writing, People's Voices had 50 advocates on their books in Buckinghamshire.</p>	<p>One-to-one advocacy is undertaken by volunteer advocates from the local community. They are trained by Barbara Poole, and assigned to advocacy partners by Becky Jones, the advocacy support manager for People's Voices in Buckinghamshire.</p>
Mental Health Advocacy	<p>People's Voices employs one full-time salaried worker to provide advocacy for people detained under the provisions of the Mental Health Act in the Haleacre Unit, Amersham Hospital and in the Tindal Centre, Aylesbury.</p>	<p>Colin Le Guillou is People's Voices mental health advocacy worker.</p>
Direct Payments Advice and Support Service	<p>People's Voices run The Direct Payments Support and Advice Service from an office in Aylesbury. The service provides information, and helps people to discuss the options which exist to suit their individual circumstances. People's Voices assists service users in the recruiting, training and supporting of their personal assistants.</p>	<p>The organisation employs three advisors and one information officer for this service.</p>
One-to-one advocacy in Milton Keynes	<p>In 2002, People's Voices received funding to develop their one-to-one advocacy work in Milton Keynes. People's Voices run two specific projects in Milton Keynes. One project supports people with learning difficulties, and the other supports people with physical disabilities and / or sensory impairments.</p>	<p>Sam Marshall is the advocacy support manager for People's Voices in Milton Keynes.</p>

The role of People's Voices advocates in Buckinghamshire

Buckinghamshire-based advocates supported services users with learning difficulties and physical disabilities on a range of issues. This included accommodation matters (helping with the paperwork; dealing with noisy neighbours); assisting people to apply for jobs; supporting parents with learning difficulties; and supporting service users when they met professionals. Sometimes the advocates were involved in small day-to-day tasks, which could be taken care of relatively quickly (for example, helping a service user to avoid getting parking tickets on a regular basis). Other issues were more complex (such as supporting someone in a lengthy legal dispute with their family), and required the advocate to support the individual over a period of months, or years.

Advocates were assigned to support individuals to deal with a particular issue (rather than to develop a long-term social relationship with them). However, some advocates worked with the same service user across a range of issues (if the partnership had been popular with both parties), and was therefore very well-known to the advocacy partner. Some advocates worked with a number of different advocacy partners simultaneously.

1.2 Talkback

Who's who at Talkback

Following its separation from People's Voices in 2000, Talkback became a registered charity and company limited by guarantee. At the time of writing it employed five full-time workers ('the team') none of whom had a learning difficulty. Jean Rein was named as the chief executive of Talkback, and there were two project workers (Simon Evans and Lyn Griffiths). Talkback also had one 'About Me Group' support worker, who joined the organisation after I completed my fieldwork (Jason Mahoney), and one administrator (Alison Ball). On a day to day basis all of the team took on support worker roles, although Jean and the two project workers also had additional responsibilities. The team worked from an office in a community centre in Amersham, although apart from the administrator they spent most of their working hours outside of the office, meeting people with learning difficulties in a variety of settings. People with learning difficulties (generally from the various 'core' groups – see below) were often present at the office, either for meetings, or to do various pieces of work for Talkback.

Chapter 4 discussed the establishment of Talkback's 'core group' in the late 1990s. This was a group of people with learning difficulties who worked alongside the Talkback

team, and who were involved in the running of the organisation. However, it is worth acknowledging that at times, the term 'team' was used interchangeably by participants to refer to both the salaried staff alone, as well as the combined efforts of the salaried workers *and* the core group of people with learning difficulties who worked at the 'hub' of Talkback (see figure 3 for a Talkback image of the team that incorporates self-advocates and staff). This may be a result of the fact that people in the core group were paid on a freelance basis for training and consultancy work they undertook with Talkback. In 2004, due to Talkback's growing workload, the core group was dissolved, and was replaced by three new groups (the Management Group, the Finding Out Group and the Checking Out Group) – the details of which are outlined below. However, throughout the thesis, the term 'core group' will be used to refer to the activities of any one of these new groups – as it effectively represents the work of self-advocates involved in the organisational maintenance and development of Talkback. A number of self-advocates from the previous core group continued to participate in at least two of the three new groups. Below is a summary of the remit of each group at the time of writing. I have not named specific individuals in these groups, as they tended to be quite fluid. Some members moved between groups, depending on what type of work they wished to be involved in at different times.

- **The Management Group** adopted the issues that relate to the internal workings of the organisation, and the members of this group worked closely with the staff team in 'running' Talkback. Eight people with learning difficulties made up this group, and they were supported by Jean, Simon and Lyn. This group discussed funding, new projects, staffing issues and any other concerns that related to the future of Talkback. The Management Group also attended Talkback Board meetings. However, a number of practical organisational activities and issues

such as health and safety at work, remuneration for the paid staff, the drafting of policy and strategy, and correspondence with the Charities Commission and Company House did not fall under the group's remit. These tasks were undertaken by the chief executive.

- **The Finding Out Group** was responsible for the research and consultation agenda of Talkback. Projects included a longitudinal evaluation of Buckinghamshire County Council's modernisation of day services, which involved the Finding Out Group conducting interviews with service users, staff and management. The group were also trained to do 'side by side' work with people who do not use speech, in order to try and include their perspective.
- **The Checking Out Group** was responsible for monitoring and evaluating the work undertaken by Talkback. It continually checked the quality and standard of the service provided by Talkback from the perspective of service users.

Co-leads and the Learning Disability Partnership Board

Another important aspect within the development of Talkback's structures has been the founding of the Learning Disability Partnership Board (LDPB) co-leads. The idea of co-leads was developed in 2004, and involved the pairing of four Talkback self-advocates with four officials from the Buckinghamshire Integrated Learning Disability Service. Each pair of co-leads worked on a specific Partnership Board theme, and assembled in advance of each LDPB meeting in order to discuss the progress of their particular service development area. Fred Charman – a member of the Management Group – co-chaired the LDPB with Peter Loose, Head of Adult Disability and Mental Health Services. The co-lead process will be discussed further in chapter 7.

Figure 3: The Talkback team - with self-advocates and staff



The Board of Trustees

During the fieldwork, Talkback's Board consisted of seven non-disabled Trustees, including its then Chair, Clare Hawes. A third of Trustees had to step down each year, although they could be re-elected at the Annual General Meetings. The Management Group also attended Board meetings, and had the same powers to vote on organisational decisions as Trustees, although the Management Group were self-identified, and thus not elected. The Board of Trustees was open to people with learning difficulties, but at the time of writing, no self-advocates had chosen to nominate themselves. Jean Rein offered two possible explanations for this (telephone conversation, 06/09/06). First, she clarified that people who sat on the Board as Trustees were precluded from undertaking paid work for Talkback, and thus could not be remunerated for training and consultancy activities. Second, she suggested that people with learning difficulties seemed satisfied

that their voices could be fed into decision-making processes through organisational structures such as the 'About Us Voice' and the Management Group. These issues will be discussed in more depth in chapter 6.

Organisational Activities

At the time of writing, it was estimated by Jean Rein that Talkback engaged with approximately 200 people with learning difficulties across Buckinghamshire. Most of these people were in contact with the Talkback team on a fortnightly basis through different 'About Me' groups. Some people with high support needs met with Talkback members every week. Beyond the Buckinghamshire borders, Talkback recently secured a tender to develop self-advocacy in Milton Keynes. The organisation was also involved in developing a training programme for national service providers, and participated in the national ethnicity and learning disability strategy. These activities – and others - undertaken by the group during the fieldwork, are outlined below:

Table 3: Organisational activities at Talkback

Activity	Description	Key players
About Me Groups	<p>These small self-advocacy groups take place in a variety of settings across Buckinghamshire. Most are service settings, such as day centres, and residential accommodation units. In the latter, some self-advocacy work is done on a one-to-one basis in the early stages. Talkback also facilitates a weekend self-advocacy group in Amersham every month for people with learning difficulties who do not use services. The activities of these groups is referred to by Talkback as the '<i>About Me Voice</i>'.</p> <p>These groups are primarily concerned with developing the self-advocacy skills of people with learning difficulties, in settings that are familiar and comfortable. About Me groups focus upon:</p> <ul style="list-style-type: none"> • developing people's 'emotional literacy', which involves thinking about feelings, and interactions with others • encouraging people to assess their life options through thinking about 'hopes and dreams' • teaching people to 'learn how to look', a process that 	<p>These groups are facilitated by members of the Talkback 'team'. This includes people with and without learning difficulties. However, About Me Groups that operate in residential homes are facilitated by a non-disabled team member.</p>

	<p>involves knowing which questions to ask, and making choices from an informed position</p> <ul style="list-style-type: none"> • building up people's confidence to speak in group situations • facilitating the group to make decisions together regarding their collective experiences in particular service settings. 	
The User Parliament	<p>The User Parliament is the element of Talkback which feeds the 'user voice' into service design and delivery. It is the means by which the 'representative' voice of self-advocates in all the different About Me groups is channelled through to important decision-making bodies, such as the Learning Disability Partnership Board. At Talkback, this is referred to as <i>'The About Us Voice'</i>.</p> <p>About Me groups are asked for their views on a range of topics, and also highlight issues that are pertinent to them. These views are collated and disseminated to different stakeholders. The aim of the User Parliament is to give people with learning difficulties an opportunity to communicate their perspectives collectively beyond the confines of their About Me group, so that other parties can hear these views, and act upon them where possible.</p>	<p>The Talkback team is responsible for collating and analysing all the views that emerge from the different About Me groups. Simon Evans takes the lead on this.</p>
Projects	<p>Talkback receives funding to develop specific projects. Some of these projects involve the undertaking of research activities in order to assess gaps in services, and to suggest and develop ways of meeting people's needs. Some of these projects have been developed in the light of issues raised by people with learning difficulties in the About Me groups. Below are three examples of current Talkback projects:</p> <ul style="list-style-type: none"> • Self-advocacy for people with high support needs. This project received funding in 2005, and has enabled the Talkback support team to facilitate very small self-advocacy groups for people with profound learning difficulties. This project emerged as a response to the challenges Talkback members experienced when trying to include people with high support needs within existing About Me groups • Self-advocacy for people with learning difficulties from Black and Minority Ethnic communities (BME). This has included setting up specific self-advocacy groups for people from BME communities in Buckinghamshire, and an involvement in the national ethnicity leadership programme • Health issues for people with learning difficulties. This project involved the development of 'Health Passports' for service users. These passports contain information about an individual which service users can show to health and social care professionals. The passports also mean that service users have a personal record of their health needs. 	<p>Individual team members, such as Simon Evans, or Lyn Griffiths will take the lead on specific projects. However, projects are a collaborative undertaking, in which members of the 'core' groups, as well as self-advocates from About Me groups are involved in researching and consulting on particular topics, as well as developing ideas for change.</p>
Training, evaluation and consultancy	<ul style="list-style-type: none"> • Talkback offers 'disability awareness' training to a number of different stakeholders working with people with learning difficulties. This includes service providers, staff, statutory authority officials, health and social care professionals and volunteer advocates • The organisation has also worked on the 'From the Inside Looking Out' (FILO) project. This has involved designing a training and evaluation programme for national providers of learning disability services, which aims to develop and support the 'emotional literacy' of service users. 	<p>The team and self-advocates from the core group undertake Talkback's training and consultancy work.</p>

2. Values and principles in advocacy

The literature emphasises the extent to which advocacy organisations are ‘values-led’ (see chapter 2). It also demonstrates that advocacy organisations tend to be guided by strong principles. ‘Values’ and ‘principles’ are often used interchangeably by writers on advocacy, which as Clement (2002) argues, can add confusion to an already complex picture. I support the distinction that values are ‘a type of belief... about how one ought, or ought not to behave, or about some end-state existence worth, or not worth attaining’ (Rokeach, 1968:124), thus providing the basis for action, whereas principles are the standards and guidelines through which values are enacted. Hopefully that distinction will clarify the assertions made about the two advocacy groups in this section.

Bearing this in mind, I set about trying to find out whether the advocacy organisations in this study claimed to be motivated by similar or different ideals to those espoused by other groups in the literature. I found that both organisations were driven by comparable goals to improve the lives of people with learning difficulties and to enable people to ‘have a voice’. The two groups were also driven by a similar set of values to one another – although at Talkback, these were primarily articulated by the staff team, rather than the self-advocates. Both People’s Voices and Talkback had a strong set of principles, although at times, the rigid application of such principles – particularly in one-to-one advocacy, appeared to reveal tensions between specific values, for example, those of equality and autonomy. Talkback was characterised by a greater multitude of perspectives regarding what self-advocacy is, or ought to be about, and there were some differences in how particular activities and achievements were framed by the non-disabled support staff, in contrast to the self-advocates. For example, the staff team tended to view learning, self-knowledge and political action as the most significant

tenets of self-advocacy, whereas some of the self-advocates suggested that opportunities for socialising and networking were self-advocacy's major purpose. However, it could be argued that both strands lead to similar outcomes – notably, personal development and the advancement of a collective identity. These issues are further developed throughout the following section.

2.1 Values, principles and goals at People's Voices: official organisational discourses

The People's Voices mission: uncovering the organisation's purpose and goals

Advocacy has a role in assisting the transition of users from institutions into independent living in the community. It has a role in ensuring that emphasis is placed on an individual's idiosyncratic needs and in defining some of the gaps left by services. And finally it has a role in helping users of services and their carers make their voices heard in improving existing services.

(Extracts from the People's Voices training manual, 2006)

This extract from the People's Voices training manual outlines the rationale for the organisation's existence. It locates the work of People's Voices both at the macro level (deinstitutionalisation, community care, service deficiencies), whilst also highlighting the role of advocacy at the micro level (working with people and their specific needs and circumstances). It acknowledges that despite good intentions, and powerful government rhetoric, the recent changes in service delivery continue to result in unsatisfactory outcomes for some people. Advocacy plays a role in articulating these service inadequacies, in order to improve people's quality of life. The Advocacy

Guidance documentation highlights that whilst people remain isolated, vulnerable, or perhaps simply in need of an independent ally, there will continue to be a demand for advocates (Buckinghamshire County Council, 2005: 9-10).

At People's Voices, advocacy was generally perceived by members as having a facilitative role. It was framed as an enabling process which offers the practical support needed for people to assert their views, and where possible, to have their wishes acted upon. It was accepted that people *can* and *do* know what they want, but might struggle (either due to circumstances or the nature of their impairment) to actively pursue their objectives. Advocacy steps in to facilitate the achievement of people's wishes:

Liz: Why does this organisation exist?

Brian: Because there are people out there who know what they want, but they cannot achieve it for one reason or the other – either because they can't communicate sufficiently, or they don't have any back-up from family. A lot of people know what they want...

(PV5, p.5/6)

It was suggested by Barbara that the one-to-one advocacy undertaken by People's Voices has one ultimate aim:

I would say that advocacy is always a means to an end - which is user control.

(Email correspondence with Barbara Poole, 10/03/06)

This statement confirms the notion that advocacy was perceived at People's Voices as a process that can facilitate individual empowerment. One of the advocates explicitly made this point:

Wilma: I am – as advocacy is understood – there to empower people to speak.
(PV6, p.2)

However, empowerment is a relatively ambiguous concept, which may or may not result in positive outcomes for the advocacy partner. Indeed, the advocates explained that some advocacy partnerships do not result in the achievement of a service user's objective, either because the aspiration was simply unrealistic on too many levels or because the resources were not made available by the respective stakeholders. As Clement (2002) has pointed out, such assertions about the capacity of advocacy to 'empower' are rarely grounded in understandings of the nature of power. Thus 'empowerment' (like the term 'advocacy partner' – discussed in the literature review) may at times be employed – intentionally or otherwise – to mask important power differentials.

Values and beliefs about advocacy partners

Volunteer advocates must believe in the dignity of all people and respect the rights and views of everyone. They help people live the lives they want to and represent their views at all times. Advocates are separate from any service providers and have no conflict of interest.

(People's Voices website, 2006)

The statement above about ‘volunteering’ on the People’s Voices website articulates some of the values espoused in the group’s organisational discourse. These written values will be compared and contrasted with what respondents told me in interviews.

The website statement reflects the basic tenets enshrined in the 2001 White Paper *Valuing People*, which emphasised the importance of rights, independence, choice and inclusion in the lives of people with learning difficulties. First, the statement suggests a number of values that relate specifically to the groups of people that come to use the People’s Voices ‘service’. Linguistically, the statement frames these values as a ‘world-view’; as beliefs that refer to *all* human beings. For example, People’s Voices claims to believe in the dignity of all people. This is borne out in the statement’s **rejection of labels**. Attention is not drawn to ‘categories’ of service users, a value which is in line with the People First slogan of ‘label jars not people’. This value was challenged in practice as interviewees regularly found it useful to distinguish between different users, leading to an inevitable taxonomy of advocacy partners:

Wilma: Well, initially I came in to work with young adults with learning difficulties and physical disabilities, which I did. My first partner had a physical disability and a learning difficulty to an extent. But now I find that I have as many partners with mental health issues...

(PV6, p. 1)

However, at times such labelling was problematised by the interviewees themselves:

Brian: The second longest partnership I've had was with a couple...I mean both have learning difficulties, although today he would not be classed as having learning difficulties.

(PV5, p.3-4)

A second core value articulated on the People's Voices website is the belief that everybody – regardless of impairment - is entitled to **rights**. This is regularly espoused by advocacy organisations, as was demonstrated in Chapter 2 (literature review):

Rights means being treated equally just like other people living in the community. It means the right to contact an advocate when they want one, the right to change or keep the same advocate, the right to be heard.

(Buckinghamshire County Council, 2005: 11)

Interestingly, respondents did not refer to 'rights' in the interviews in any explicit sense. This suggests that in practice, members of People's Voices may have perceived rights as so integral to the work they do, that they did not warrant a specific reference. Alternatively, it may suggest that members were somehow uncomfortable with an overt articulation of the rights agenda.

Third, the People's Voices website statement suggests that the organisation believes in the **acknowledgment of individual perspectives** – regardless of whether particular people, or groups of people have traditionally had their views silenced or ignored. At People's Voices, acknowledgement of the partner's view led directly to a corresponding action on the part of the advocate. Even if other people may have disagreed with the

perspective of the partner, it was the advocate's role to support the service user to reach their particular goal:

Brian: Yes, in this particular case I was keeping in contact a lot until just after the father died, and then the mother decided that she didn't want her daughter to move after all. It was very difficult. Because if you appreciate that my job is to try and achieve what the person themselves wants to achieve, then her mother's thoughts on it didn't really matter to me. But obviously she was a strong influence on her daughter.

(PV5, p.2-3)

The fourth value that emerges from the People's Voices statement with regard to advocacy partners, is the belief that they should have **choice and autonomy** in their lives. People's Voices' official documentation suggests that all human beings – including the most vulnerable and disadvantaged – should be enabled to make their own decisions, and be supported to follow those decisions through by those around them.

This was further emphasised by Anita English, chair of the Board:

...the whole purpose of people living in the community is to start making their own decisions about their own lives, even if they make mistakes.

(PV2, p.13)

In the context of self-advocacy, recent research has argued that an important element of people's development and growth as individuals is being permitted to take chances, make mistakes and learn from the experience (Chapman, 2005), which corresponds with the views of Anita English raised here.

Values and beliefs about advocates and the advocacy relationship

The People's Voices statement about its beliefs also indicates that at the official level, the organisation values the **independence of advocates** from service providers.

Independence is valued because it rests upon the assumption that people from a service background are likely to experience a conflict of interest in their role as advocate.

Neutrality of the advocate is perceived as an essential means of both enabling the advocacy partner to voice their own desires and act upon those wishes. This has been a key principle from the earliest history of advocacy, and continues to be valued by many advocacy practitioners today (Wolfensberger, 1973; Monaghan, 2005).⁷ Wilma Smith argued that independence from providers ensured that she could avoid a potential conflict of interest:

I'm not paid by anybody, and therefore I don't have a loyalty to anybody, except for the advocacy service that I'm working for.

(PV6, p.6)

This quote raises the issue of whether an advocate is ultimately accountable to the advocacy partner or the organisation. I did not hear about any instances at People's Voices in which the two came into conflict. Rather, stories were relayed to me by the advocates and managers about cases in which the organisation, advocate and partner all rallied together against other stakeholders in order to pursue a particular outcome. Nevertheless, Wilma's quote does indicate a potential tension for advocates regarding with whom their loyalty resides. The framing of advocacy as a 'service' is another

⁷ However, it should be noted that The Mental Capacity Act consultation on advocacy demonstrated that a small percentage of contributors were not averse to non-independent advocates (DoH, 2006).

finding in my work on People's Voices, (as articulated by Wilma in this quote, and by a number of organisational members) and will be discussed in detail in chapter 7.

Principles guiding People's Voices

At People's Voices, advocates are never given licence to make a decision *on behalf* of the advocacy partner, or provide them with personal advice (such as 'I think you should do 'x'):

The service user's choice must always be supported, providing it is within the law. A boundary is crossed when an advocate expresses their own views or encourages a particular course of action. (Buckinghamshire County Council, 2005: 1)

This is in line with recent ARX stipulations, although arguably the People's Voices' position is less ambiguous:

It is essential that advocates strive to define situations from their partner's perspective thus ensuring that the views of the person with a disability carry as much weight and do not become distorted by the interests of others.

(ARX, 2006)

A core principle of People's Voices is that **advocates never take action that is not agreed to by the advocacy partner**. As both the advocates commented, there have been instances in which they felt that the advocacy partner may be making a mistake.

However, as People's Voices advocates, they have been instructed to reserve their judgement, and support the service user's decision:

Brian: Well yes, and that's a problem of doing this job to some extent. It's telling other people that really, you're not interfering, you're not trying to do what you think necessarily is even right for them, at the end of the day it's about what people themselves want to do.

(PV5, p.3)

Wilma added that there can be benefits in allowing people to follow their chosen path, because undertaking the process can be a significant learning experience:

Sometimes you realise that it wouldn't really be a practical proposition for what they want as the end product as it were. But you still help them on their way, because sometimes in the finding out, they discover that it's not something they could necessarily do anyway. We're obviously not in a position to advise or counsel or whatever. But if you feel that's what they need, I have referred one lady onto bereavement counselling, and another onto just counselling.

(PV6, p.2)

A second core principle at People's Voices was the organisation's 'no befriending' policy, representing a fundamental division between the group and other organisations operating with the typical citizen advocacy model.

This principle has arisen as a result of Barbara Poole's perception that citizen advocacy relationships can foster an unhealthy dependency. Barbara said that she valued the

autonomy of the advocacy partners over the skills, knowledge and capacity for decision-making that an advocate might possess. She viewed some citizen advocacy partnerships as potentially paternalistic in their reverence of advocates. In her 'hierarchy' of values (Rokeach, 1968), Barbara ranked the enabling of people's independence above the necessity to facilitate friendships for them. A consequence of this is that advocates at People's Voices are instructed **not** to socialise in any way with partners. This principle is in stark contrast to the earlier advocacy organisations, whose very *raison d'être* was to develop social relationships between advocates and partners (Simons, 1993). The quote below illustrates how Barbara has sought to distance People's Voices from one-to-one advocacy's roots in protective services, which referred to partners as protégés, and placed them under the care of others (Wolfensberger, 1973; Clement, 2002):

I think one of the main problems around citizen advocacy is it creates another level of dependency. And we don't want our advocates to involve their advocacy partners in their own lives...That is not something that we do as an organisation. If somebody wants to go out to the pub, or wants something like that, then we'll help them find that person. I mean, as an organisation, training is committed to the whole idea of social inclusion, obviously, but it's not social inclusion as modelled by the advocate – that's not their responsibility. Their responsibility is to help somebody sort something out, and find the person that can help. I mean we do do the emotional bits, helping people to find friends, but we don't do the befriending, that's the difference...I suppose if you say advocacy is instrumental / expressive, we're closer to the instrumental end.

(PV1, p.6)

This quote presents a number of findings about the position that has been adopted by People's Voices - through Barbara – on one-to-one advocacy. Inclusion was raised in

the literature review as a driving principle of many advocacy organisations. On an instrumental level, it refers to people physically living in the community, and having access to the kinds of resources accessible to much of the population. However, early advocacy pioneers argued that inclusion is also about relationships and developing a rewarding social life. Citizen advocacy schemes rest upon the assumption that for people with learning difficulties, this may be difficult to achieve on their own – thus the advocate can provide a pathway to this more complex notion of ‘inclusion’. However, Barbara problematised this perspective, suggesting that it may inadvertently preference the advocate’s concept of inclusion over and above the partner’s own perspective. Instead, she perceived the advocate’s role as being a means for the partner to find their own pathway to a fulfilling social life.

2.2 Resistant narratives: negotiating tensions and boundaries in the practice of one-to-one advocacy

Tensions between different values

Barbara Poole accepted that advocacy has historically been defined by a particular set of values and principles. However, she argued that tensions have occurred among advocacy organisations due to the original citizen advocacy model’s inflexibility around principles (for example, refusing to pay advocates’ expenses; a preference for long-term as opposed to short-term partnerships). People’s Voices was framed by Barbara as the more ‘pragmatic’ type of organisation that has adapted itself to local needs and resources:

I mean one of the problems has been first of all that it came across, certainly with Wolfensberger and O'Brien, it started in this country really as a very principled, values-based idea, the whole idea of advocacy, and citizen advocacy in particular. So there has been, over the years some considerable tension I think you could say with organisations which have stuck very much to the Wolfensberger model, and those that I would suggest have been more pragmatic about things...which is where I would put People's Voices as an organisation.

(PV1, p.1)

However, despite Barbara's suggestion that People's Voices has fostered a climate of flexibility, there were also indications that advocates did sometimes feel the need to stick rigidly to organisational principles – even if this raised tensions between organisational values. Brian Drew recounted an incident in which his advocate role was challenged by a partner who suggested going out socially for a drink. Despite the partner's acceptance that he could develop a more 'expressive' relationship with his advocate, Brian stuck to the People's Voices principle of *not* taking on any kind of 'friend' role:

And that was something that was stressed right at the beginning – ours is not a citizen advocacy organisation...So no way would I take my partner along to meet any of my family or friends. There was one chap I was partnered with for a time, and he had cerebral palsy and was in a wheelchair, and he was very well educated, and a very astute person. And he was keen go down the pub and have a drink, and maybe make it more of a social activity. I had great difficulty in saying 'I can't do that, it's not my job'. If it's part of the broader situation that we needed to go to the pub to meet somebody who can help in what you're trying to do, then that's a different matter. But I'm not

going to go down the pub with you just for a drink because that's not my role. And because in a friendship, you might not know where you are. So I've always been very careful about that.

(PV5, p.5)

The penultimate sentence of this passage seems to suggest that in Brian's view, developing a friendship with an advocacy partner might somehow be a perilous undertaking. This stands in contrast to other People's Voices' values which purport to believe in equality among all human beings. If service users are equal, then why is it less appropriate or more risky for advocates to develop friendships with them as they would do with others? This illustrates some tension between different organisational values at People's Voices, and also demonstrates a certain rigidity in their enactment. Later in the interview, Brian provided an explanation for his comment. He argued that as a friend, one is less likely to be 'objective' about another person's situation, and could be more inclined to interfere and provide them with advice. An advocacy partner might be surrounded by people trying to intervene in this way, and therefore an advocate's role as a neutral individual (whose purpose is solely to provide back-up for the wishes of the partner), becomes even more pertinent:

Brian: ... a lot of well-meaning friends, carers, whatever, will say 'so and so should be doing this'. Well, unless they decide that's what they want to do, then as an organisation we shouldn't be interested.

(PV5, p.7)

Organisational principles versus human obligations

The quotes above suggest that Brian Drew was able to accept the central tenets of the People's Voices 'no befriending' policy. This may be because Brian believed in the possibility of neutrality, and strove to reach a position of objectivity in his role as advocate. Friendship was thus perceived as clouding this intention.

However, this organisational principle is complicated when an advocate takes a different philosophical position – one which problematises their ability to be completely impartial within the advocacy relationship. Wilma Smith - the other advocate that I interviewed - acknowledged that sometimes the relationships do become highly charged and emotional. She admitted that in her first few cases, she became so anxious and worried for the advocacy partner that she had difficulty sleeping. A consequence of Wilma's position was that she sometimes did offer something of a 'befriending' role. Wilma argued that at times this is a natural – and necessary - precursor to being an effective advocate:

Strictly speaking we're not supposed to (befriend), but at times I do. Because in order to get somebody's confidence, you have to befriend a bit. You have to be sympathetic – and what is that if it's not befriending to an extent? I mean, that's what friends do.

(PV6, p.3)

However, Wilma pointed out that the befriending activities were not recorded as 'People's Voices' time:

Because strictly speaking I suppose befriending is accompanying someone to places which they don't need to go to with an advocate – it might be a meeting at the MS society, or it might be going off to buy clothes, or something like that, which we're not supposed to do. I must admit that I do do some things like that, although I never record that as time for People's Voices⁸ – so that doesn't really come under the advocacy.

(PV6, p.4)

Wilma believed that it was possible to separate her roles into 'advocacy' and 'befriending', although the passage above also signifies the blurred boundaries that exist with regard to what is, and what is not advocacy. Wilma also highlighted the difficulties experienced by advocates who may feel the human obligation to act outside of the restrictions imposed upon them by organisational principles. The desire to make a distinction between 'befriending' and 'advocacy' may have arisen from Wilma's understanding of the policies of People's Voices advocacy. It seemed that a combination of Barbara Poole's training programme and the advice and support passed through the advocacy coordinator (Becky Jones), had successfully instilled advocates with a number of the values and principles that People's Voices was founded upon. However, as Clement (2002) has argued, members of organisations may hold these values in tandem with their own personal beliefs, which have been developed through a lifetime of experience. Whilst these values may not be entirely contradictory, they may be ordered in a hierarchical value system (Rokeach, 1968). When situations arise that appear to force a decision between different values, individuals may need to draw upon their own 'rules' for prioritising one value over another. Despite Barbara Poole's

⁸ Every month, advocates are asked by the organisation to quantify the total amount of time spent on each advocacy case (this includes face-to-face meetings and telephone calls). The advocates must also inform the organisation how many letters they write on behalf of the advocacy partner. This originally stemmed from a commission-led objective to 'unit cost' face-to-face advocacy interactions. However, Barbara Poole now encourages advocates to record other types of activity that take into account all the different facets of an advocacy partnership (such as telephone calls and letter writing), in line with a full cost recovery approach. (Telephone conversation with Barbara Poole, 02/03/07).

success in disseminating People's Voices' values to advocates, there are clearly times when the advocate has to take the initiative, even if this means compromising the rigidity of a particular principle. As Becky Jones acknowledged:

Becky: ... if it's small things, an advocate will make up his or her own mind as to what they do.

(PV4, p.4)

Volunteering, altruism and alternative narrations of advocacy

The official documentation, coupled with Barbara Poole's transcript, conceptualises advocacy as a path to user control and empowerment. The advocate is constituted as a tool that facilitates the process. However, the transcripts of other interviewees included alternative ways of narrating the advocate's role which acknowledged their own personhood and personal motivations. Primarily, these passages highlighted the advocates' desire to 'do good' and to 'help and support' people:

Anita: Advocacy is there to support the vulnerable.

(PV2, p.14)

Existing research into the nature of volunteering has demonstrated how volunteers tend to be motivated by a combination of factors, including a desire to achieve something positive for others, a quest to explore new experiences, and for self-reward – such as professional development and status enhancement within the community (Hustinx and Lammertyn, 2003; Okun et al, 1998; Rehberg, 2005). Whilst space precludes an in-depth discussion of the motivations driving volunteer advocates, it is interesting to note

how such discourses did permeate some of the People's Voices interviews, despite Barbara Poole's 'neutralising' of the advocate role and efforts to frame advocacy predominantly within the language of rights and empowerment.

Along the 'altruism-egotism' spectrum (Rehberg, 2005) the data suggested that advocates of People's Voices were motivated primarily through a desire to help others, although Wilma also indicated that she became involved for her own personal development:

I think the appeal was that it was something more than cups of tea and pushing library books around - it looked a little bit of a challenge.

(PV6, p.1)

Wilma Smith and Brian Drew both said that they joined People's Voices after retirement, in a bid to give something back to the community. Wilma gave strictly altruistic reasons for this, although she did acknowledge that having financial security and a previous career made it easier for her to fulfil such perceived social responsibilities:

And I do think there's a certain obligation on us all...That's what being a human being is all about. You can't take a totally selfish, negative view on other people. (PV6, p.8)

Brian moved away from explicit People's Voices' values, and spoke from a personal perspective about why he is an advocate:

As far as I'm concerned, that's a person there who is wanting help, and that's what I'm there for.

(PV5, p.4)

He went on to acknowledge that the partnership is partly about the outcomes of a particular situation, but also about the process of supporting someone through a difficult point in their lives:

It's nice to achieve something, but equally, if I don't achieve it, then I'm still hopefully doing some good.

(PV5, p.6)

Reviewing the central ideas of the humanist approach to social work, Clark highlights the:

essentially personal nature of the relationship...this is not identical with friendship; it occurs within a conventionally defined system of expectations which set it apart from unofficial relationships. Nevertheless, it entails a direct and sometimes intuitive apperception of the other (1991: 24).

The quote below demonstrates how Wilma instinctively enacted the type of empathetic role that Clark is writing about:

...I go through a period of getting to know the person, and when I begin to understand what it is I'm really there for, I try to put myself in their position. You know 'if this was

happening to me, how would I feel and what would I do about it?' And that really is my approach with everybody.

(PV6, p.3)

These passages indicate some discrepancy between the dominant organisational discourses at People's Voices and the narratives produced by some participants which countered them. Barbara Poole and the organisation's official documents neutralise the role of advocate as a means of empowering service users. However, the advocates that I interviewed were at least partially driven to do advocacy work as a means of 'helping' others. This might stand in tension with the organisation's aim to reduce 'levels of dependency'.

2.3 Values, principles and goals at Talkback

Unlike People's Voices, Talkback's official documents (including its website) do not explicitly outline its organisational values and principles. Instead, the Talkback literature makes a number of claims about what Talkback is and does, for example:

Talkback is a Buckinghamshire based, user led organisation for people with a learning disability. Talkback and self advocacy help people to build self confidence, feel good about themselves and to have more say and control over their own lives. (Talkback website, 2006)

Therefore, in order to elucidate the value-system subscribed to by Talkback, I had to explore the organisation's written records with greater sensitivity, listen carefully to both the overt and implicit comments made about values in the interviews that I conducted with organisational members, and observe whether these values were borne

out in practice. Unlike Clement's findings that the self-advocacy group in his research seemed to be privileging values 'over and above what needs to be done' (2003: 228), I argue that the 'doing' of self-advocacy takes precedence at Talkback. This can be evidenced by a wide range of activities that the organisation undertakes at any one time (see section 1). It is also demonstrated by the ways in which values and principles were articulated by staff and service users primarily through reference to specific Talkback pursuits.

I found that despite the lack of an explicit formal statement of its values, Talkback was still a values-led organisation (Hudson, 1995). It also became apparent that Talkback was driven by a greater variety of values than People's Voices. Indeed, this might be one reason for the breadth of Talkback activities, which members argued have taken them beyond the sphere of a 'typical' self-advocacy organisation. The diversity of values might be explained by the comparative youth of the group (in contrast to People's Voices, which has had longer to articulate and crystallise its primary values). However, I see this assortment of values as a consequence of Talkback's larger paid 'team'. Although Jean Rein did stand out as the group's principal driving force (see chapter 6 for a more in depth discussion about this), the support team members appeared to recognise and celebrate each others' previous experience and contribution to the organisation's growth:

Lyn: I think it's come about because of the different skills within the team, and experiences within the team...Like Jean's specific knowledge, and that combined with all our other skills which come together in a very creative way.

(TB6, p.8)

As was discussed at the beginning of section 2, values and principles were articulated most explicitly by the paid support team, rather than the self-advocates. This suggests that values may not be shared – or at least not articulated - by all the members of the organisation. It certainly indicates that there are multiple analyses of what self-advocacy is or should be, among different organisational players. This reveals a complex picture of organisational life and in turn has implications for the role that people with learning difficulties play in shaping and directing the organisation. These issues are raised in the following section, and will be developed further in chapter 6.

2.4 Values, principles and goals in self-advocacy: the perspectives of the support team

The rationale for Talkback

The staff team primarily saw the purpose of self-advocacy as enabling people to ‘have a voice’. Tied to this was the frequently espoused goal that people should be able to ‘say a real yes and a real no’, which came up in interviews and can be seen on the Talkback website. According to the support team, these goals rest upon values such as equality, inclusiveness, independence, choice and autonomy. The belief that Talkback should be user-led was also voiced by Jean Rein, although this tended to be overshadowed by a dominant discourse around ‘team-work’. The tensions between these ideals will be discussed further in chapter 6, where the tensions within the practice of advocacy are the focus.

The rationale for Talkback's existence was also framed around the goal of **improving people's quality of life**. Talkback's objective is, according to Simon Evans (project worker), to facilitate people to undertake this process for *themselves*:

I see it very much as being bottom-up, that's the first priority. It has to be people with a learning disability in Bucks who are empowered to improve their own quality of life – that's got to be Talkback's highest priority. All of the other work we undertake is to enable that to happen...it's done as a means to an end, to improve an individual's quality of life.

(TB5, p.2/3)

This quotation highlights an issue raised by Chapman's (2005) research, regarding whether self-advocacy takes the form of 'service advocacy' or 'grassroots' advocacy. Simon suggested that the former acts as a prelude to the latter, eventually leading to increased control for people with learning difficulties. However, the important role played by non-disabled staff in the management of Talkback (see chapter 6) and the power maintained by commissioners of advocacy in the service structure (see chapter 7) indicates that the empowerment of self-advocates in Buckinghamshire *on their own terms* remains an ongoing challenge for Talkback.

Lyn confirmed Simon's point, whilst also suggesting that people can become empowered to improve their own lives when they have the means to do so:

I suppose in the back of my head, all of the time, where I want to get to, is helping people to understand and make sense of the world as much as possible, and helping

them to equip themselves with all of the skills that you need to operate in the world.

(TB6, p.5)

Lyn generally framed the notion of ‘skills’ around facilitating self-advocates to develop an understanding of their emotions, and to question the options presented to them, in order to minimise their passivity, and increase their autonomy.

Values at Talkback

1. Equality and ‘the team’ approach

Like the People First self-advocacy organisations in Chapman’s (2005) study, the Talkback support team also appeared to be working to a disability equality agenda. This is evidenced in a phrase that appears on much of Talkback’s publicity material, including a recently produced short film about the group. The sound-bite *‘at Talkback, everyone matters, everyone is equal’* is one of the organisation’s few openly espoused values. In part, it may be that the phrase is used to signify a belief in ‘intrinsic equality’, or people’s ‘equal moral worth’ (Bamfield and Brooks, 2006), thus redressing the historical devaluation of people with learning difficulties. The phrase may also be used to justify the prominent role played by the non-disabled support team in the organisation’s development.

Also linked to the team approach was the belief among staff members that people with learning difficulties should be involved in the running of their organisation. However, as I argue in chapter 6, the term ‘user-led’ is ambiguous within Talkback, and is an example of where rhetoric may cloud reality.

2. Choice and autonomy for people with learning difficulties

As I indicated in the literature review, choice and autonomy are values espoused by most organisations practising advocacy (Atkinson, 1999; Simons, 1992; Goodley, 2000a). Lyn explained what this meant in practice at a self-advocacy group meeting. This meeting took place at a work-based scheme in Buckinghamshire, (anonymised in the quote as X) and Lyn used the example to indicate how little control some people with learning difficulties have in their day-to-day lives:

I don't have rules about you can't go out and get a drink – people are adults, they can come and go as they want. But everyone chooses to stay, and if they want to drift off, they come immediately back, like they've had a break. It's very different to how things usually happen in X - it's very, very controlled, and there's lots of people shepherding you around, and if you don't do this, then you'll get told off...they aren't empowered to be in charge and make real decisions.

(TB6, p.3-4)

Making 'real decisions' also entails deciding whether to stay at a self-advocacy group meeting or not. Lyn reported instances in which staff at centres where the About Me groups occur had 'forced' people to attend. If service users walked out it was cited as evidence of challenging behaviour, for which people were reprimanded. Despite an accusation of being 'soft' by one staff member, Lyn claimed that she makes it clear to people with learning difficulties that they have absolute freedom to come and go as they wish during an About Me group session. Having observed Lyn facilitate a number of core group meetings at Talkback, it seemed that she allowed considerable space for

service users to exercise choice – both in terms of the pace and structure of the meeting, and the issues that were raised. This is explored more thoroughly in chapter 6.

3. Inclusion

With regards to inclusion, Talkback had recently been awarded funding to facilitate About Me groups specifically with people who have high support needs. This raised an interesting dilemma for Talkback in deciphering the environments that are more likely to lead to the inclusion / exclusion of people with multiple and profound learning difficulties in the broader self-advocacy project. Whilst people with high support needs were often present at the generic About Me groups in the different resource centres, the team felt that it was important to assist these service users to develop self-advocacy skills in much smaller groups – sometimes on a one-to-one basis. Lyn Griffiths explained the rationale for developing specific groups for people with high support needs, even though in principle she believed that the About Me groups should be all-inclusive:

...my thinking is, you learn how to communicate by being treated as if you can communicate, and if you want to communicate. And we learn how to communicate by interacting with other people...This new project will be working specifically with people, and so we'll be able to really slow things down, and work at that pace. It'll be a lot easier not having to think about the whole group with all of the many, many different needs and abilities to concentrate on.

(TB6, p.1-2)

Talkback's decision to establish a project that focuses on developing self-advocacy among people with high support needs, addressed a common critique which argues that the self-advocacy movement has historically ignored this particular group of people (Mack 2001). Clement (2003) questioned whether it was truly possible for people with high support needs to engage meaningfully in self-advocacy. He wondered whether their inclusion necessitated stretching the boundaries of self-advocacy so far that it could refer to behaviour in any form (2003: 556). Members of the support team at Talkback (and the self-advocates – see below) contended that it *was* possible to include people with multiple and profound learning difficulties in the wider self-advocacy project, but that this required a more specialised way of working. They also argued that it involved focusing upon people's personal development, rather than trying to engage such individuals in organisational tasks. This is built upon a conceptualisation of self-advocacy which views personal development as both a valid and intrinsic element of it. This seemingly distinguishes Talkback from the People First group at the centre of Clement's study, or alternatively, from Clement's own view about what constitutes self-advocacy.

Principles at Talkback

1. A commitment to developing the emotional literacy of self-advocates

The support team illustrated the ways in which their organisational ideals were being put into practice. For example, service users' self-awareness (or 'emotional literacy') was being developed through the establishment of the FILO (From the Inside Looking Out) project, viewed by the members of the support team as an important precursor to successful self-advocacy. Learning how to judge your own feelings, as well as the feelings of others is a corner-stone of the self-advocacy work undertaken at Talkback,

and is becoming increasingly significant as the FILO project gains currency across the country. Jean explained the premise behind this:

...it gives you a better understanding of yourself, and what's happening, and how to cope, and all those things. And a better understanding of other people's emotions. It underpins all those things that are at our core, which is the whole thing about independence, self-advocacy, because knowing yourself enables you to do things differently.

(TB1b, p. 1-2)


It was argued that integral to the development of personal self-awareness is having the time, space, and skills to allow for reflection. Lyn Griffiths also argued that people with learning difficulties are often encouraged to undertake practical tasks, whilst time for reflection is not fostered:

...with all of the emphasis being on the doing, on doing the practical, then there's no time for people with learning disabilities and staff to step back, and actually think about what they're doing, and why they're doing it, and maybe, you might actually want to do something else.

(TB6, p.2)

This highlights that members of the support team believed that personal reflection and emotional literacy were important tenets of self-advocacy.

Figure 4: Talkback flier about emotional literacy



Feelings are not 'Good' or 'Bad'
they just are.
How you manage them and how
you are supported to manage
them is what Emotional Literacy
is all about ...

"Feelings Happen"

Emotional Literacy

Means

- Being aware of our own emotions
- Understanding and respecting the feelings of others
- Responding to the feelings of others

2. Focusing upon 'learning to look' in self-advocacy

Closely linked to the emotional literacy element of Talkback's self-advocacy, was the support team's belief in 'learning how to look'. Lyn explained:

*And so, you know, there could be things around understanding about feelings, understanding about relationships, personal development – all that kind of stuff. But then, when people have the knowledge, and have the skills, and **know how to ask** – then you can start making choices. (TB6, p.5, my emphasis)*

Developing people's confidence and knowledge were two recurring and interweaving objectives that arose in the interviews that I conducted with the staff team at Talkback. Being presented with choices was considered to be of less worth if service users do not have the confidence or knowledge to understand those options. Crucial to Talkback's approach in this area was helping people to 'learn how to ask'. Knowledge is not something that can necessarily be 'taught' or 'absorbed' through Talkback, but people can be supported to learn how to ask questions about the options available to them. In the passage below, Jean outlines how this element of the Talkback approach has been central to the organisation's way of 'doing self-advocacy' from the very early stages. The extract refers to the first major piece of consultative research that Talkback undertook, in the context of Buckinghamshire County Council's proposed cuts and modernisation of existing day services:

And so we'd ask (the service users) 'what did you think about that?' 'well, it was nice'. Ok, but what was nice about it? So we did this whole thing about learning how to look, what the benefits were, what the disadvantages were, and all of those things. And through that, people learnt the skills of self-advocacy, in a very natural way. And they learnt them in a way that they could generalise them. And they also learned to look at their own services: what was good and bad about them?

(TB1a, p.4)

Helping people to 'learn how to look' is not only a key organisational objective, it is also an important tenet in the wider philosophical aim voiced by Lyn, to help people make sense of the world around them. Although a visual metaphor, the term refers to a process of becoming more inquisitive, more questioning, and more confident to assess life options and make informed decisions about them. It also involves the development

of good research skills. This is an interesting accompaniment to three other idioms – ‘speaking up’ ‘having a voice’ and ‘being heard’ – all of which have become popular within self-advocacy discourse, and also appeared in interviews with many different Talkback members (including service users) and throughout their publicity material. Among the Talkback team ‘learning how to look’ was perceived to be a crucial prelude to ‘speaking up’ in a meaningful way. Likewise, ‘being heard’ involves developing skills which enable you to communicate effectively to the person who is listening. At Talkback, ‘learning how to look’ was considered an essential premise for dialogue between people with learning difficulties and others (even when the person does not use speech), as it helps people to be prepared and informed.

3. A commitment to developing reciprocal communication in self-advocacy

The staff team argued that another important facet to self-advocacy is assisting other people to better communicate with people with learning difficulties. In practice, this has resulted in a number of consultancy contracts, in which Talkback have undertaken ‘disability awareness’ training with professionals, local authority officials and students.

Talkback were also doing more work to assist the support workers of people with multiple and profound learning difficulties. The rationale for this work lies in the belief that people who have high support needs may be dependent on those around them to enable them to self-advocate:

Lyn: It will involve a lot of observation really, and probably checking things like how staff know that people with learning disabilities know that an interaction is about to begin, and what opportunities there are for people with learning disabilities to lead an

interaction. Because quite often, I think, what happens is, especially with people with kind of multiple learning disabilities, they are very dependent on the skills of the staff to interpret their behaviour. They can end up, quite often, sitting around waiting for life to happen around them.

(TB6, p.1)

A commitment to developing both the communication skills of individuals with learning difficulties and the people around them, is a principle linked to the organisational value of inclusion, referred to earlier. Lyn suggested that one method to help achieve real inclusion is facilitating people to understand one another. This principle also indicates that some players within Talkback draw upon elements of the social model of disability in constructing their organisational value-system. This is discussed further in section 3.

4. A commitment to accessible information in self-advocacy

The staff team also emphasised the role that accessible information plays in enabling people to self-advocate. This referred to the need for accessible information both within Talkback structures, and beyond them. This principle indicated that some members of Talkback viewed wider political endeavours as being an important part of self-advocacy's remit. It also signalled an acknowledgement of the reality of people's intellectual impairment, offering accessible information as one means of addressing this issue in practice.

In the passage below, Simon Evans discusses his perception of how Talkback influenced the Partnership Board to become more accessible. A significant part of Simon's role has been to utilise multi-media technology in order to produce accessible

material at Talkback – and so he has a particular interest in the wider impact that such developments might have:

Talkback introduced a large number of the accessible methods of the meeting... the idea of using pictures in real time to help information to be understood... presentations in a wide variety of formats... Talkback, I think, also had a strong influence on the speed and the pressure of meetings... and that was something that really enabled for my mind, the Partnership Board to stop being a tick-box filling meeting, and actually turn into something that can change and shape policy above.

(TB5, p.5)

Another story builds upon Simon's belief that Talkback has influenced the expansion of accessible information for people with learning difficulties in Buckinghamshire. The passage below comes from an interview with Rob Beattie, a Talkback self-advocate, who was recalling the contribution Talkback made to the Health Passports for people with learning difficulties, initiated by the local health authority. Rob and Simon explained how the original document was rejected by self-advocates at Talkback, who then became involved in designing an accessible version:

Rob: It was small, and not colourful, so disabled people couldn't read it.

Liz: So somebody else had been working on this?

Simon: There was an initial meeting, wasn't there Rob, at which Talkback were part of a multi-professional team, who all agreed that something like the Health Passport was needed, and that was the version that was made by the local secretary, and all of the professionals said that this was ready to be piloted, but what people like Steve, and a few others -

Rob: They said 'no it isn't because it's not readable for disabled people'.

Liz: So were you then involved in redesigning it so it then became readable?

Rob Yeah.

(TB3, p.3)

Interestingly, when I interviewed officers from Buckinghamshire County Council, they attributed the development of accessible information to the work of their own department. This raises a broader issue of the difficulties involved for researchers when trying to gauge the actors and events that influence change (Tilley, 2006). This will be discussed in more depth in chapter 7.

Talkback developed a number of accessible 'paper-rolls' to explain events that might be happening in the lives of people with learning difficulties (figure 5). During and after the About Me and Management Group meetings that I observed, thoughts, ideas and comments were 'written up' (using simple words and images) by Lyn Griffiths as an on-going record for service users to refer to. At the start of meetings, the group looked at the accessible 'minutes' of the previous meeting in order to refresh their memories of the discussion. Talkback had developed a number of accessible DVDs on a range of topics (including the organisation itself) to show to service users as they joined About Me groups. I noted a significant breadth of accessible material used by Talkback members (both within and outside of the organisation), and from my observations, service users seemed to be closely involved in the development of new forms of information production.

Figure 5: A Talkback paper-roll about de-registration for people with learning difficulties



2.5 Values and goals in self-advocacy: the perspectives of service users

Service users at Talkback did not articulate values and principles in the same way that staff members did. There was less explicit discussion about beliefs and goals from self-advocates, which may indicate that the values voiced by the support team had not been disseminated throughout the organisation. However, this analysis suggests that service users played a passive role in the shaping of Talkback. Instead, it seemed that service users were framing their understanding of Talkback's work in a different way, thus contributing their own narratives to knowledge about the group's value-system. Service users focused more on the 'doing' of self-advocacy, although occasionally they did voice particular beliefs and values which stood in contrast to those articulated by the support team. Service users described their views about Talkback predominantly in terms of achievements and outcomes, rather than focusing on future goals and ideals.

1. Self advocacy and rights

One example of where members' value-systems appeared to be in conflict is in their discussion of rights. In the passage below, Jean Rein outlines her views on rights, and how they have been adopted by some groups within the wider self-advocacy phenomenon:

I mean, even from the early days, we grew in quite a different way to a lot of other self-advocacy organisations. We've never been the banner-waving 'it's our right' type organisation. It's really been through learning through negotiation, and being there – finding out and being there.

(TB1a, p.4)

This indicates that Jean believed that rights can be something of a red herring in self-advocacy; a rhetorical flourish which disguises the extent to which people with learning difficulties remain limited in their ability to change their own life prospects and expectations. 'On the ground experience' was cited as having greater value than a potentially empty concept of rights. Jean also suggested that being a 'banner-waving, it's our right' type of group may lead to negative responses from others – whereas Jean preferred a strategy of negotiation. This is more understandable when one considers the history of Talkback, and the context in which it has grown (see chapter 4).

However, this perspective is complicated when we look at a quote from self-advocate Jackie Brodie. This demonstrated that Jackie not only drew upon a rights discourse, but that she also attributed her knowledge of it to her experiences with Talkback:

Chris: Yeah, we got involved, we got involved in Talkback through Barbara Poole.

Jean: Can you remember why, Chris?

Chris: 'Cause it gave us a chance to, speak up for ourselves, didn't it Jackie?

Jackie: Get your opinions.

Chris: Gave us, yeah, gave us our opinions.

Jackie: And our rights.

(TB2, p.2-3)

Jackie reiterated the point at a later stage in the interview:

Jean: And can you remember what you two were involved in, in trying to get people to

Jackie: Come to the meetings, and listen to all your rights.

(TB2, p.10)

This suggests that there may have been some conflict between the values aspired to by the staff team and self-advocates at Talkback. Alternatively, 'rights' may have been used as short-hand by self-advocates, to refer to a wider set of values and goals.

2. Self-advocacy, speaking up and inclusion

Two self-advocates focused specifically on Talkback's role in supporting people to speak up for themselves. Steve Dean used himself as an example, to demonstrate how Talkback has helped him to overcome his shyness and speak up:

How my life has changed is, as I've said before, before Talkback I was very quiet. I never used to speak up for myself, but now, through Talkback, Jean, you can't shut me up now!

(TB4, p.7)

Steve also commented that he is now confident enough to give public presentations. He explained how Jean encouraged service users to begin by giving presentations about themselves within the group:

Steve: And how the presentations started, we all chose something, we all had a practice, of something which we could do, and we did a presentation about it in our Core Group... And I did mine about my disability.

Liz: Do you feel more confident doing presentations, speaking in meetings?

Steve: Yeah, I do. 'Cause I don't go quiet.

(TB4, p.5-6)

Rob Beattie reiterated Steve's point, and extended it to other people with learning difficulties, who he perceived as having benefited from Talkback's work:

Liz: People who have a learning difficulty in Buckinghamshire, how do you think Talkback has changed their lives?

Rob: Quite a lot. They're talking up for themselves. Like, some people was a bit shy.

(TB3, p. 4)

Fred Charman makes a similar point in the passage below. Most of his interview was framed around how Talkback has supported other people with a learning difficulty to speak up:

Fred: Well the most important thing they do is they give people a voice. And people should have their voices heard. But not everyone actually uses words to communicate. There's lots of people who have to use different forms of communication, and they're normally the ones who are left out, because they don't actually use words.

Liz: And how does Talkback go about involving those people?

Fred: Well, I think how they resolve that one would be they work with them, but they take them in their own little room and let them work at their own pace. They don't say sort of 'come on – get on with it!', they let them take it at their own leisurely pace, and they get them to talk that way.

(TB8, p.2-3)

Fred's words were interesting, because he also dealt with the issue of inclusion. Fred acknowledged that a challenge for Talkback was involving people with high support needs in its self-advocacy work. He explained his understanding of how such work is undertaken, which corresponded with the description given by the support team.

Throughout his interview, Fred referred to Talkback as 'they', thus seeming to detach himself somewhat from the organisation. Fred's interview suggested that he understood much of Talkback's work as being undertaken by the paid support team.

3. Self-advocacy, choice and change

Chris and Jackie spoke at length about an incident at their day centre in which the About Me group initiated the closing down of the Tuck Shop and campaigned for its replacement with a vending machine. Supported by Jean, they explained why it was important for them to do this, and how their affiliation with Talkback helped to bring about a positive outcome:

Jackie: We wrote letters, didn't we? We got answers back – about the vending machine.

Chris: We had a word with Alistair, our unit co-ordinator. And he organised getting a vending machine. You used to get the snacks from the cash and carry.

Jean: Why did you want a vending machine?

Chris: Because it was, it was important to choose what snacks you wanted.

Jean: But, but what was it about the Tuck Shop that wasn't right... Can I just explain to Liz what happened?

Jackie: Yeah

Jean: In the Hillcrest About Me group, one of the things that people wanted to talk about, was the fact that the Tuck Shop didn't open reliably.

Chris: No, it didn't reliably. So we had a lot of staff that used to run it.

Jean: But they didn't know when it was going to be open, or for how long. And people tried lots of different things, like Jackie and David used to go around and say 'The Tuck Shop's open!' and things like that, but it was very unreliable. So they wrote to Alistair and invited him to a meeting.

(TB2, p.15)

Once the vending machine arrived, the interviewees told me about how they adapted it in order to make it accessible for a range of service users at their resource centre. This included putting pictures against different food and drink options so that people could see what items were available. A system was also set up so that it would be somebody with a learning difficulty who shopped for items when the vending machine was running low. Jackie, Chris, and Jean explained how a decision was reached at the outset about which items would be stocked:

Jean: Can you remember we did the,

Chris: Survey.

Jean: That's right.

Jackie: Yeah we did, didn't we – the survey!

Chris: Like, I don't know if you watch the quiz show 'Family Fortunes'?

Liz: I've seen it, yes.

Chris: Yeah? So if I give you an example, we asked the service users what packet of crisps, chocolates, sweets, drinks would come out on top.

Liz: Oh, I see!

Jean: And that's how the machine got filled!

(TB2, p.16)

The story about the vending machine was discussed by service users and support members on a few occasions during my time in the field. It seemed that this story was told and re-told to make a point about the potential of self-advocacy to effect concrete changes in people's everyday lives. However, it is also possible that this story was retold because of its rarity. This was one of only a few specific examples I heard about successful 'outcomes' of collective self-advocacy at Talkback. Chapter 6 will develop

the notion of whether members view self-advocacy as being primarily about processes or outcomes.

4. Self-advocacy, socialising and networking

Some service users focused upon how their work with Talkback had enabled them to meet new people, and enjoy social events. Chris discussed his memory of a Talkback trip to Milton Keynes, in which the group visited a day centre. Although Jean Rein was keen to stress what the group had learned from the day, Chris emphasised the fun he had at the pub:

We had a brilliant day. We went down by the Lord's Tavern.

(TB2, p.9)

At another point in the interview when I asked what activities he'd been involved in the past year he said:

We've been going through the personal centred planning, and we had a Christmas Party.

(TB2, p.11)

Chris also made a number of references to the people he had worked with over the years through Talkback. This included the organisation's support workers, professionals, officers from the local authority and other service users. Describing a Talkback self-advocate from the early days, Chris said:

He was a lovely chap to work with.

(TB2, p.4)

It seemed that for Chris, an important part of his role at Talkback was using it to network with other people, and make new contacts. This corroborates findings in other research, which have highlighted the development of social networks as an important motive in people's involvement in self-advocacy groups (Chapman, 2005). However, this was not explicitly emphasised as an important feature of self-advocacy by members of the staff team, suggesting a potential conflict in views with regard to what self-advocacy is in practice.

3. Constructing the value-systems in advocacy organisations

The theory-practice relationship

Having examined the value-systems in the two advocacy organisations in relation to the question 'what is advocacy in practice?' I now turn towards an exploration of how these systems have been constructed. In order to do this, I have drawn upon Walmsley's (2002) suggestion of looking more closely at how the practice of advocacy relates to the two principal theoretical positions that have impacted upon learning disability in the past thirty years. In what ways (if any) have the social model of disability and normalisation / social role valorisation informed the practice of advocacy at Talkback and People's Voices?

In relation to his research into the theory-practice relationship in social work,

Clark surmised:

...that practitioners probably do often use knowledge and theory in subtle and sophisticated ways which are simply not accessible if the researcher requires the practitioner to articulate his theory in the abstract (1991: 7).

Bearing this in mind, alongside recent research on the role of theory in self-advocacy organisations (Chapman, 2005), I decided to approach the theory-practice question by looking for implicit, as well as explicit references to theoretical perspectives. In order to better understand what leads to the development of particular values within an organisation, it is necessary to consider the alternative means by which people acquire their knowledge. It goes without saying that the life experiences that members bring to their respective groups is of great significance here, and has become a crucial facet in the wider research into self-advocacy (Goodley, 2000a).

The data showed that members of both organisations drew implicitly upon elements of the social model and social role valorisation, although explicit references to either were rare. It seemed that the advocacy practised by People's Voices and Talkback was underpinned by both theoretical perspectives. This may not be quite as contradictory as first appears. Whilst the two theories prescribe different courses of action – with the social model stipulating societal responsibility for negation of the causes of disability, and SRV recommending that individuals should reduce 'differentness' (or at least the perception of it) - it could be argued that both theories attempt to address the consequences of impairment. Bearing this in mind, it is less surprising to note that some respondents adopted both perspectives (albeit implicitly) when making sense of the advocacy undertaken within their organisation.

Advocates at People's Voices were trained in the major sociological developments of learning disability over the past three decades. Barbara Poole suggested this was partly for contextual knowledge, but it might also be related to the perception that grounding advocacy within wider theoretical frameworks helped to legitimise its practice. The advocates, on the other hand, were keen to distance themselves from the theory, and instead legitimised their work through notions of common sense and 'on the ground experience'. For Wilma and Brian, being an advocate was not something that could be 'learned' through gaining knowledge of theoretical arguments. Instead, advocacy was framed as an instinctive activity, reliant upon viewing each person as a unique individual. The advocates suggested that their responses to particular situations, issues and people were constructed from their own practical experience, and not from a theory that was taught to them.

Whilst theoretical perspectives may be influencing and informing the practice of the support staff in self-advocacy organisations, it should be acknowledged that they were not articulated by people with learning difficulties themselves. I did not find instances in which self-advocates seemed to be drawing upon social model or SRV theory, either implicitly or explicitly. Like Chapman (2005) it seemed that people with learning difficulties were more concerned about the practical 'doing' side of self-advocacy. However, I did find evidence in which comments made by self-advocates inadvertently addressed the contested issue of impairment as an essential versus socially constructed phenomenon. This reflected Goodley and Moore's (2000) assertion that people with learning difficulties can - and do - inform theoretical knowledge about the nature of impairment.

3.1 People's Voices and the role of substantive social scientific knowledge

The People's Voices training programme included an in-depth discussion of three theoretical perspectives. These three perspectives (normalisation / SRV; the social model of learning disability; and the Independent Living Movement) were included in order to explain the development of policy and services for disabled people over the past three decades. When I probed Barbara Poole on this further during an email exchange, her response seemed to suggest that she also informed trainee advocates of the theories and models so that they could understand how these 'big ideas' have impacted upon the values and principles of advocacy:

SRV was a major influence on the development of advocacy because of the involvement of Wolfensberger and John O'Brien who have been formative in the UK as well as the States. The social model of disability started with physical disability and the whole impetus around the independent living movement also underpins the principle of user involvement and control in their own lives. I would say that advocacy is always a means to an end - which is user control. I think that one of the dilemmas of advocacy delivery is when we are supporting someone who would prefer institutional services to independent services but obviously all change is scary and we have to support what people want, not what we think they should want - that is totally against advocacy principles.

(Email correspondence with Barbara Poole, 10/03/06)

Barbara acknowledged that the history of one-to-one advocacy is inextricably linked to Social Role Valorisation because the foundations of both lie with the same individuals - something that has already been pointed out in the literature (Walmsley, 2002).

However, in the passage above, Barbara also suggested that the development of advocacy at People's Voices has been more in line with the principles enshrined in the social model of disability, and the closely related Independent Living Movement. The dilemma she raises also corresponds with a social model principle that empowerment and freedom cannot be a 'top-down' action; it is something that needs to originate from service users themselves. The challenge for an advocate who espouses values such as independence for service users is how to marry this with a partner's decision not to choose an 'independent' course of action. The potential for assuming that a state of 'false consciousness' clouds the partner who cannot see what is 'best' for them in social model terms, risks undermining the very principle of user autonomy. Whilst advocacy at People's Voices is viewed as a facilitative process (to support service users to achieve their aims), Barbara was concerned that it should not be used as a process through which advocacy partners are 'taught' what to do by non-disabled people.

Implicit use of theory at People's Voices

The influence of the social model

I found some evidence of members of People's Voices drawing implicitly upon elements of the social model. Brian discussed comments made by an advocacy partner on how they perceived the role of advocacy. It implicitly draws on a central tenet from the social model which argues that the problems facing disabled people are not a result of their impairment, but of a disabling society:

And what she has said to me is 'at least you have made me see that it isn't us that's doing anything wrong – it's the system. It was achievable what we wanted, but there was something there standing in our way'.

(PV5, p.6)

Wilma also acknowledged that the actions of others can negatively influence a person's life, thus disabling them unnecessarily. She spoke about an advocacy partner who she was supporting into employment. The partner had supposedly displayed evidence of 'challenging behaviour', which Wilma tried to explain:

I had a young lady that I was working with, and she is very capable, although she's lazy as well. And she really needs to do something that uses a bit of thought and so on. But she was pushed into work experience into a cancer charity shop, where she was working with two old ladies who were getting her to carry all the heavy stuff, and really she was absolutely bored to tears. So she was rude to them. Well, I can understand why she was, but of course immediately what happened was 'well, we'll have to take her back to the psychiatrist', and it wasn't that at all. She didn't need to just have a few pills shoved in to calm her down. They'd fixed her up with something, and that was going to be it, and I think she could see that it was going to be it for ever.

(PV6, p.5)

One criticism levelled at the social model, has been its denial of the reality of impairment in the lives of disabled people (French, 1993). Wilma Smith addressed this issue when she expressed her personal belief in the essential nature of learning disability:

With learning difficulties, as you can imagine, it is ongoing if you like, because their particular problem, or particular disability is a learning difficulty...

(PV6, p. 1)

Wilma acknowledged that in her experience of advocating for people with learning difficulties, the nature of their impairment means that they may require assistance every time a significant new issue arises in their lives.

Denying the importance of theory: making a case for 'on the ground' experience

As Clark (1991) has argued, practitioners rarely articulate abstract theory, and will sometimes deny its utility or relevance for the day-to-day reality of the job in hand. This was something that I found among the two People's Voices advocates that I interviewed. Brian acknowledged that he learned about theoretical perspectives, but has found little use for them:

Yes, we have learnt something about the theories I suppose. And probably because I'm on the Board of People's Voices I hear more about it than the average advocate. The fact is, it just washes over me – I'm not interested in theories.

(PV5, p.4)

This viewpoint is worthy of note, as Brian's decision to resist friendships with advocacy partners did appear to have been informed by theoretical perspectives (see section 2.2).

Wilma made this point more forcefully and dismissed the notion that theory informs the advocacy that she practises. Wilma argued that she was guided in her role by the advocacy partners themselves; it was through getting to know them as individuals

(rather than evaluating them as part of a generalised category of people) that she judges how best to advocate, and how the partnership should develop:

It's on the ground experience. Yes, of course you're aware, and you become more aware. And sometimes you think 'what utter rubbish'. Because you are very close to these people.

(PV6, p.4-5)

The point that Wilma made about the utility of theory can be better understood in light of a comment she made about the uniqueness of each advocacy partner:

Everyone is different, that's another thing. No two are ever the same – even if the issue at the end of the day might be similar, no two people are the same.

(PV6, p. 1)

Wilma further developed this point in relation to what she interpreted as the potential risks involved in over-theorising. She spoke about her perception regarding the consequences of theories that had presumed to 'know' everything about a particular group of people – only to result in damaging the very individuals they purported to help.

Wilma viewed her own role as a means of dealing with the fall-out from policies derived from particular theoretical positions:

...there are professionals there who have studied and qualified to know what's best – although whether they do or not, I don't know...But there is a deeper something which in some instances, I don't think has been tapped. And that's the ability to make decisions and the levels of intelligence. Because sometimes they're farmed out to a day

centre and they're bored to tears. And then there's the other aspect, when they've sent a very introverted young man to learn car mechanics. Well, he can't concentrate yet on how to eat his food. But, it was a course that was available there.

(PV6, p.5)

Whilst elements of the social model certainly underpinned the practice of advocacy at People's Voices, particularly in relation to the core organisational goal of 'user control', interestingly, none of the participants that I interviewed at People's Voices drew attention to the fact that services users (with the exception of one mental health service user) have no influence in the running of People's Voices. Clearly, people without learning difficulties control People's Voices. What questions does this raise about the applicability of social model principles in the practice of advocacy? This will be discussed further in chapter 6.

3.2 Talkback and the role of substantive social scientific knowledge

At Talkback, there were no explicit references made to any theoretical positions. However, as with People's Voices, I did find evidence of members of the organisation drawing inadvertently on social role valorisation and the social model of disability.

Implicit use of theory at Talkback

The influence of Social Role Valorisation

Jean Rein explained how Talkback has always organised events at venues that are valued by the wider community. This reflects a central position of SRV that states that

people with learning difficulties should be positioned in places and roles that are valued by others, in order to reduce the likelihood of stigmatisation (Wolfensberger, 1983a). Jean's broader focus on the importance of 'quality' also reflects SRV ideas – as quality is a highly valued feature of organisational practice. For Jean, it is important to demonstrate that people with learning difficulties are capable of undertaking roles and responsibilities (such as presentations) as effectively as anybody else:

One of the things we focus on strongly is quality, because it underpins everything we think about values. And so whatever we do, wherever we hold it, quality is always there. So, if we're going to hold a conference, or whatever, we make sure that it's in a place that's valued, and it's a place where anybody could come. It helps people to break down barriers in the wider community.

(TB1a, p.13, my emphasis)

The passage below refers to a day when Talkback visited a new resource centre in Milton Keynes. The discussion shows Jean attempting to clarify the valued roles that people with learning difficulties held at this particular centre, such as running the bakery and the gardening centre, and serving customers. Interestingly, making this point is of less concern to Jackie and Chris (both Talkback self-advocates):

Jean: And can you remember where we went after the bakery?

Jackie: Oh, the shop? Was there a shop there, that did sweets, drinks?

Jean: That was a bit – yeah, there was, but didn't we go from there to the garden centre?

Jackie: Oh, yeah, we did.

Chris: Yeah, the horticulture. The horticulture. Now, if you go into the horticulture, they have all sorts of plants, like,

Jean: Who ran it? Who was doing the work, in the bakery, and then in the garden centre?

Chris: Volunteers

Jean: What sort of volunteers?

Chris: Erm,

Jean: Were they people with a learning disability?

Chris: They were, yeah.

Jean: And then you wanted to go to the shop, didn't you?

Jackie: Yeah

Chris: And had a little go on the cash register.

Jean: Who had a little go on the cash register?

Chris: Me.

Jean: And you were serving the customers then, weren't you?

(TB2, p.2-3)

This example also demonstrates differing perspectives amongst Jean and the self-advocates regarding the nature of impairment and reveals a notable tension in the narrative. This arises as a result of the conflict between Jean's need to highlight people's intellectual impairment in order to make her point about the valued roles they held at the resource centre, and Chris's identification of them as volunteers in the first instance. This short piece of conversation effectively encapsulates the complex debate regarding the contested nature of learning difficulties as a naturalised impairment (Goodley and Moore, 2000: 878). This will be discussed further in chapter 6.

Jean also drew implicitly upon SRV when she recounted the experiences of Talkback at the Consultation Group meetings, back in the late 1990s (see chapter 4). Jean attributed the permitting of service users to speak at meetings as a direct result of the professionalism among people with learning difficulties. Again, the narrative demonstrates a message about valued social roles that Jean aims to convey. Steve (a Talkback self-advocate) was keener to communicate the administrative role he played in events:

Jean: You were involved earlier on in the delightful, er do you remember, the Consultation Group

Steve: Yeah, was that the one I did the note-taking for? 'Cause I used to bring the pads and pens, and sat there taking notes, and then I discovered...

Jean: And I think, you know, that it's quite key that Rob and Steve were very involved in the early involvement in the changing culture.

Liz: And can you remember much about those meetings?

Steve: Erm, the only thing I can remember is, they were very long, they were always over in Aylesbury and I always did the note-taking. There was me, I used to bring a pad and pen, and do the notes, and at that time, I had a computer, which was given to me by Talkback.

(TB4, p.5)

However, it should be acknowledged that this passage also demonstrates Jean's aim to support people in remembering their achievements. As I discussed in chapter 3, Jean's presence throughout some interviews appeared to assist participants in remembering past events and experiences. In this way, Jean played a significant role in enabling some

people to remember and celebrate accomplishments at Talkback, albeit through a particular lens which did not always correspond with that of the self-advocates.

The influence of the social model

There is also evidence that Talkback members drew implicitly upon the social model of disability. For example, Simon and Jean articulated the belief that barriers in communication offer a significant explanation for the day-to-day difficulties experienced by people with intellectual impairments. In this way, they were reflecting a social model assumption that it is societal structures (including institutions and other people) that lead to disability:

Simon: That is still a large proportion of my remit, and that's around identifying barriers to healthcare for people with a learning disability, with people with a learning disability – building partnerships in the healthcare settings, outside of the specialist learning disability services, and finding ways to overcome those barriers.

(PV5, p.1)

The disability awareness programme that Talkback was running did not refer explicitly to the social model of disability. However, as the passage below indicates, its very purpose was to redress a disabling society, in which people without learning difficulties lack the skills to communicate with people who have learning difficulties:

Jean: And the gem of it is, we also get to do some disability awareness training with bus drivers...And we said that we felt that in order for this to be successful, that it needed to be broader than teaching people the practical skills of travelling around... Because the

reason that things go wrong is because people are not communicating well, and I don't always mean on the part of the person with the learning disability. (TB1b, p.4)

This 'disability awareness training' is also compatible with SRV's stress on community acceptance and integration.

Simon Evans believed that Talkback should aim to be a self-limiting organisation. This is because he hoped that the organisation could help to facilitate a future in which people with learning difficulties no longer need the assistance of an organisation in order to self-advocate:

I'm sure Talkback is, to a certain extent, a self-limiting organisation, in that I firmly believe that when Talkback's done everything Talkback can do, Talkback needs to stop. It's not a body that should continue permanently. However, I don't see that position being reached for some time...

(TB5, p.6)

Simon's point does, of course, raise all sorts of interesting issues about the nature of support for people with learning difficulties, and how Talkback might be compared to self-advocacy groups that focus more heavily on group consciousness-raising, rather than the development of individual skills. The quote also reveals Simon's assumption about the nature of learning disability. In line with the social model, he views learning disability as something which is primarily constructed by social structures. Thus the intellectual impairment itself is framed as having the most minimal impact upon a person's lived experience.

Conclusion

This chapter has demonstrated that the advocacy practised at People's Voices and Talkback was a values-led activity, with strong guiding principles, although these were not always clearly articulated by all organisational members. For example, people with learning difficulties tended to discuss the important elements of self-advocacy through anecdotal evidence, and descriptions of specific activities, as opposed to the staff team's more abstract analyses of the organisation's remit. The chapter also highlighted some of the contradictions and tensions emerging from the enactment of specific organisational principles. Despite an emphasis on 'no befriending' at People's Voices, one of the advocates communicated the difficulty she sometimes experienced in straddling this with her human response to develop more expressive relationships with advocacy partners.

Another key finding presented here has been the multiple ways in which advocacy was conceptualised by different organisational players. Whilst the 'official' position at People's Voices stipulated the advocate's role as being a facilitative tool for user control, the advocates also articulated what they did in more altruistic terms. Whereas the staff team at Talkback framed the purpose of self-advocacy around educational and political aims, some of the self-advocates were more likely to emphasise Talkback's role in facilitating friendship networks and social activities. These issues and tensions will be developed in more depth in the following chapter.

Chapter 6: Tensions and challenges in the practice of advocacy

Introduction

This chapter explores tensions and challenges that face organisations which undertake advocacy work – in particular, issues concerning how advocacy organisations are managed and led. Other tensions linked to questions about the nature of intellectual impairment and whether advocacy is constituted by processes or outcomes are also addressed. Chapter 5 examined the value-systems of People’s Voices and Talkback and the extent to which these values were borne out in practice. This chapter builds upon some of the issues raised in the previous chapter, and considers what Clark (1991) has described as ‘organisational maintenance’: the processes and structures which enable organisations to deliver their aims and objectives on a day-to-day basis. It will focus on the broad themes of user control, decision-making, representation, stewardship and leadership. This chapter explores the following research question:

What are the tensions and challenges that arise in the practice of advocacy?

In the context of advocacy, ‘user control’ has been used to refer to individuals being enabled to take more power over services (Downer and Ferns, 1993). However, it has also been used to promote the concept that users should manage and lead their own organisations. Discussing the establishment of CHOICE – an advocacy group for disabled people - Dave Morris wrote that ‘one of the fundamental criteria for the new organisation was that it would be managed and administered by disabled people’ (1993:

46). Downer and Ferns adopted a similar position when writing about self-advocacy organisations for people with learning difficulties:

A self-advocacy group has to...be controlled by people with learning difficulties; be advised by experienced disabled people and /or non-disabled people skilled in enabling self-advocacy (1993: 142).

Research has shown the complexities involved in trying to ascertain where ‘advice’ or ‘support’ become ‘influence’ or ‘power’ in People First groups (Chapman, 2005; Clement, 2003). This chapter builds on such research by looking at the specific ways in which governance structures at People’s Voices and Talkback have been developed to negotiate some of these tensions. In particular, it will investigate the interface between ‘user control’ – an ideal highlighted in the previous chapter as being central to the value-bases of both groups - and governance systems. The chapter highlights that in both groups, pragmatism (linked to a desire for organisational sustainability) was frequently prioritised over values and principles. It demonstrates the different ways in which organisational members narrated their own perceptions about the way that their organisation is managed and led, presenting a complex picture of both consistencies and discrepancies. The findings in this chapter indicate that boundaries exist around concepts such as ‘user control’ and ‘user participation’, which may be closely linked to members’ perceptions about the reality of intellectual impairment.

The chapter also considers how decisions are made within advocacy groups, and the structures that impact upon the decision-making process. For example, the relationship between the board and the executive at People’s Voices and Talkback is appraised. This is an issue which has been identified as a key factor in voluntary organisational growth

(Dartington, 1996; McCambridge, 2004; The Giving Campaign, 2006). The chapter demonstrates where the tensions lie within this relationship, and how the organisations have attempted to address such challenges.

The roles of leadership and stewardship in advocacy are also addressed in this chapter. These constructs were discussed in the literature review, and I suggest here that rhetoric around equality and user control has discouraged a focus on leadership in advocacy. However, my research demonstrated that influential figures did emerge in People's Voices and Talkback, although their roles were complex and sites of contestation. I argue that the notion of 'stewardship' presented a more accurate reflection of the governance systems found in both groups than that of 'leadership', and seemed to have particular relevance for Talkback. However, one issue that complicated this picture - emerging as a significant finding in relation to self-advocacy - was that prominent non-disabled figures tended to narrate themselves out of their positions within the organisation. Although this appeared to have the well-intentioned aim of emphasising the influence of people with learning difficulties in the running of Talkback, I argue that clarity in this area is important if the organisation is to survive beyond the tenure of particular individuals. Central to the stewardship concept is its objective to 'build the capacity of the next generation to govern themselves' (Block, 1993: xx). The data suggests that establishing precisely *who* this next generation is and how their capacity might be developed in the context of advocacy's current climate, were pertinent issues for both organisations.

Attention will also be paid to the 'About Us' voice at Talkback - a term used by the group to refer to the views of the wider network of people with learning difficulties who have an involvement with the organisation. The tension between the individual and

collective voice in self-advocacy has been highlighted in the literature (Buchanan and Walmsley, 2006), and this chapter highlights the innovative structures developed by Talkback to address this challenge.

In the light of these themes, this chapter has three main sections:

1. Governance and People's Voices
2. Governance and Talkback
3. Tensions concerning the nature of impairment and expectations of advocacy

1. Governance and People's Voices

Chapter 4 traced the history of People's Voices from its origins in the late 1980s until the point at which Barbara Poole joined the organisation in 1995. In the light of changes within the group over the past ten years, the following two sections explore some of the tensions and challenges faced by the organisation as it has become more established. The findings here suggest that with regard to governance structures, People's Voices has favoured pragmatism over principles in an effort to ensure the organisation's survival, and has thus minimised the role played by service users in the running of the group. It is suggested later in the chapter that this may be the result of an assumption among members that people's intellectual impairment precludes them from being involved in the 'organisational maintenance' of People's Voices.

In relation to members' desire to increase sustainability, People's Voices distributed organisational responsibilities among a number of players, including staff, board members, and advocates. In this way, it can be argued that leadership was 'shared' at People's Voices. However, a number of respondents remained anxious that an element of organisational risk persisted with the integral role played by Barbara Poole in the running of the group. Although Barbara was recognised as the organisation's principal driving force by interviewees, members were also conscious of the challenges this presented for People's Voices. Respondents thus highlighted a wider tension facing small voluntary groups with regard to the advantages and disadvantages that arise as a result of organisational dependence on a very small number of key players.

1.1 User control in governance structures: principles versus survival

Chapter 4 revealed that whilst statutory officials and representatives from the local voluntary sector were integral in the early part of the People's Voices story, service users themselves played no role in establishing and developing the organisation. I was interested in finding out whether or not this picture had changed over the past decade. Chapter 5 demonstrated the significance of 'user control' in the People's Voices value-system, although members did not specify whether this referred to control at the individual level (control within a service user's own life), or to the collective control that comes with managing an organisation that places service user needs at the centre of its remit. Barbara Poole identified the link between the principle of user control in advocacy and organisational processes, and the challenges this can present:

... you've got a fundamental argument that regardless of whether it's self-advocacy or advocacy, if you're setting up an organisation based on user empowerment, then users should have control. And advocacy organisations have been run by people who run advocacy organisations, rather than users. And then if you get to the situation of 'well, which users?' then you've many squabbles between different disability groups. I know the first ever national meeting I went to, which was about 10 years ago, which was trying to set up a national organisation, and, they didn't like anybody who had used mental health services, it was only for people with learning difficulties.

(PV1, p.1)

This narrative demonstrates that Barbara had deliberated upon the issue of service users taking more control in the running of advocacy organisations. The passage also suggests that in terms of People's Voices, she had (at the time of writing) concluded that inviting users to play a greater role in the group's development would be too problematic. Barbara's knowledge of advocacy organisations founded by users (self-advocacy) impacted upon her views about the management of one-to-one advocacy groups, and she believed that placing service users in positions of control was likely to lead to internal conflict at People's Voices. Establishing collective 'user control' over the organisation was viewed by Barbara as potentially hindering the group's principal aim of facilitating 'user control' for individuals.

This view was supported by David McCluney, who believed that service users were rarely equipped with the relevant experience that would enable them to manage busy voluntary organisations. Like Barbara, he conflated one-to-one advocacy and self-advocacy, and his knowledge of the latter informed his thinking on how People's

Voices should be governed. David claimed to have seen a number of advocacy organisations 'die' because service users assumed too much control at the outset:

...we found and I felt, that users tended to be very narrow-minded, and not understanding the needs of an organisation, as opposed to advocacy, and the advocates themselves. They wanted to articulate for themselves, and they hadn't the time and energy and knowledge to organise. These were the sorts of organisations that would die as soon as the motivation of the particular people flagged. There were some national conferences going on that Barbara went to...and there was a strong tendency for service users to believe that if a third party hadn't experienced their particular problem then they would be unable to help.

(PV3, p.3)

David suggested that whilst service users are able to articulate a vision, they may not have the capacity to develop the organisational structures that enable the enactment of that vision. He was frustrated that some service users seemed to reject outside 'help' from people who do not share the same 'user' life experiences, although such a conflict is not uncommon in the growth of self-help organisations (Wallcraft, 1994). David felt that advocacy groups should be run by people with previous experience of managing organisations. Unlike Barbara, David did not acknowledge the tensions and complexities around issues of power and control that may be particularly pertinent to organisations undertaking advocacy activities. David's perspective was framed by his wider experiences in managing a range of voluntary and private sector organisations:

Trying to see it as a business, rather than just a voluntary organisation, is the whole key to whether it's successful or not. And the difficulty that other voluntary organisations

have come across, particularly if they're user-run, is that they don't necessarily understand the business processes that need to be in place, or the administration. And it all needs doing – you've got to have that in place so that they can get on with doing what they've actually got to do.

(PV3, p.8)

Dart (2004) has contended that over the past decade, voluntary organisations have been encouraged to be more 'business-like' on a number of fronts. The implications for voluntary organisations who endorse the adoption of private sector strategies have been neglected by academics in organisation and voluntary sector studies, as have the ways in which a business-like discourse is used by members of voluntary organisations (Dart, 2004). In the passage above, David McCluney focuses on the utilisation of private sector *processes* in his conjectures regarding the comparative success of People's Voices in relation to other failed advocacy organisations. For David, the business discourse is not used with regard to an outcome of revenue generation (highlighted by Skloot's, 1987 and Weisbrod's 1998 definitions of commercial activity by voluntary organisations). Instead, business strategies are highlighted as a means of achieving survival. In David's opinion, values alone do not ensure the long-term sustainability of a small voluntary organisation – a view illustrated by the findings of Clement in his ethnographic study of a self-advocacy organisation (2003).

Addressing the fragilities of a small voluntary organisation: management alternatives to user control

Bearing in mind that service users played only a marginal role in the running of People's Voices at the time of writing, what alternative governance structures had the

organisation developed? Due to funding restrictions, the group did not have a core management and administrative team in place. One consequence of this is that historically, members of the board have regularly stepped in to take on many of the tasks associated with managing People's Voices on a day-to-day basis. This may have compromised its independence:

Anita: Yes. I mean, they were working as managing directors, unpaid managing directors really.

Elizabeth: They were there on a daily basis running it.

Anita: It's not ideal. People on the board should really be there in a supervisory role, rather than a day-to-day running of the organisation.

(PV2, p. 10-11)

The history of the People's Voices' board has been a troubled one. Anita and Elizabeth described some of the difficult events of recent years which threatened to disrupt the sustainability of People's Voices. This made some board members wary about relying too heavily on one person to sustain the organisation:

Anita: We've had such a hard time on this committee, I don't think it has happened anywhere else, in any of the other organisations that I've been with, that people have actually died.

Elizabeth: Well, we lost several. We were having board meetings, in the end, every two weeks.

Anita: I think it draws you to the conclusion that you really must not rely on any one person; that everybody within the board must have a real knowledge of the organisation.

Elizabeth: And a role.

Anita: And that you should be prepared to step down and allow younger people to actually come on to the board, and actually start taking over.

(PV2, p. 5-6)

In the period following on from the official establishment of People's Voices in 1996, all of the statutory services representatives left the board, leaving only three or four official board members. David McCluney was acting both as chair, and as honorary managing director; unofficially running the organisation in a voluntary capacity on a day-to-day basis. In 1998 an external consultancy project concluded that David McCluney had taken on too many responsibilities within the organisation, potentially leaving People's Voices vulnerable if he were to cease his involvement with the group. Although steps were taken to address this issue (for example, a book keeper and auditor took on some of his workload), when David became seriously ill in 2000, it left People's Voices' future decidedly uncertain:

Anita: Then David was ill, and we appointed John Aylott, who was a businessman, and he'd also trained as an advocate, as the Chairman. And he ran with it for a while, acting as a Managing Director, and then John became seriously ill, and Sheila Fairbrother, who'd been the first Chairman, he and Sheila at the same time died – both of them from cancer. So the committee was me...And we spent a long, long time – about 9 months, really trying to work out how to run the organisation. Because what we realised was that we were relying too much on people who, you know, if they were run over by a bus, that meant that the organisation virtually sort of ceased to operate.

(PV2, p. 3)

Following on from these events, Anita began building up a larger management board with members from a range of voluntary, statutory and commercial backgrounds. The new governance structures also afforded a greater place for advocates to become involved in helping to oversee the organisation. For example, Brian spoke about his involvement as a board member, particularly his role in human resources. Brian believed that his experience as an advocate was useful in helping to develop policy and procedures around training for other advocates:

I've now got involved in making sure that advocates get the right information that they want; that we inspect advocates in the right way; that advocates are given the right training when they should be trained – all that sort of thing. It's quite interesting really, having had the experience of being an advocate.

(PV6, p.6)

In 2003 it was agreed that People's Voices would be managed through a series of committees, which would all feed into the main board. In the following months, committees for operations, human resources and risk management were appointed, made up of existing board members, employed staff, and in the case of human resources and risk management, at least one advocate. Adapting the constitution in order to involve more individuals in the management of People's Voices has been an effective response to the position of isolation that Anita English found herself in after David McCluney retired from the organisation in 2000:

Anita: So, we've really pulled the organisation apart. We've got various committees now, each of which will know their own particular part of the work situation of People's

Voices... And the board meets every two months, where the committees all come together with reports, and highlight any part of the work that needs to be looked at.

(PV2, p. 4)

At the time that interviews were conducted, the organisation had developed governance structures that enabled it to expand its range of activities, and protect it from the risks posed to a small voluntary organisation that relies upon the commitment of a limited number of individuals. Whilst charitable boards are traditionally in place to oversee and monitor the work of the executive, for some smaller organisations, it is appropriate for board members to have a sound working knowledge and involvement in the group's operational structures (The Giving Campaign, 2006). Nevertheless, some members that I interviewed did have concerns that the central role played by Barbara Poole in the organisation might continue to pose a risk to the organisation's long-term survival. This is discussed below.

1.2 Layers of leadership and organisational risk at People's Voices

In the literature review I discussed the complexities surrounding the leadership construct, and indeed whether we can refer to 'leaders' in organisations at all. Certainly, the notion of a 'charismatic' front-person, who persuades organisational members to 'buy in' to values that may conflict with their own personal principles has been questioned (Alvesson and Sveningsson, 2003; Collinson, 2005). Whilst these authors do not dismiss the possibility that some people are identified by themselves and others as 'leaders', they do alert us to approach such constructions with an awareness of their inherent ambiguities.

Although People's Voices has retained a relatively flat structure in formal terms (during the fieldwork there was no acting managing director or chief executive), as Chapter 4 indicated, individuals such as David McCluney and Sheila Fairbrother were key in shaping the organisation's early development. More recently, it is evident that Barbara Poole has played a crucial role in cultivating a particular organisational culture and identity for People's Voices that has distinguished it from citizen advocacy organisations, in particular Aylesbury Vale Advocates, the other significant group in Buckinghamshire.

It was clear from the interviews that Barbara Poole was seen by members as the lynchpin of the organisation, and the person who had moved People's Voices forward in the past few years:

Brian: She's the one person who has carried this organisation through. Certainly after David McCluney had his heart attack, she's been the driving force behind the organisation, because in that time we've been through three chairmen. And of course the whole organisation has expanded – and that's happened because of Barbara. She really is the driving force.

(PV6, p.7)

Although chapter 5 demonstrated the tension that sometimes exists when advocates feel a human obligation to cross the 'boundaries of practice' laid down in the People's Voices training programme, Barbara's programme seemed to be an important channel through which values were communicated to prospective advocates. It also provided a means for her to have a direct input in evaluating and monitoring the organisation's human resource base:

Anita: Because she's very, very conscious you know, that the training is so, so important... Barbara vets people, and she's very exacting about who becomes an advocate, and the standards that they have, which of course, is very important. And knowing about the legislation, because that's constantly changing, isn't it?

(PV2, p.12)

Barbara has also helped to shape the organisation in ways beyond her training programme. Her networking skills have become an integral part of her role, and this can be traced back to some of the early years in the history of People's Voices. In particular, she has made connections with representatives in the statutory sector, putting People's Voices 'on the map' in Buckinghamshire – a behavioural practice which could contribute to her identification as a 'transformational' leader (Hussey and Perrin, 2003). Some members clearly perceive her relationships with statutory officials as being beneficial to the organisation. Barbara's connections are viewed as a vital means of People's Voices acquiring knowledge about services and service developments:

David: She was a huge asset in her relationships with all the statutory authorities and in training the advocates.

(PV3, p. 8)

Anita: She sits on various committees – mental health; learning disabilities - that sort of thing...that really is the way that you get to know what's going on; what's needed.

Elizabeth: She's very well known.

(PV2, p.12-13)

Some interviewees also believed that Barbara's networking skills contributed to the securing of particular service level agreements. Anita and Elizabeth discussed their understanding of how People's Voices were awarded the contract to provide advice and support for people accessing Direct Payments. Barbara was placed at the centre of events by these members:

Anita: And I think you'll find that this was a result – why we were included in this – is that Barbara sits on a lot of committees in the county, that work with the statutory authorities, for different services. So she would be consulted and probably advising them on which way to go forward.

(PV2, p. 6)

According to Anita English, Barbara's role as the lead spokesperson and public face of People's Voices has also led to her being seen by other stakeholders as the central figure within the group:

...Barbara... is really perceived out in the statutory sector, as being People's Voices.

(PV2, p. 4, my emphasis)

However, Barbara's perceived prominence within the organisation has also led some organisational members to feel anxious about the organisation's future:

Anita: If anything was to happen to Barbara, it would be disastrous for the organisation. And gradually Barbara's now beginning to realise that she's doing more and more of a chief executive's role, and she's got some excellent managers now, for different projects, which are all funded separately. (PV2, p. 4)

David: The other thing I found was that Barbara was so important for one person in an organisation. And as soon as we got another person involved there didn't seem to be any linkage, or togetherness.

(PV3, p. 8)

On a number of occasions – often within the same interview – Barbara's central role in the organisation was referred to within broader narratives of organisational risk.

Whereas all interviewees lauded the work achieved by Barbara in shaping the organisation's vision as well as managing it on a day-to-day basis, there were also concerns regarding her level of control over the organisation. Wallcraft (1994) highlighted the difficulties that small voluntary groups can face when early influential leaders become frustrated by the emergence of bureaucracy and threaten to leave. At People's Voices, this issue was encapsulated in the debate around 'rolling-out' elements of People's Voices' best practice – which included Barbara's training programme:

David: The idea of rolling out never took off in my time. I could never gently coax Barbara into investing the amount of time it would take to actually document and specify her training in order for it to be rolled-out for others to deliver.

(PV3, p. 7)

As David argued, this was as much an issue of ownership as it was quality:

I don't know whether she felt vulnerable - there were two things I think. She felt she was very good at it, and if she didn't own it then it wouldn't be that high quality – that was something that also worried me, but you have to try and solve the problem, rise to the

challenge. I thought sometimes that perhaps she also felt that training was the essence of the job – and if she wasn't doing it then there wasn't a job. Which certainly wasn't true, but it was a constraint on growth from my point of view.

(PV3, p. 7)

Barbara rarely alluded to her role within the organisation. However, in a discussion around her own employment history, she spoke about her commitment to the People's Voices 'cause', and how reluctant she would be to cede control:

...they'll take this (People's Voices) away from me with my dying breath! (laughs)

(PV1, p. 8)

Learning from the board's experiences over the past five years, trustees were taking steps to help minimise the organisation's vulnerability should Barbara Poole leave People's Voices. This involved encouraging Barbara to delegate the training of advocates, and to take on the role of chief executive. It was argued by some interviewees that in this role Barbara could spend more time developing the strategic vision of the organisation, thereby allowing more people to be involved in its everyday activities. According to some interviewees, this was an essential element in protecting People's Voices beyond Barbara's tenure:

David: ...a vital ingredient in getting growth is being able to cope as an organisation when Barbara is no longer there – which has to happen sometime.

(PV3, p. 7)

Anita: So we're looking in the future for Barbara to delegate the training – which has been her expertise so far – to other people. Or to another person. And for her to take on the role mainly of the chief executive.

(PV2, p. 4)

The way in which members of the board have discussed and contributed to Barbara's changing role at People's Voices corroborates the suggestion made by Hay and Hodgkinson, that 'leadership' is 'a collaborative process of interaction' (2006: 152). However, this process is a complex one, and some members of the board articulated a belief that they have an ongoing responsibility to monitor how the leadership role is played out by the executive, whilst allowing Barbara sufficient freedom to develop and implement a vision for People's Voices. This picture was further complicated by the personal investment made by Barbara into the organisation:

Anita: Barbara's absolutely excellent. But we've got to have an eye for the future.

Elizabeth: And she works so hard.

Anita: And that's what happens in the voluntary sector. People do work way beyond what they're paid for. And often it's because they love it. And they're often given the responsibility to almost run with it. I mean, the board checks that everything has been done properly with the policies and procedures, etc. But it does give quite a lot of responsibility to the executive, to actually you know, work the way they feel they need to. It's a fine line, a fine division between boards and the non-executive and the executive. And you have to get that right.

(PV2, p.10)

Whilst Barbara can be seen to be holding a prominent position in the group, the data suggested that the 'leader-follower' binary often depicted in the organisation theory literature masks a more complex picture at People's Voices. Some writers have developed ideas around 'shared' or 'distributed' leadership (Gronn 2002; Pearce, 2004) and this notion seems to better reflect the way that key players have evolved at People's Voices. For example, in the early days, David McCluney played an integral role in concretising Sheila Fairbrother's vision into something that could become a workable organisational entity. This meant taking the steps to ensure that the group could secure both funding and a full-time member of staff. Such pragmatism can be seen as a vital ingredient in stabilising a young voluntary organisation (Dartington, 1996; Myers and Sack, 2001), and established David as an early leading figure in People's Voices. Anita English illustrated how David McCluney used his experience to drive forward the changes needed to get the organisation off the ground:

And it wasn't long before he just took it over and ran with it. I mean, he was a mover, and he knew how to move it along. And before we knew it, we were applying for money for a trainer and that sort of support that really, the organisation needed.

(PV2, p.3)

David McCluney concentrated his attention on the various organisational and performance-based elements of People's Voices; characteristic of a typically transactional form of leadership (Barker, 2000). Section 1 outlined David McCluney's belief that the survival of People's Voices has largely rested upon his implementation of effective management strategies. He argued that his previous experience in both the corporate and voluntary sectors was integral to helping him achieve sustainability at People's Voices:

I think that probably because I worked for a large organisation and you were always saying 'how can I do this so that I don't have to do it? Can't we make it deliverable?'
(PV3, p. 7)

People's Voices seems to have developed as an organisation through the combined efforts of Barbara Poole's commitment to the organisation's principles (which she has been significant in defining) and David McCluney's pragmatism. The organisation may also have one other 'unsung hero' in Anita English, the longest-standing member of the People's Voices' board. As the chair, Anita guided the board through its difficult period following David's illness, and largely designed a governance structure that would permit the organisation to continue. David also highlighted her other strengths of networking and delegating work:

She's very good at belonging to, and going to committees, and something I can't do – she is able to largely express opinions without getting lumbered with the work. Which is an excellent thing to be able to do – to be able to act as a sort of communication channel between the different groups.
(PV3, p.11)

Anita can be seen to have acted as the organisation's principal 'steward' – facilitating the organisation's development and protecting its future interests, without assuming control of its structures (Block, 1993). Whilst it has been argued that boards run the risk of stifling the executive in small voluntary organisations (Dartington, 1996), it seems that Anita has played an important role in supporting Barbara and providing stability at points of crisis.

2. Governance and Talkback

This section explores how different members of Talkback articulated the role played by people with and without learning difficulties in managing and shaping the group's development. It is supplemented by notes that I made whilst observing some internal Talkback meetings.

In Chapter 4, Jean outlined the rationale behind the Talkback members' decision to leave People's Voices, and establish a separate organisation that would be 'user-led'. 'User-led' is at once both an assertive, yet ambiguous term. It implies that people with learning difficulties are *leading* the organisation. But what does this mean in practice? The term may suggest that users assume full control of all the management and decision-making processes. Alternatively, it may refer to users adopting a high level of participation within the organisation's structures, for example, as trustees on the board. In the quote below, Jackie Brodie and Chris Eastwood discuss an early conference that the group organised. The conference theme drew upon a well-known People First slogan. Talkback members may have become familiar with this slogan as a result of the introductory meetings they had with People First groups in the organisation's early days:

Jackie: And we did 'nothing about us' didn't we?

Chris: Yeah, 'cause that's our slogan you see.

(TB2, p.6)

'Nothing about us without us' implies a high level of organisational involvement by service users, but it does not necessarily suggest that people with learning difficulties

are in positions of leadership. The following sub-themes explore how the ambiguity surrounding concepts such as ‘user-led’ and ‘nothing about us without us’ are borne out in practice at Talkback. The data suggested that different participative forums at Talkback appeared to facilitate varying levels of inclusion for people with learning difficulties, with the in-house core group meetings being the most supportive. The findings also demonstrated that there were boundaries around user participation in the running of Talkback, with non-disabled staff (in particular the chief executive) taking responsibility for most of the ‘organisational maintenance’ tasks, such as writing bids, remunerating employees, dealing with legal issues and monitoring organisational capacity. This corroborated the findings of other research into self-advocacy organisations (Chapman, 2005), and highlighted the organisation’s pragmatic response to the requirements of running an efficient and expanding organisation. It did however, reveal tensions with regard to members’ perceptions about the extent to which people with learning difficulties have the capacity to undertake such activities – which is discussed further in section 3.1 of this chapter.

Whilst this demarcation of tasks was not hidden from view, I did find instances in which non-disabled staff attempted to narrate themselves out of their roles – often as a means of emphasising the responsibilities and valued positions held by self-advocates. Nevertheless, the data revealed staff roles to be a site of contestation, raising impending governance issues for the group. An acknowledgement of the integral role played by Jean Rein may be crucial for the group’s future – particularly if they are to develop a succession strategy that protects the organisation beyond Jean’s tenure.

Another key finding presented here suggests that Talkback also faced the challenge of developing a form of self-advocacy that supported both the needs of individuals and the

wider collective. Talkback had devised some interesting mechanisms through which to address this tension – most notably the ‘About Us’ voice, and the User Parliament. These appeared to be more successful at achieving the inclusion of a wide variety of service users in the overarching self-advocacy ‘voice’ than the efforts of some other self-advocacy organisations (Clement, 2003). How this representative element of Talkback operates in practice is discussed further in Chapter 7.

2.1 The role of service users in governance structures: control or participation?

The structure of Talkback was outlined in the previous chapter. It demonstrated that people with learning difficulties made up the ‘core’ groups which broadly dealt with management issues and interacted closely with the board of trustees. Jean summarised this structure, suggesting that service users retained a central role in the various elements of organisational life at Talkback:

You know in our info pack we describe it with the circles, and in the middle are people with learning disabilities, well, that’s how we see ourselves.

(TB1a, p.5)

This was illustrated by Rob Beattie, who outlined some of the roles he undertakes in the group:

Liz: And what do you do now at Talkback?

Rob: I go everywhere.

Jean: You’re one of our trainers.

Rob: Yeah, one of the trainers. Part of the Men's Group, Finding Out Group, Management Group.

(TB3, p.2)

Board meetings

Steve Dean discussed his role on the board, and outlined the board's responsibilities:

Steve: And also I'm part of the, also I come to the Talkback board meetings.

Liz: And what do you talk about in those meetings?

Steve: We talk about just about anything and everything to do with Talkback, don't we?

We talk about funding, money, then the finances come out, and we see how much, see whether Talkback's overspent or not spent enough. We talk about new people coming in, and we give our apologies if people aren't there.

(TB4, p.4)

I observed one of the Talkback board meetings. Usually there would be six service users at this meeting, but on this particular occasion, two had sent their apologies. Simon, Lyn and new employee Jason Mahoney, attended as support workers. The roles of 'chair' and 'treasurer' were taken by two non-disabled women, and there were two other non-disabled trustees present. Jean attended in her role as chief executive. Below are some of the fieldnotes that I wrote up straight after the meeting:

- The room was quite clearly split between the non-disabled board members at one end of the table, and people with learning difficulties at the other. This may have been for purely practical reasons – because Lyn and Simon were

effectively supporting service users by explaining aspects of the discussion to them.

- Parts of the meeting seemed to me to be quite inaccessible – particularly the Treasurer’s Report. Certainly, this was complex material anyway, but it seemed to be rushed through quite quickly. People with learning difficulties did not seem to be following this report, although Lyn and Simon were attempting to explain elements of it throughout the presentation. However, the board was trying to keep the meeting as short as possible, as one person present was unwell.
- People with learning difficulties became much more involved during the ‘activities and organisation update’ part of the meeting. It felt as though this is the area of Talkback’s organisational remit in which they have the greatest involvement (i.e. conferences, research projects).
- Service users seemed to have very little involvement with the budget. It appears that this is predominantly Jean’s remit. From what I learned at the meeting, Jean seems to have some meetings with officials from Buckinghamshire county council on her own. It is at these meetings that issues of funding, performance indicators, unit costings and outputs are discussed.
- Jean’s presentation at the meeting was much more accessible than those given by other non-disabled trustees. I noticed that when she was speaking, Lyn and Simon were doing much less supporting.

(Field notes from Talkback Board meeting, 10/02/05)

My sense was that people with learning difficulties did contribute to this meeting, but at times the pace was too fast for them to be meaningfully involved. Some trustees did not appear to convey information in a way that was particularly accessible, and this seemed

to impact upon the level of service user participation. This is interesting in light of Simon's comment (in chapter 5) that Talkback has been integral in influencing the accessibility of the Learning Disability Partnership Board in Buckinghamshire. However, it was also clear that the organisation had a significant amount of work to get through within the timeframe available. Two hours were scheduled for the meeting (which took place in the evening to ensure that more people could attend), and the group only just managed to deal with all of the items in time. This may help to explain why some of the budgetary items were addressed quite quickly. Alternatively, fully explaining all the elements of Talkback's finances to service users may not have been a priority issue for the board member responsible for the organisation's budget. This reveals a tension concerning the boundaries around the involvement of self-advocates in the running of Talkback – and perhaps raises questions about the level of financial detail they were perceived capable of understanding.

The core group

In the quote below, Jean outlines the historical position of the core group at Talkback:

That group of people were more involved in Talkback the organisation, the development of where we are, what should we do, what should we take on.

(TB1a, p.2)

This quote suggests that the core group have played an important role in influencing the direction of the organisation. It implies that service users are involved in the decision-making process around the contracts that Talkback bids for, and the types of projects that should be developed. I observed two core group meetings (one was with the

Management Group, the other with the Finding Out Group). Unlike the board meeting (described above), both core group meetings were conducted at a slower pace. Crucially, this permitted more time for people with learning difficulties to ask questions. In contrast to the board meeting, people with learning difficulties were also more vocal in the Management Group meetings, which may suggest that service users perceived them as being a 'safer' environment in which to raise and debate issues. From my observations, it appeared that service users were consulted on a range of 'management' issues. These included matters such as:

- Bidding for new contracts. This included an in-depth discussion of the challenges involved in tendering for a self-advocacy contract in Milton Keynes. The service users argued that despite the difficulties, they believed that Talkback should still pursue the contract.
- Future Talkback conferences.
- Issues to be raised at the next Partnership Board meeting.
- The ongoing development of the 'Black and Minority Ethnic' (BME) agenda within Buckinghamshire's integrated learning disability services, and how Talkback was contributing to this.

During the Management Group meeting that I observed, I followed a decision-making process in action. Simon communicated to the group that Buckinghamshire County Council had asked whether Talkback would add their name to a forthcoming leaflet that was being produced by the integrated learning disability service. Simon asked the group for their opinions about this. The debate among the group was as follows:

- Rob said that in his opinion, the group shouldn't do that, because Talkback is an independent organisation.
- Simon said whilst that was understandable, Talkback could ask Buckinghamshire integrated learning disability services (ILDS) to explicitly state that they are an independent organisation. Simon said that on the positive side, it would be free publicity for Talkback. The downside was that the ILDS had only given them three days' notice to look over the document and give feedback.
- Rob reiterated that he was uncomfortable with the idea.
- The group asked Simon for a bit more information. Simon said that he was told that Talkback was the only voluntary organisation to have been invited to contribute to the publication, because their work is considered to be so unique.
- After further discussion, the group agreed that Talkback would not contribute to the publication, in case people with learning difficulties thought that Talkback was part of Buckinghamshire County Council.

(Field notes from Management Group meeting, 21/03/05)

The anecdote reveals that service users were not just consulted on this particular issue, they also had the final decision about which course of action to take. This demonstrated Lyn and Simon's belief that self-advocates who are involved in the core group take on a significant amount of responsibility within the organisation. In the passages below, they suggest that the work involved in being a core group member requires commitment, and therefore it does not appeal to all of the Talkback self-advocates:

Simon: ... the amount of people with a learning disability that are taking on an enhanced role, who are taking on a specific role, has grown. And they are generally

self-identified people who wish to be able to contribute something to mostly assist their peers.

(TB5, p.8)

Lyn: The Management Group is self-elected... But anybody, in any of the groups can be involved in various ways – through training, conferences...But the people who are currently in the Management Group, they're there because they have a real interest and want to be involved, and they're all committed, and they all work really hard to be there. They're all really professional. You know, there's lots of people and they say 'yeah, I want to be more involved', and we say 'yeah, great, come along'. But then in reality, they want to go to Gateway, or to a disco. Because if you've committed to be involved in the Management Group, you need to go to those meetings to talk about budgets... the Management Group isn't a pretend thing...people in the Management Group have responsibility.

(TB6, p.5)

Lyn was keen to emphasise that the Management Group is 'real', and has a genuine role to play in the organisation's development. Both Lyn and Simon narrated self-advocates into 'steward' roles – in which individuals become active agents in developing their organisation for the benefit of the wider constituency. Jean reiterated this point on a number of occasions, arguing that Talkback had developed a number of mechanisms to ensure that service user involvement in the organisation was not 'tokenistic'. She explained one major step that was taken to strengthen the involvement of people with learning difficulties in the organisation's development. Jean argued that this necessitated the splitting of the core group into three small groups (Management;

Finding Out; and Checking Out), so that people could become ‘experts’ in specific elements of organisational life – another element integral to the stewardship model:

And so one of the difficulties that we’ve come up against is that we had our core group of people who were involved in the running of Talkback. They were there because they were the most experienced and they were developing their skills as trainers. And so we got ourselves into a situation where there was a lot of pressure on a small group of people...And so we’ve now started to split things off a little bit... so we can move away from a situation where people are seen, or are expected to be experts at everything. So people will learn as they develop their skills and interests, to focus on something that’s particularly interesting for them, or that they feel they’re good at. Which is quite advanced.

(TB1a, p.6)

This principle of developing people’s specific expertise has helped Talkback to avoid the position described by Clement (2003) as ‘absurd’, in which self-advocates are expected to undertake all manner of organisational activities in ways that would not be expected of people without learning difficulties working in similar small organisations.

Boundaries of user control and participation in self-advocacy

Through observing internal Talkback management meetings, I gathered evidence of significant user participation in decision-making processes. However, it should also be noted that many of the items discussed were *initiated* by the support team. It appeared that they were the people through whom knowledge from the external environment (particularly the local authority) was channelled back to other Talkback members.

Receiving information in this way may have had implications for the level of control self-advocates had in prioritising organisational issues and concerns.

As explained in chapter 5, Jean Rein in her role as chief executive dealt with a number of practical (and necessary) organisational tasks, which she described as ‘the things that need to be done so that Talkback can work properly’ (telephone conversation with Jean Rein, 06/09/06). This issue indicates that boundaries exist with regard to *how* and *where* service users were ‘in control’, ‘leading’ or ‘participating’ in Talkback’s development. The organisation framed these boundaries around the notion of the Talkback ‘team’ in which it was contended that people take on different roles within the group, depending on their particular expertise:

Teamwork works and we are a team that works.

(Talkback Annual Report, 2005-2006)

Chapter 5 illustrated that whilst organisational members were broadly working to the same agenda, values and goals were not consistently shared. In this respect, the language of the ‘team’ at Talkback may be ambiguous. Jean’s frequent use of ‘we’ when describing how actions were taken and decisions made at Talkback, was illustrative of such ambiguity. When I pursued this issue with Jean she said that it was not the first time that she had been asked about it:

I’d worked with people with learning disabilities for a lot of years, and when I worked in one place, one of the people said ‘Jean, whenever you talk, you always say “we did this” or “we went there”, who do you mean?’, and I said ‘people with learning

disabilities'. And it was just so natural to me...there was nothing I was doing on my own, there was nothing that I could achieve on my own. It's a 'we'!

(TB1a, p.3)

Jean appeared to use language such as 'we' and 'the team' so as not to distinguish her work from that of the self-advocates. On the one hand this reflects a political position in which non-disabled people's contributions are not privileged above those of people with learning difficulties. Indeed, Jean acknowledged that her own job was dependent upon people with learning difficulties being committed to self-advocacy and continuing to require her assistance. However, discourse can (intentionally or otherwise) camouflage people's experiences, as well as clarify them, and as this chapter demonstrates, the concept of user control at Talkback, was a site of contestation and complexity. None of the service users expressed views on the 'team' issue, which revealed another interesting tension within self-advocacy. Without their perspectives, it was difficult to establish the extent to which self-advocates themselves had chosen to cede control of certain organisational processes to the non-disabled staff, or whether these decisions had been made on their behalf.

Talkback and the 'About Us' voice: representation and the tension between individual and collective self-advocacy

In chapter 5 I explained how Talkback distinguished between the 'About Me' voice and the 'About Us' voice in self-advocacy. The former relates to self-advocacy on an individual basis; the latter to collective self-advocacy for people with learning difficulties:

Steve: With the User Parliament, well, Simon and Lyn go around to different resource centres.

Jean: Yeah, they go all over the county, don't they, doing the About Me groups.

Steve: Yeah, it's county-wide. Finding out what people want to do, don't want to do, like doing, don't like doing.

Jean: You were involved in helping to develop the User Parliament voice, which people have had a real problem with, so now we distinguish by saying the 'About Me Voice', which is all about the personal development, self-esteem, self-confidence, and then the 'About Us Voice' which then feeds into service-planning, delivery.

(TB4, p.4)

It has been acknowledged that operating individual and collective self-advocacy in tandem has been an ongoing challenge for organisations since self-advocacy's beginnings (Buchanan and Walmsley, 2006). Organisations have struggled to reconcile the two, even though many groups' objectives suggest that this remains a guiding principle. In his study of a self-advocacy organisation, Tim Clement wrote:

I suggested in my feedback to the organisation that it was possible to make a case that the steering group were People First Anytown, an accusation that undermines the espoused aims (2003: p.269).

Talkback sought to address this issue by developing the 'About Us' Voice, which has subsequently been linked into the Buckinghamshire 'User Parliament'⁹. Jean described

⁹ The idea of the User Parliament was originally initiated by representatives from Buckinghamshire social services in the late 1990s as a means of including a wide range of service user perspectives in the planning and delivery of services. Talkback - who were already consulting members of all the About Me groups on various issues - were funded to develop this aspect of their work further by operating a User Parliament. The relationship between the User Parliament and service structures in Buckinghamshire will be discussed further in the next chapter.

how the organisation utilised the About Me group networks to start gathering the views of self-advocacy groups who were not involved in Talkback's core groups:

The User Parliament is the representative voice of people with learning disability, linking into the Partnership Board. And that runs alongside the About Me groups. There are some specific groups, and there is a lot of overlap as well. There's a number of reasons for that. One is that we already have an established county-wide network of people who are regularly inputting into Talkback, you know working with us. And, so we need to include those people. And also, we've reached new people at different times - maybe some groups may run something in the evenings. We've reached people who don't use services, or who use very little. The difficulty around it is that there is very little money attached to the User Parliament, so we link our self-advocacy funding and our User Parliament funding together, to enable us to have a voice as big as we've got.

(TB1a, p.10)

This idea of the User Parliament has been adopted by other self-advocacy organisations such as Speaking Up (Cambridge), although unlike these groups, the User Parliament at Talkback has not evolved as a quasi democratic body in which people vote on particular issues. That model has recently been critiqued by Redley and Weinberg (forthcoming) in their ethnographic study of a 'User Parliament' meeting, in which they discuss the 'limits to liberal citizenship' as a means for effective service user involvement. Simon Evans, who took a lead on the User Parliament project at Talkback, appeared to reflect a similar position:

It is not about elections, it's not about constituencies, which is how I'm aware other areas have set up a User Parliament, and have put a lot of time and effort into elections

to identify local representatives, who will get together and the group of twenty local representatives decide what everyone wants. The way we work, is of course, much more to do with all of the members of the About Me groups – so we're not talking about the views of twenty representatives, we're talking about a couple of hundred individuals, with a range of needs. Hopefully, it's a much more useful system.

(TB5, p.2)

Gann (1996) has argued that representative democratic structures may be seen as requiring only the minimum participation from constituents. He suggests that organisations may need to consider more innovative processes to ensure greater participation of members. Talkback has attempted to do this by regularly consulting people with learning difficulties in the About Me group meetings on their opinions on particular issues. People are also encouraged to raise matters that they perceive as being important – which Talkback then introduce within appropriate forums, such as the Learning Disability Partnership Board:

Jean: And when we were talking to people about the fact that there was a partnership board meeting, and what did the User Parliament want to say, the thing that they talked about, that they wanted to take to the board was about bullying, and how they were treated by the community, and it fell just when the children were on school holidays, and people had real stories about how they were treated by the kids, which is dire. But the good part about it all, they are now in a position where that was taken into the partnership board, 'this is what we want to bring to you, this is something that really, really matters to us', and as a result, the partnership board have taken it on board... the lead councillor is an ex-policeman, and so he's actually taking the issues to the police, so that we can join the whole thing up. So the good thing about it is, something's

happening. And I think that's a real key message, that people are now able to make a change.

(TB1a, p.11)

The support team also emphasised that despite the preconceptions of other stakeholders, the team aim to include the perspectives – where possible – of people with high support needs in the collective self-advocacy voice at Talkback:

Simon: Someone from another advocacy organisation was sat opposite me in a meeting and said, 'well, I know that Talkback only works with people who are verbal', but we work with many more people, and those people should very clearly be considered as working partners.

(TB5, p.3)

Lyn: From the outside it can look as if their contribution is very small, but their contribution is actually very, very real.

(TB6, p.2)

Simon also acknowledged that there were some limits to how effectively Talkback could represent the wider voice of people with learning difficulties, particularly those individuals who do not regularly use services:

... those people that dip in and out of services need their voice heard, and there are voices that we know we're not reaching as effectively. That is a definite gap in the work that Talkback does. The number of phone-calls we get, and the number of enquiries we

get around 'I don't go to a day service, how can I find out more about self-advocacy'- it is a difficulty, but it is something that we work on.

(TB5, p.4)

The role of the User Parliament in representing the 'collective voice' of service users in the Learning Disability Partnership Board will be discussed in the next chapter.

2.2 Stewardship and the role of the staff team in self-advocacy

Formal roles

In contrast to People First self-advocacy organisations, it is the non-disabled staff team at Talkback who hold formal job titles. Jean Rein is the organisation's chief executive, which (symbolically at least) denotes a position of leadership within the group.

However, Jean was keen to stress that the staff team rarely use these titles:

We very rarely use job titles when we go out. As far as we're concerned, we're the Talkback team, but we have to have job titles for lots of various reasons. So I carry the very grand name of 'chief executive' (laughs), which I use very rarely. And then there's Alison, as our administrator, and Lyn and Simon as project coordinators, who work on involvement and inclusion.

(TB1a, p.5)

Jean suggested that whilst job titles were not an indication of hierarchy within the group, relationships with external stakeholders made the adoption of such titles an organisational necessity. By focusing the narrative away from the titles adopted by the

staff team, Jean seemed to acknowledge the implicit tension between her role as chief executive and the organisational ideal of user control at Talkback. Lyn, however, appeared to be more comfortable about explaining her role in 'leading' some of the Talkback projects:

My role's actually changing, but I'm still called project coordinator, and my main area has been around coordinating self-advocacy across Bucks. And what that has meant is really planning and facilitating what we call the About Me groups...And we're starting a new project with people with multiple and profound learning disabilities and I'll be taking a lead on that, but working in a very different way.

(TB6, p.1)

Jean appeared to introduce the idea of the 'team' in her narrative to emphasise parity among different organisational members within Talkback. However, self-advocate Fred Charman offered a different picture – one in which the staff team were conceptualised by service users as having influential roles within the organisation – corroborating the findings of Clement (2003). This suggests that despite Jean's attempt to narrate herself and the other team members into less prominent positions, service users may still have perceived the non-disabled staff team as 'running' the organisation.

Liz: So when did you first get involved with Talkback, Fred?

Fred: In 2000. Yeah, and the first three team members I got involved with were Jean, Cath and Tony.

(TB8, p.1)

Fred reiterated the point later in the interview:

Liz: Ok, so how did you develop more involvement with Talkback? How did you get more involved?

Fred: Well I was actually asked by Tony, one of the founder team leaders, if I'd like to help them out with some of the projects they were doing at the time.

(TB8, p.1)

The role of Jean Rein: steward, facilitator, or reluctant leader?

Section 3 demonstrated that whilst people with learning difficulties have played a valuable participative role in shaping the development of Talkback, the support team continued to hold important positions of influence within the organisation. Jean Rein stood out as being a particularly significant key player in the group's growth:

Clare: I think it was, well, a lot of it was down to Jean, and her huge professionalism.

Once she started networking, the proof of the pudding was, you know, what she delivered was of such high standard, that once people understood what she was about, and could see the results of it.

(TB7, p.1)

Clare Hawes was chair of the Talkback board. When discussing Talkback's development, she emphasised Jean's leading role. Clare attributed the development of self-advocacy in Buckinghamshire to Jean's personal commitment to the cause, and the 'vision' she held for Talkback. Defining a 'vision' and imparting it to others is an integral aspect of the transformational leadership model (Bass, 1997). Alimo-Metcalfe and Alban-Metcalfe (2001) also found in their research that members of organisations

were often inspired to act by 'nearby' leaders who appeared to display traits of openness, vulnerability and humility. This corresponds with Clare's recollection about Jean's ability to persuade people to take on active roles within Talkback:

For example, there was one person I remember, that when Jean first went in to the day care centre, the staff there had said that she just sat there in a chair, in a corner, with her head down, playing with her hands. But Jean really pulled her out, got her chatting and into the group, and she ended up doing quite a lot of work for Talkback. And I think when people saw that, then it gave her work credibility.

(TB7, p.2)

Some of the self-advocates also highlighted Jean's important role within Talkback.

Chris Eastwood identified her as co-running the organisation in the early days with a service user called Andrew. Interestingly, in the passage below we can see how Jean attempted to steer the conversation away from a focus upon herself and towards the role played by people with learning difficulties in taking on leadership positions:

Chris: Well Andrew ran Talkback with Jean for about 4 years.

Jean: Who else? There was Andrew and

Chris: Myself.

Jean: Absolutely.

Chris Myself and er. So we ran it together for about ooh, about, can't remember what year.

Jean: So there was you and Andrew, you used to co-chair, didn't you – or you used to take it in turns to chair.

Chris: I used to take it in turns with him. (TB2, p.2-3)

By narrating herself out of the story, Jean seemed to be minimising her own role in managing the group in the early days, whilst trying to focus attention on the positions of influence held by self-advocates at Talkback's outset. This tactic has also been highlighted by Walmsley and Johnson (2003), in which supporters camouflage their significance with obscurantist language. Jean attributed other developments in Talkback's history to service users, emphasising their power to affect change. For example, as shown in chapter 5, Jean emphasised the role played by self-advocates via the Consultation Group in shifting the perceptions of people with learning difficulties held by other key stakeholders such as carers and statutory officials.

Jean also highlighted the role played by Adnan Haroon in the development of Talkback's Direct Payments project:

He's developed a great role, with all the Direct Payments stuff, and he's made a DVD, which is growing and growing. We got an email yesterday from BILD, saying would Adnan go and lead a session – I don't know all the details yet – on the stuff that he's done, and how he receives his direct payments.

(TB1b, p.9)

It has been argued that an environment in which different group members value and respect each other's qualities and contributions is a key factor in avoiding conflict and disputes in voluntary organisations. Gann argues that leaders in organisations have a responsibility to cultivate such good practice by openly recognising and identifying the merits of individual workers in order to 'remove the obstacles to cooperative working that bedevil teams, which are often as much about personal incompatibilities as about an effective blending of skills' (1996: 65). In contrast to the findings of Clement (2003)

and Goodley (2000a) I did not witness any evidence of conflict or bullying among the self-advocates at Talkback. In general conversation, people spoke highly of one another and often identified the strengths and talents of other individuals. In group situations, Jean repeatedly drew attention to the skills and qualities of various organisational members. This environment may also have been fostered within Talkback's broader 'emotional literacy' approach to self-advocacy. As Jean explained, the FILO (From the Inside Looking Out) project focused self-advocates' attention as much on the emotions of other people as themselves:

People are really beginning to say...that it (FILO) gives you a better understanding of yourself, and what's happening, and how to cope, and all those things. And a better understanding of other people's emotions.

(TB1b, p.1)

The apparent lack of tension and competitiveness among members of Talkback may be a consequence of organisational processes which have reduced the level of personal investment made by people with learning difficulties in running the organisation (in contrast to People First groups for example, where service users hold positions such as chief executive, treasurer and chair). An alternative explanation may be found in the organisation's value-system, which emphasised both a 'team approach' and a form of self-advocacy which develops awareness of other people's emotions. By observing Talkback both formally (in meetings) and informally (in the office) it appeared that both values were frequently reinforced by Jean Rein.

I discussed in the previous section how Jean took responsibility for a number of organisational maintenance tasks, such as writing bids for funding contracts, which she

argued all contributed to fulfilling the broader objective of service user involvement in organisational processes and decision-making:

So managing the budget, and all of the planning and development work that has to go on, obviously your priority is people having their voice, and people being involved in all of that decision-making – that's taken as read as far as we're concerned - but you have to do a lot of juggling to ensure that once you've got your good staff team and your good mix, that you can maintain that, and that I find quite scary.

(TB1b, p.7)

Jean acknowledged the financial fragility in sustaining an organisation such as Talkback in the longer term. It seemed that in order to protect the organisation's future (and thus its values and aims), Jean had assumed a number of roles and responsibilities which would, in other self-advocacy groups such as People First, be undertaken by self-advocates. When asked about the purpose of the board, Clare Hawes replied:

Supporting Jean primarily...It's helping to do the things that Jean's very capable of doing - but really we want her out there working with people, because that's what she loves to do.

(TB7, p.2)

Jean was spoken about in positive terms by the self-advocates. For example, Rob recalled the time when he and another self-advocate approached officers at the Buckinghamshire integrated learning disability team for help in organising an event for Jean and another support worker. The gathering was kept secret from Jean and was intended to thank her for her work with Talkback:

Rob: That reminds me, that me and another person done a story on how Jean's helped us, without her knowing.

Jean: Ahh, yes...they were rotters, it was brilliant.

Rob: One day, you used to phone us up and say 'What are you doing today?'. And 'Nothing' 'Why?' 'We're doing something else'.

Jean: Yeah, Rob and Christine, who used to do quite a bit with us, said to Jenny (from Buckinghamshire ILDS) that they wanted to do something for me and for Cath, who used to work with us. Erm, to sort of say 'thank you' wasn't it?

Rob: Like, we didn't know what to put, and we couldn't say to the Talkback office, can we like, have a computer for it?

Jean: They wanted to put it onto PowerPoint, but of course they couldn't do it through us, so they went to Jenny, and Jenny and Max helped. And they did rotten things! Yeah, and they invited people from all over the county to come along, and then invited Cath and I to go along to a 'feedback' meeting... And we didn't know that Rob was going to be there, we were just invited to this meeting with Jenny. And we went along to this meeting, and they invited us into this room and it was just this sea of people, and professionals from all across Bucks, and they did this brilliant, very moving PowerPoint presentation...I mean, it was real self-advocacy in action.

(TB3, p.7)

This story suggested that the service users both acknowledged and appreciated the responsibilities taken on by Jean within Talkback. Jean perceived Rob and Christine's actions as an example of 'self-advocacy in action', because the event required initiative, confidence and the ability to utilise connections. The story also denoted self-advocacy

in another form. Organising the event symbolised Rob and Christine's valuing of the role taken on by Jean – a role that they appeared happy to endorse in the belief that she supports the organisation to meet members' shared aims (a fundamental element of stewardship). Gann (1996) has highlighted the dilemmas facing leaders in voluntary organisations whose position requires them to develop structures and processes that enable those who have traditionally been silenced to speak up and become more participative. The challenge for such leaders lies in avoiding the reproduction of embedded power dynamics where 'the powerless collude in any attempts to exclude them – in simple terms, by learning to "know their place"' (Gann, 1996: 67). Chapter 4 illustrated the extent to which people with learning difficulties had been excluded from the planning and evaluating of services in Buckinghamshire until the late 1990s. This historical view may help to contextualise the level of user control undertaken by service users at Talkback. It also positions Talkback at the second stage of Bylov's (2006) 'generations' model, in which a self-advocacy organisation moves from being a group organised 'for' people with learning difficulties, to one which is organised 'with' people with learning difficulties. In this stage, non-disabled people retain positions of influence within the organisation – although this influence can manifest in either a controlling or facilitative way. A partial explanation of Talkback's current governance system was given by Jean, who suggested that whilst Talkback played a significant role for some service users, it was by no means the most important factor in their day-to-day lives. Indeed, the decision to split the core group and distribute responsibility more evenly between the self-advocates came about after group discussions in which it seemed that some people had become overwhelmed by the amount of work they were undertaking with Talkback:

Jean: It was at that stage we decided...there's a lot of pressure getting put on people, and actually, people have their own lives to lead as well.

(TB1a, p.6)

Governance issues for the future

The third stage in Bylov's (2006) model describes the establishment of 'self-controlled' organisations for people with learning difficulties. Bylov traces the transition of self-advocacy in Denmark from stage two, which necessitated the 'personal commitment and experience' of people with learning difficulties, to stage three, which required the 'collective mobilisation and responsibility' of self-advocates – although he is ambiguous with regard to what such 'responsibility' entails (2006: 144). The role of Jean that has been outlined in this chapter suggests that Talkback was not at Bylov's third stage at the time of writing. What has been more difficult to ascertain is precisely *who* at Talkback would have the power to influence whether or not service users could move into positions of greater authority; and indeed whether this is something that people with learning difficulties expected or aspired to. This was not an issue discussed by any of the self-advocates throughout the interviews or in the meetings that I observed, and mirrored the findings of another self-advocacy study (Chapman, 2005). The issue was, however, raised by the staff team. For example, Jean was considering the idea of developing Talkback as a social firm. Social firms have been defined as businesses 'set up specifically to create employment for disabled people' (www.socialfirms.co.uk, 2006). Becoming a social firm would allow Talkback to diversify its funding away from a reliance on the local council and develop its remit (particularly around issues such as emotional literacy and communication) at the

national level. It would facilitate the employment of a number of people with learning difficulties in a range of organisational roles:

Jean: One of the things that we would like to develop - and we're going to make some enquiries around this - is a social firm. Because ...it's important to have other streams of funding to give us our independence. ...And we think that people could be much - well people are obviously involved - but we think that we could develop that whole thing much more.

(TB1b, p.10)

The nature of Talkback's governance arrangements at the time of writing meant that people with learning difficulties had considerable freedom to move in and out of the organisation, and 'use' the group as it suited them. Non-disabled people were tied more firmly to the organisation as a result of their employment contracts. Simon Evans argued that on the one hand, this system was in line with the group's broader self-advocacy principles, in which people with learning difficulties should be able to choose how, where and with whom they spend their time. This included the level of commitment they were willing to make to Talkback. However, like Jean, he also envisaged a time when people with learning difficulties would also be paid for their work at Talkback:

... there are a number of people, and I'm sure that it will continue to happen, for whom Talkback for a period of time, proves to be a total success. They become empowered, they are able to say a real 'yes' and 'no', they have greater self-confidence, they are more aware of their skills and how to use them, and therefore after a period of time they no longer need Talkback, and they move on, and they improve their quality of lives

themselves...That's always one of the nice things with Talkback having a very much self-identified way that people get more involved, it means that there's this ability for change. It means there's the ability for people to move on, although I do want to move on to see Talkback able to employ people with a learning disability properly.

(TB5, p.8)

This is evidence that Talkback may reach Bylov's third stage in the future. An impending challenge for the group - should they decide to employ people with learning difficulties - may lie in how they reconcile the principle of personal freedom with the responsibility and commitment required by paid employment. Transforming Talkback into a social enterprise firm, in which at least 50% of the organisation's turnover must be earned through the sales of goods and / or services (www.socialfirms.co.uk, 2006) may also have further implications for how self-advocacy is understood and conceptualised by people with, and without learning difficulties.

Unlike People's Voices, there was not the same concern among Talkback members that the organisation may have become too reliant upon one individual. Lyn, however, did comment upon the need for the group to document its organisational processes; partly as a record of good practice, but also to protect the organisation's future should the 'mix' of the current staff team change:

But the strength of the team, so that isn't lost in a way that it can never be done without the team we have now, I feel there's a real urgency to get it down.

(TB6, p.9)

3. Tensions concerning the nature of impairment and expectations of advocacy

3.1 The reality of impairment or the reality of experience?

A tension that has arisen at different points throughout this chapter is the question of whether the nature of intellectual impairment precludes – or is *perceived* to preclude – the extent to which people with learning difficulties can be involved in running advocacy organisations. In People’s Voices, one user of mental health services was invited to join the board, although to date, there are no representatives among people with learning difficulties. There was no suggestion among respondents that the user component on the board is likely to increase and diversify to include users of other services in the coming years. Barbara Poole did allude to the fact that the growth of Talkback in Buckinghamshire had slightly re-orientated the focus of People’s Voices towards mental health services users. She felt that the self-empowerment of people with mental health problems remained under-developed in Buckinghamshire, in contrast to learning disability, which had its own user group (Talkback). This may provide a partial explanation as to why the representative on the People’s Voices’ Management Board was a user of mental health services, rather than learning disability services. An alternative explanation might be that the organisation assumed that service users who do not have an intellectual impairment would find it easier to contribute to the minutiae of running an organisation, and therefore it would be less challenging for the group to include a user of mental health services instead. It is also possible that this service user had previous experience working for an organisation. Bearing in mind David McCluney’s argument that organisations require people with experience and expertise

to survive, this may help to explain why people with learning difficulties continue to be excluded from the Management Board at People's Voices.

The data from Talkback seemed to reflect a similar position. Jean was explicit in stating that there are certain tasks that need to be undertaken both thoroughly and efficiently so that Talkback can develop its wider (and more urgent) remit, such as the About Me Voice and the User Parliament. These were articulated as the core elements of self-advocacy by a range of organisational members at Talkback, whilst organisational maintenance tasks were viewed by Jean as activities that simply needed to happen. It was difficult to establish whether this situation was driven by the assumption that people with learning difficulties *did not want* to undertake these tasks, or that they *could not* undertake them – either as a result of their specific impairments, or because of their lack of experience. If it was the former, then arguably this demonstrates self-advocacy in action, with people with learning difficulties making the conscious choice to delegate responsibility to individuals with the relevant expertise. This position was signalled in the anecdote provided about the service users' presentation about Jean. However, the overall picture is somewhat more ambiguous. There were certainly a few occasions which highlighted conflicting perspectives between the self-advocates and the support team with regard to the 'essential' nature of learning difficulty, which may have had implications for the extent to which service users were supported to learn new organisational skills. For example, in the passage below, Jean attempts to steer the narrative to demonstrate how people with learning difficulties can adopt valued social roles. However, tensions in the narrative arise as the self-advocates do not comply with Jean's efforts to identify 'people with learning difficulties':

Chris: Like the group from Endeavour, they used to have a Tuck Shop, and a good mate of mine, Tony Greenley,

Jean: But theirs was different, wasn't it?

Chris: But theirs was different.

Jean: Can you remember how it was different?

Jackie: Erm

Chris: They used to bring the trolley.

Jean: But, but who ran the Endeavour Tuck Shop? Who used to serve the drinks and serve the food?

Chris: It was Francis, it was Tony.

Jean: Yes, it was the people who used the service, wasn't it? The people with the learning disability. But here, it was the staff, and it wasn't reliable.

(TB2, p.15)

Alternatively, were self-advocates excluded from organisational maintenance tasks because of their lack of experience? Chapman (2005) argued people with learning difficulties only gain experience by being encouraged to learn new skills. However, Clement (2003) has argued that there may always be organisational tasks that will be beyond the capabilities of some people with learning difficulties, as a result of their specific intellectual impairments. This is an ongoing tension in self-advocacy, and one which had yet to be fully addressed within Talkback.

3.2 Self-advocacy: a matter of processes or outcomes?

There was also an identifiable tension at Talkback with regard to whether self-advocacy was framed primarily in terms of processes or outcomes. Most examples in which

Talkback action led to the achievement of specific objectives were raised by members of the staff team, such as the example cited earlier about bullying. Members of the staff team also articulated the role of self-advocacy as a process activity, particularly in the light of Talkback's emphasis on 'learning how to look' and 'emotional literacy'. As the previous chapter illustrated, people with learning difficulties were more likely to highlight the purpose of self-advocacy in terms of socialising and networking. The service users also discussed Talkback in terms of how it had provided them with opportunities for new experiences. For Steve Dean, this was primarily framed around work opportunities made available to him in the Talkback office. In the passage below, he explains how he was compiling a data-base of Talkback literature:

Yeah, well, what the database is, is books and journals, which they've got in the Talkback office on certain aspects of disability, and I have to put the number of the book, the title, the author, the publisher, and then I have to do a synopsis, just a small one detailing what the book's about, and also a year if there is a year...

(TB4, p. 7)

Rob discussed how after he joined an About Me group – despite his initial reluctance – he soon came to have a greater involvement in Talkback's core group. This involved presenting at a large conference:

Right, I used to go to the Endeavour, in Chesham, and Jean used to come up, like occasionally, and run a group, and I was involved in a small group like that. Then, Jean was asking people to help Talkback, and she kept coming, so in the end I said 'No, I'll think about it'. And when she, like come up afterwards, I said, 'Yeah, I'll help'...And the first thing I knew, I was doing a big conference, talking to about 70 people.

(TB3, p. 1)

These examples suggest that there may have been some discrepancy among players at Talkback with regard to whether 'real' self-advocacy was constituted by processes or outcomes, although overall there seemed to be greater emphasis on the former. This is, however, indicative of a wider tension in self-advocacy, with some self-advocates calling for more direct action and long-term changes backed by 'rules, policies or legislation', and less emphasis on 'saying how we feel' (Aspis, 2002: 4-5).

Conclusion

This chapter has highlighted a number of tensions that arose in the practice of advocacy at the two organisations. In particular it has illustrated the dilemmas facing the advocacy groups as they attempted to develop governance systems that reflected their organisational principles. Concerns about sustainability led People's Voices to protect the group from an over-reliance on one or two key individuals, although people with learning difficulties continued to be omitted from more recent governance arrangements. Staff members at Talkback emphasised the role played by service users in running the group, and in doing so often narrated themselves out of their own role. In contrast, the self-advocates identified non-disabled people as leading figures in the organisation, demonstrating that multiple perceptions about who runs Talkback were present among group members. The chapter also showed that ideas about the nature of intellectual impairment were at variance amongst different organisational members, which had implications for the level of involvement obtained by people with learning

difficulties in directing the advocacy groups. These issues are explored further in the concluding chapter.

Whilst advocacy outcomes were seen as important within the groups, many members – in particular people with learning difficulties – highlighted that the process of undertaking advocacy was just as (if not more) important. The following chapter will explore whether such a perspective stands in tension with the views of those who commission and fund advocacy. Chapter 7 also considers how policy (at the national and local level), institutions, and key players in Buckinghamshire affected the advocacy agenda, and the ways in which People's Voices and Talkback negotiated such pressures.

Chapter 7: Advocacy and the external environment

Introduction

This chapter positions advocacy organisations within the external environment. The previous two chapters explored the internal dynamics of People's Voices and Talkback, focusing upon the processes, relationships and tensions that have shaped advocacy within its organisational boundaries. This chapter explores the relationship between advocacy organisations and other influential stakeholders, paying particular attention to their engagement with statutory authorities. It develops a number of key themes raised throughout the thesis and demonstrates how knowledge about advocacy is deepened through an analysis of the groups' relationships with other individuals and organisations. In doing so, it addresses my final research question:

How do relationships with external stakeholders impact upon organisations that practise advocacy?

Identifying and analysing the themes

Whilst advocacy organisations may be important agents of change, they are themselves also being shaped by outside forces. These include specific health and social care policies (for example, *Valuing People*), as well as broader initiatives in New Labour's 'modernisation' project – such as the Best Value directive (Henderson and Pochin, 2001). Recent years have seen the mainstreaming of user involvement and participatory forms of governance in the health and social care sectors, which has generated a significant body of research seeking to analyse the impact of such measures (Hodge,

2005). In the current climate, user groups are frequently being invited to speak on behalf of other users, described by Tritter (2005) as 'subcontracting user involvement'.

Learning disability services have not been immune to these developments, and recent studies suggest that advocacy organisations are increasingly being utilised as the means through which the involvement of service users is channelled (Dearden-Phillips and Fountain, 2005). Many advocacy organisations now rely upon statutory bodies for much of their funding (Buchanan, 2004). Developments in how advocacy is commissioned and funded, coupled with its growing role in service structures, led me to view an appraisal of People's Voices and Talkback's relationships with the Buckinghamshire statutory authorities as an integral component of this study.

Drawing upon Barnes's (1999) work on user groups, I went into the field with the intention of revealing the perceptions of advocacy held by influential statutory stakeholders. I aimed to find out the nature of the role(s) deemed appropriate for the groups; whether they are considered to be legitimate stakeholders in local policy and practice; and the officials' experiences of the groups. I have analysed the narratives of officials in Buckinghamshire, and contrasted these with the perspectives held by organisational members themselves. Perceptions were mixed and sometimes contradictory, suggesting that the advocacy concept continues to be a site of confusion and complexity.

I also set out to appraise the role of advocacy in 'partnership' working in Buckinghamshire, particularly in the light of the development of Learning Disability Partnership Boards since the introduction of *Valuing People*. As Talkback are embedded in service structures to a much higher degree than People's Voices, these themes are dominated by a consideration of self-advocacy as a means to facilitate the

'user voice' in the development of local policy and practice. Writing in 1993, Downer and Ferns argued that self-advocacy should 'have funding without 'strings' attached...not be shaped by the 'outside' expectations of non-disabled people...have real power and representation in important decisions about the services which affect users' lives' (142). These were important points to consider when analysing the development of Talkback in recent years. A number of researchers have highlighted the challenges that can befall initiatives around user involvement (Aspis, 1997; Buchanan and Walmsley, 2006; Beresford and Croft, 1993; Hogg, 1999). These include the utilisation of users to legitimise services, and being trapped within structures that discourage any real attempts by users to challenge 'normative frameworks' (Hodge, 2005). The findings reveal that whilst Talkback had developed a number of innovative and effective strategies to increase participation, the involvement of service users was also limited by a number of factors. These included meetings that – despite good intentions – retained a format that discouraged self-advocates from participating in the confident and challenging ways that I witnessed at other times.

The chapter also looks carefully at the role played by commissioning in the development of advocacy. The precarious and often short-term nature of funding for advocacy organisations has led Jackson to argue that 'advocacy services have only an ephemeral existence' (2005: 19). Chapter 1 argued that elements of New Labour's modernisation project have (perhaps inadvertently) led to a situation in which activities such as advocacy are now being reconstituted as 'services', specified by explicit outcome targets and measured against performance indicators in order to evaluate whether they provide 'value for money'. This raises a number of important issues around the ownership and control of advocacy, which are considered through the experiences of People's Voices and Talkback.

Some of the themes in this chapter were 'anticipated' through a broad reading of the experiences of user groups in health and social care settings, as well as a number of studies that have focused on the issues facing advocacy organisations for people with learning difficulties. Other themes emerged from the data, and therefore offer new insight into some ongoing debates. The chapter opens with a section on the local policy context which builds upon some of the issues raised in chapter 4, and highlights the current priorities facing the statutory authorities as identified by officials throughout the interviews, in particular, that of Best Value. The data demonstrates that whilst advocacy was viewed as a significant priority within Buckinghamshire, it was also overshadowed by concerns considered to be more pressing by learning disability managers.

This chapter is organised into four sections:

1. The local context: policy and practice

2. Perceptions on advocacy

3. Participation and partnership working

4. Commissioning advocacy

1. The local context: policy and practice

In chapter 4 it was argued that the agendas set by *Valuing People* and the reorganisation of learning disability services under the Health Act, 1999¹⁰, had presented officers with a number of operational difficulties which were only just beginning to be resolved when the interviews were conducted. This section extends the contextual picture of Buckinghamshire through a discussion on the impact of Best Value policy. The data suggested that statutory officials have been under considerable pressure to demonstrate that commissioned learning disability services provide value for money – which has, at times, distorted local priorities. Advocacy was framed as one such service – although respondents argued that the publication of *Valuing People* has made its funding easier to justify. Although advocacy was perceived as having an important role to play within the overarching learning disability strategy, it appeared that statutory officials were more concerned with how they would be able to meet their policy objectives within the constraints of limited resources.

1.1 Demonstrating value for money

The interviews with officials illustrated that pressures to demonstrate value for money had directly affected both the executive team and on-the-ground staff within Buckinghamshire's learning disability services:

Jenny: ...we've been very focused on performance measures, in terms of the county council issue as well. I mean, a good performing council is very, very important, to

¹⁰ Moves towards the joint planning, joint commissioning and the integrated delivery of health and social care services for people with learning difficulties in Buckinghamshire, were made with the setting up of the New Partnership Executive Board in July 2001. In July 2002, health and social care services in learning disability were officially integrated, with the County Council as the lead agency. 'Pooled budgets' were agreed upon under the flexibilities permitted under Section 31 of the 1999 Health Act.

elected members particularly. And up to point I think, perhaps it doesn't feel like it to start, if you're working in an authority with a good star rating, it gives you some sort of kudos...

(BCC1, p.6)

Whilst Jenny highlighted some of the positive outcomes of an increasingly target-driven local government culture, Stuart emphasised that some directives had the unintended consequence of distorting priorities, at times to detrimental effect:

... we have done incredibly well in our performance measures and care plan reviews, and the carers' assessment one has tailed off. And the question was asked: 'Why?' And the response was 'well, because we're not being measured on it anymore'. So the fact that it's best practice is secondary to the fact that it's not being measured anymore.

(BCC1, p. 6)

The 'Best Value' concept extends beyond services provided by the council and is applied to those services contracted out to private and voluntary providers. Chris Flahey, Buckinghamshire's commissioner for advocacy, explained how she was often asked to justify to councillors whether advocacy organisations were providing value for money:

One of the other things we couldn't measure and probably are still not very good at measuring was the value for money aspect, which is around 'how much does advocacy cost? What do you get for your money?' which is something that elected members always ask me when I'm presenting the information to them. And we're working very hard on trying to develop some unit costing approaches. We've got quite a way with

that, so we are at least now able to get some idea of the volume of direct advocacy that we get for a certain amount of funding.

(BCC3, p.2)

Interestingly, Chris also believed that the publication of *Valuing People* had made it easier for commissioners to demonstrate the 'value' of advocacy, as the directive gave the activity increased credibility at the local level. She explained that historically, councillors in Buckinghamshire were reluctant to accept the worth of advocacy in promoting social inclusion – perceiving it instead as a glorified complaints service. The white paper provided an important *national* recommendation of the need to invest in advocacy services:

Chris: ...in the early days advocacy wasn't seen as a priority for us to fund. It was always 'well, why would we fund it? We actually could be funding something that could be causing us a problem', there was that sort of perspective on it in the early days. But I think we got through that and we had got a reasonable amount of funding going into advocacy and reasonable services before Valuing People, but it does underpin what we are doing. It gives it some sort of credibility.

(BCC3, p.9)

1.2 Balancing local needs and resources

The officials also emphasised that whilst they were all committed to modernising services and improving the quality of lives of people with learning difficulties, they were sometimes frustrated in their efforts by a lack of resources:

Peter: Most of us came into this line of work in order to make a positive difference to the lives of people with a learning disability. And yet we spend most of our time, (and I certainly spend more of my time) telling people what they can't have, rather than what they can have.

(BCC2, p.14)

Stuart Mitchelmore also suggested that in recent years, the statutory authority had become more mindful of listening to, and acting upon, the views of carers in the development and provision of services – although this did present some challenges in terms of what the council could afford to pay:

Because I think there can be some tensions between operations and resources, and the aspirations and carers' needs, and we try to marry the two much more than previously.

(BCC1, p. 4)

Peter Loose supported Stuart's point, arguing that recent years had seen a shift within Adult Social Care, in which the views of users and carers were taken into consideration more extensively than previously. However, he acknowledged that the learning disability executive had to straddle this development alongside the ongoing culture of conservatism within Buckinghamshire. Peter suggested that long-standing barriers between councillors and social services officers had to be tackled in a non-adversarial way:

I realise that it's no good standing up and saying to people 'you must, you must', because that's going to...well, it's not necessarily going to enhance people's lives, so we're trying to tackle it in a different way. (BCC2, p.5)

The following sections will consider how advocacy organisations manage to negotiate a role for themselves within this context, and the extent to which the environment in which they operate has impacted upon their development.

2. Perceptions on advocacy

Jenny: I think there's a growing acknowledgement and desire for people to have the opportunity for advocacy, and I think we invest quite heavily in Buckinghamshire in advocacy.

(BCC1, p.12-13)

Although the interviews with statutory officials were dominated by the operational issues outlined in section 1, the managers also acknowledged the role that advocacy played in smoothing some service users' transition to community living, and in enabling a range of people with learning difficulties to voice their perspectives in participative structures. However, the narratives also demonstrated confusion around the advocacy concept, and conflicting perspectives on the appropriate remits for advocacy groups.

The data indicated that the nature of an advocate's role and the extent to which self-advocacy groups are considered to be representative of the wider constituency of people with learning difficulties, were particularly contested issues. For example, the commissioner who was interviewed suggested that funding for one-to-one advocacy might be more efficient if the organisations focused on developing short-term, rather than long-term partnerships. Statutory officials also held concerns that advocacy

organisations might create unrealistic expectations among service users. Another key finding was that self-advocacy was utilised by statutory officials to facilitate the inclusion of the user voice within wider service initiatives, and to meet various policy obligations. As a result, some service users perceived Talkback as being an extension of statutory structures. These findings all raised important issues about the influence of statutory agendas over the practice of advocacy.

2.1 Confusion and misunderstandings

Jean: I think there's still a lot of confusion between self-advocacy and advocacy. I seem to have been having this discussion quite a bit recently, and I found myself saying to people, you know, self-advocacy is proactive. It's about helping people to develop confidence, helping people build self-esteem, to learn new things, to prepare, to be able to make more choices, to have more influence. By its very nature, advocacy is reactive, in as much as if you are in a one-to-one partnership with someone, it's because you need support to get through a particular issue.

(TB1b, p.6)

Jean's observation that people in Buckinghamshire often confuse and conflate different types of advocacy, was borne out in my data. An analysis of the transcripts, alongside my field notes from a Learning Disability Partnership Board workshop on 'advocacy', demonstrated a lack of clarity among statutory officials, staff and carers regarding the activities and aims of the different advocacy groups in Buckinghamshire. Stuart Mitchelmore suggested that there was particular confusion regarding the differences between self-advocacy and citizen advocacy (field notes, LDPB, 18/11/05).

Likewise, there also appeared to be some uncertainty regarding the point at which 'citizen advocacy' became 'befriending'. People's Voices was framed as undertaking 'citizen advocacy' in contrast to the 'befriending' roles pursued by Aylesbury Vale Advocates. This contradicted the perspective of People's Voices' members, who actively described themselves as 'one-to-one / situation-based' advocacy as opposed to citizen advocacy (see chapter 5):

Stuart: That's why it's so important to me to be clear about what type of advocacy it is.

Is it self-advocacy, or is it citizen advocacy?

Jenny: Or is it befriending?

Stuart: Yeah, is it befriending? Because sometimes I think the three get all mixed up together.

Jenny: And I think there's a place for everything. I'm not saying that it's wrong, but it's being clear about what their roles are.

(BCC1, p.12)

Stuart Mitchelmore also acknowledged that advocates were sometimes mistakenly used by services as 'mediators', which sometimes created tensions:

Stuart: I think often we use advocates inappropriately, like to sort a problem out. The service user wants 'a', the carer picks 'b', so we rely on the advocate to make a decision. And I think that's quite convenient for care managers to use sometimes. But the carer will say 'but how can you? I've known my son or daughter for 20 years, and here you are, someone who doesn't know them making a decision about their life'.

Jenny: I think there's a lack of understanding about the role of advocates. And then they find themselves trapped in that role, and they assume that role, and then it gets even more complicated. They're not mediators.

(BCC1, p.13)

In order to clarify some of these issues, a workshop on advocacy was organised for the Learning Disability Partnership Board meeting on 18 November 2005. I requested permission to attend this meeting, which was granted by Peter Loose. I was informed that three advocacy organisations had been invited to join the workshop (People's Voices, Aylesbury Vale Advocates, and Talkback), and that staff and a carer representative were also likely to be present. On the day, members from only one of the advocacy organisations (Talkback) attended. Jean Rein was present, with Rob Beattie and Fred Charman. Stuart Mitchelmore and Jenny Harris also attended, as did a few staff from learning disability services, and the Partnership Board carer representative.

The workshop began with a brief discussion about the Buckinghamshire standards for advocacy, which had recently been updated (the original standards were produced in conjunction with all the advocacy organisations in 2000). Jenny Harris then invited attendees to discuss their views regarding 'the difference between advocacy and self-advocacy'. The response illustrated that fifteen years after organised advocacy was established in Buckinghamshire, it still elicited considerable confusion. The carer representative was particularly concerned about the boundaries surrounding advocates' roles, and the extent to which they would support a service user's wishes. Jean Rein was asked to reply to this query and commented:

The advocate is there to ensure that the service user's voice is heard and if necessary to give them information. It is not to recommend a particular course of action.

(Field notes, LDPB, 18/11/05)

Stuart Mitchelmore also asked Jean to comment on how advocates 'interpret' the wishes of people with high support needs. Jean responded:

Interpreting behaviour is only one part of the process. The rest would involve getting to know the whole 'circle of support'.

(Field notes, LDPB, 18/11/05)

Jean fielded a number of complex questions from attendees at the workshop, predominantly about one-to-one advocacy. When she was asked to distinguish the work that Talkback undertakes from that of People's Voices and AVA, she gave an explanation very similar to the interview extract at the beginning of this section. The meeting seemed to be a useful exercise in 'de-mystifying' the different forms of advocacy, although it was interesting to see how little clarity advocacy evoked. It appeared that carers continued to be quite anxious about the advocate role, although Jean Rein seemed to be successful in alleviating some of these concerns. The meeting was dominated by queries about one-to-one advocacy. From that perspective, the presence of the other two groups may have been useful. Certainly, there seemed to be much less ambiguity in the meeting regarding the role played by Talkback in Buckinghamshire. This illustrated a point raised by Jean a few months earlier, in which she suggested that the increasing visibility of Talkback over the past few years had contributed to a greater understanding of self-advocacy in Buckinghamshire:

I guess that's also because of what we do, and as Talkback, because of what we do and the way we do things, then we are much more visible, and so people see people having their voice in lots of different ways. Whereas I guess one-to-one advocacy is different in that way, isn't it?

(TB1b, p.6)

2.2 Boundaries around appropriate behaviour in one-to-one advocacy

The interviews with officials from Buckinghamshire also suggested that they had various views regarding what constituted 'appropriate' advocacy. In particular, the interviewees appeared to be dissatisfied with advocacy that tipped into 'befriending':

Jenny: I think there's an awful lot of advocacy that still is befriending, it's somebody else talking about what they think is good for the person, instead of truly representing what the person's views are. And that does worry me, particularly around people with high support needs. Some people have got it, and some people just haven't got it. ... And there are a lot of people who just go in and see people.

(BCC1, p.12)

'Befriending' prompted Jenny Harris to have cause for concern for two reasons. First, it was framed as a relationship in which the advocate dominates the partner, and thus makes decisions on behalf of the service users. Second, Jenny seemed to suggest that 'going in and seeing people' does not hold significant value. The advocacy

commissioner, Chris Flahey, also held views regarding the appropriateness of funding ‘befriending’ activities:

They (Aylesbury Vale Advocates) probably have a slightly larger base of citizen advocacy – longer term. That will gradually change I think. It’s not to say that we don’t regard that as an important area, but I think they have a number of long-standing relationships which may be slightly tipping over into befriending, and that’s something they’re starting to look at. You know, they will start to review some of those, just to make sure there is still a need for an advocate’s support. And we’re not going to suggest that they terminate those relationships after a long period of time at this stage, but they just might want to start to consider whether those get slightly reduced, you know, a slight reduction in the level of input into those relationships.

(BCC3, p.4)

Aylesbury Vale Advocates secured a contract to provide advocacy for service users who were leaving the Manor House long-stay hospital. AVA continued to support a number of these individuals in their new homes, but Chris Flahey indicated that commissioning was not entirely satisfied with how the service had developed:

...and I think we need to now make sure that that moves on, and that the service continues to support people in the right way – rather than develop just another dependency, which there’s a danger that it can do.

(BCC3, p.5)

The extracts above suggest that befriending was viewed by statutory officials as an inappropriate activity because it could induce a sense of ‘dependency’ among service

users - mirroring the argument made by People's Voices. However, the desire for advocates to reduce their input into particular relationships also suggests that commissioners may have perceived an advocate's time more efficiently spent providing a greater number of 'instrumental' relationships. Chris Flahey suggested that commissioners might be better placed than advocacy organisations in judging the 'right' way to support service users.

Stuart and Jenny also had concerns regarding the use of advocacy in the lives of people with high support needs, particularly those who do not use speech. They were anxious that advocates might assume a course of action on behalf of the service users, and emphasised that communication skills training was integral in order to ensure that the advocate did not simply voice 'what was comfortable for them':

Stuart: But the type of advocacy I have concerns around is where someone may be displaying a behaviour, and that is interpreted as a form of communication about their life's aspirations and wishes. I think we've got to be very careful about that...it's always like making assumptions.

Jenny: I think there is a real issue about making assumptions about things, and actually the advocates need a lot of support and training. A willingness is wonderful, but they need more support than merely a willingness to want to do it, in terms of what it all means.

(BCC1, p.13-14)

Officials from Buckinghamshire also perceived advocacy as creating expectations that could not always be met by service providers:

Stuart: And also, quite a bit of it is we can't develop a range of services that's going to meet everybody's needs. We can roll out a whole spectrum of services to meet the majority, but you're never going to get everybody's individual choices – there will be exceptions.

(BCC1, p.14)

Jenny Harris suggested that advocates have a responsibility to relay to service users the pressures faced by services, and discuss whether their aspirations are realistic – something that People's Voices, in principle, would eschew (see chapter 5):

I think the role of the advocate in actually helping people to understand what the services are saying back – it's a two-way process. They can advocate all they like, but that may not make any difference... it's trying to help them to understand the reasons why a decision has been made. Say 'it must feel really, really awful they're not doing what you want them to do, but this is what they've said', and putting it in other language.

(BCC1, p.14)

These narratives raise issues around whether advocacy organisations' agendas are driven primarily by the priorities of commissioners and managers, rather than the needs of service users.

2.3 Talkback and representation: self-advocacy as an individual or collective activity

Officials from Buckinghamshire expressed a number of perceptions on Talkback's activities, and the extent to which Talkback were 'successful' in achieving their espoused aims.

Talkback and individual self-advocacy

Chris Flahey and Peter Loose both discussed their perceptions regarding Talkback's work developing self-advocacy with individuals. Peter suggested that in terms of his previous experiences with self-advocacy organisations, Talkback were particularly adept at ensuring that a range of people with learning difficulties were included in the skills development process:

I wouldn't like to say they're a unique organisation, but they are unique in my experience... they have a nice way of ensuring that those who don't communicate, can communicate, through simple things like a stuffed toy as a means of drawing out feelings and emotions, and keeping it sufficiently light-hearted for somebody to be able to express a feeling. So I think that they work quite well with those who are poor communicators.

(BCC2, p.6)

Chris focused upon the 'emotional literacy' side of Talkback's work as an example of their distinctive approach:

...training all people with a learning disability to be able to develop communication skills, self-esteem, those things, so that people are able to represent their own views and actually feel confident at these bigger meetings where they're surrounded by so-called professionals, which could be quite intimidating.

(BCC3, p.4)

Talkback and collective self-advocacy

The managers of learning disability services articulated a less consistent picture of Talkback as the 'collective' user voice. Peter Loose believed that Talkback had been highly successful in developing the 'representative' aspect of self-advocacy, in which a few individuals were able to present the views of many. Peter argued that Talkback self-advocates managed to resist discussing personal anecdotes at partnership board meetings, and were able to convey perspectives that may not have been their own:

The other thing that I think they do spectacularly well is the representative role. I think they're the closest I've ever seen an organisation get to cracking how they can enable a person with a learning disability to represent other people with a learning disability.

Far too often I think learning disability representatives tend to be a sample of one person or two people, rather than representative. It may be largely due to the skills of Jean Rein, but they are using the User Parliament to make sure that they collect in a wide range of views. And then they help the service users to express those views. I've been quite encouraged a couple of times to see a service user convey a message that I don't think he personally believed, but he knew that he had to represent the message because other people had said to him 'this is what we think'. I've never ever seen a person with a learning disability do that as well as this.

(BCC2, p.6)

Peter suggested that Talkback had successfully developed its representative wing because the organisation had focused upon training a few key individuals:

A criticism of Talkback would be they do fairly consistently work with the same group of people. Now, I think that's how they can achieve some of the strengths I've talked about, because they've been able to train those service users to represent the views of other people. But it tends to fairly consistently be the same half a dozen who come to things. Not that that's a bad thing.

(BCC2, p.7)

This demonstrates the tension noted by Chapman (2005), that self-advocacy organisations need to develop the skills and expertise of self-advocates in order to survive, whilst continually 'reinventing the wheel' in order to permit a constant flow of service users to become involved. Similarly, in Baggot et al's study of health consumer groups, the authors found that 'a small number of individuals from the voluntary sector, considered to be key players, were frequently asked to participate. This brought problems of overload and accusations of elitism and self-selection' (2004: 328).

Talkback was aware of this issue, and consequently developed the co-leads structure and split the core group into several specific working groups (see chapter 6).

In contrast to Peter Loose, Stuart Mitchelmore was less convinced about Talkback's ability to represent the views of people with a learning difficulty in Buckinghamshire:

...they're a self-advocacy group, but they're sent to the Partnership Board to represent all people with a learning disability. And sometimes you think, right, hold on a minute, you're speaking up for yourself, but you also represent people with a learning disability – what advocacy is that?... If they represent their personal view, then fine, but don't think you're representing everybody's views. You can only say that if you've spoken to everybody with a learning disability in Buckinghamshire.

(BCC1, p.12-13)

Stuart Mitchelmore was sceptical as to whether these tensions had been resolved in Buckinghamshire. Harrison argues that it is common for service users in participative structures to be 'accused of not being representative', and suggests that double standards often operate at meetings in which professionals – but not service users – are permitted to express a personal opinion (1993: 164). This seemed to be reflected in Stuart Mitchelmore's narrative. Stuart also commented that self-advocacy in Buckinghamshire was perceived by some stakeholders as being for the 'most able' service users only. He was concerned that self-advocacy had not, as yet, made sufficient progress in including the perspectives of people with high support needs:

I think the area we're still trying to establish more credibility on is how we involve people with high support needs in that agenda. Because you can still see the anxiety in the carers, also I suppose in some professionals, in how representative we are being of people who maybe have peg-feeds, or who are very aggressive and challenge services.

(BCC1, p.6)

Simon Evans from Talkback commented that this 'misapprehension' about who Talkback works with was frequently levelled at the group:

There are misapprehensions that Talkback works with the most able. That's something I haven't had said to my face in a meeting, for more than three days now! That happened on Tuesday.

(TB5, p.3)

As chapter 5 demonstrated, Talkback were beginning to implement some innovative means of cultivating the personal development and communication skills of people with high support needs, as well as developing training with the key people in their lives. However, Stuart Mitchelmore's comments suggested that perhaps the 'articulate user syndrome' (Keay, 1993) still pervaded the perceptions of some stakeholders in Buckinghamshire.

2.4 Developing Buckinghamshire's profile and services through advocacy

The Buckinghamshire officials also illustrated how advocacy – and Talkback in particular - had proved useful in raising the profile of the local authority and highlighting elements of good practice in partnership working being undertaken within Buckinghamshire:

Jenny: Together with Talkback, the profile is upped all the time, and the different ways of doing things and putting information across....I mean, Talkback have got a national profile, with the work they're doing. Rob Greig¹¹ knows who we are!

(BCC1, p.6)

¹¹ Rob Greig is the National Director of *Valuing People*

Chris Flahey also emphasised the role played by the advocacy organisations in enabling the implementation of key parts of the *Valuing People* strategy. Chris did not distinguish advocacy as an activity undertaken by the voluntary sector, but rather framed it as part of the overall provision of the Buckinghamshire learning disability services:

I would think now it's much more accepted that it's (advocacy) an intrinsic part of the work we do with people. And it has enabled their involvement at a much greater level, if you like, with things like the Learning Disability Partnership Board. If it hadn't been for advocacy I suspect it would have been quite difficult for people to engage with those processes.

(BCC3, p.4, my emphasis)

Peter Loose also commented upon how Talkback were perceived by managers as a useful means of facilitating greater service user input into services:

I suppose I've also used them in trying to make sure that service users drive everything we do.

(BCC2, p.7)

Some members of Talkback also reflected upon the perceptions held about them by statutory officials. Both Lyn Griffiths and Jean Rein believed that Talkback had developed good working relationships with the council, and that their participation in a range of statutory initiatives was now part of institutional practice:

Lyn: Well we have a very good reputation, and we're taken seriously... And a lot of people want to be associated with us.

(TB6, p.7)

Jean: I think one of the key things is about how everything's beginning to join up... we're now in a situation where – I can't really say what's behind it – but there's very little they'll do without us! (Laughs). They tend to think, you know 'Talkback need to be involved in this'. (TB1b, p.2)

Simon Evans also acknowledged this issue, although he suggested that at times, the 'closeness' of the organisation to the county council led some people to assume that the group was a 'branch' of learning disability services – thus threatening to compromise Talkback's efforts to assert their independence:

But probably the most common misapprehension is that Talkback is a branch of Bucks County Council. Which is presumably because we work very closely with a large number of people in Bucks County Council – and that is how most people see it.

(TB5, p. 3-4)

The next section will consider how these 'perceptions' about self-advocacy were borne out in practice, through an analysis of different participative mechanisms in Buckinghamshire.

3. Participation and partnership working

...at certain junctures it is possible for those who are excluded from such networks to challenge the prevailing institutional arrangements governing access...To be successful, excluded interests must create new policy images that facilitate the use of their perceptions, definitions and resources, and thus legitimate their involvement in policy-making....Once change is effected, this tends to have a long-lasting impact on policy as the new institution becomes entrenched. (Baggot et al, 2002: 55, drawing upon Baumgartner and Jones, 1993)

This section considers the role played by advocacy organisations – in particular Talkback - in Buckinghamshire's partnership arrangements. Whilst authors such as Baggott et al (2002, 2004) contend that it is possible for user groups to develop strategies of resistance against powerful institutional bodies, thus strengthening their part in the decision-making 'mix' (Dearden-Phillips and Fountain, 2005) other researchers have remained sceptical (Aspis, 2002; Hodge, 2005). In particular, studies that have reflected upon the implementation of the Learning Disability Partnership Boards (LDPBs) have shown that despite some good practice, the role played by service users continues to be weak, and at times symbolic (Clement, 2003, Fyson et al, 2004). On this very point, Jean Rein commented:

One of the beliefs that we hold strongly, is that we don't believe in any form of tokenism ...Sometimes we'll be asked if we'll attend a meeting because the providers can show that they're including people with a learning disability. But we're not about presence, we're about participation. (TB1a, p.3)

Drawing upon data from interviews, documents and observation of three 'partnership' meetings (including two LDPBs), this section considers the extent to which self-advocacy has assumed an influential position in partnership arrangements in Buckinghamshire, and highlights a number of important findings. Talkback had developed a considerable participative track record – most notably through undertaking consultation and evaluation projects. Whilst these provided significant scope for involvement, it appeared that some participative mechanisms were not always as inclusive or as accessible as they purported to be. Talkback members were perceived by themselves and other stakeholders as being effective negotiators. The organisation's non-combative style, coupled with their use of humour, were viewed as being particularly useful strategies for gaining influence. However, the data also revealed that there were boundaries around discourse in meetings between self-advocates and other stakeholders, suggesting that traditional power dynamics had not been completely eradicated.

3.1 Official rhetoric and grand visions

The Board truly is a 'partnership' and this is in strong evidence through its working arrangements and membership. At the Board meeting in November, representatives from Talkback, a user led advocacy organisation for people with a learning difficulty, presented a vision for Learning Disability services. The vision to 'improve the lives of people with learning disabilities to ensure that everyone achieves their full potential as a citizen of Buckinghamshire' was agreed by the Board and a work programme has been developed to translate words into service improvements.

(Buckinghamshire County Council, 2001c, Report of the Cabinet Member for Adult Social Care (D) 28/11/01)

These minutes from a cabinet meeting in 2001 emphasise the high hopes held for the Buckinghamshire LDPB in the early stages of its development, and highlight the centrality of Talkback in helping to shape the board's progress. Jenny Harris argued that whilst carers had played an important role in creating the cultural shift that enabled the voices of people other than professionals and staff to be heard, Talkback's determination had been integral in persuading different stakeholders to include people with learning difficulties in discussions around the development of services:

And the engagement of people with a learning disability themselves, has increased significantly. And I think we have to acknowledge a huge debt to the people at Talkback in getting that to happen. Because they were very determined, and they weren't giving up, and that was the people with learning disabilities themselves who were really subject to quite a lot of abuse about their ability to speak up for themselves, and to represent other people with a learning disability.

(BCC1, p.2)

Barbara Poole suggested that whilst the grassroots work of Talkback had been important in enabling shifts in attitudes around participation to occur, the employment of new members within the learning disability services executive following the Longcare scandal and carers' protests about cuts to services, had also provided a key stimulus for change:

You do need some sort of lead from the top. Subsequent directors, or assistant directors with an interest in and responsibility for learning difficulties care, have been very proactive and supportive. So, I think you need both sides, but nothing would have happened under the previous regime...

(PV1, p.4)

Changes among heads of services in learning disability in the late 1990s were accompanied by the first calls to develop a formal mechanism through which the voices of people with learning difficulties could be integrated into the service system. Ideas concerning a 'user parliament' were aired by the statutory services in 1998, although it took a further five years before Talkback were funded to officially implement the concept. The User Parliament (described in chapter 6) is now formally linked to the Buckinghamshire LDPB:

Simon: ...it was used in the context of 'let's have a structured system for getting the views of people with a learning disability to the planning and strategy process'. It has never been the intention of Bucks to have lots of elections, and set up a mini-political system...it's become much more around supporting the co-leads, supporting involvement in the Partnership Board, and working in partnership with senior managers in social care, to make sure there is inclusion.

(TB5, p.1)

3.2 Talkback: presence or participation?

The staff team at Talkback all argued that the organisation had become an intrinsic element of the overarching planning and delivery system within Buckinghamshire's learning disability services. Jean Rein spoke about Talkback's 'proven track record' in working to foster people's individual skills, whilst developing ways of working with other stakeholders to enable the collective voice of self-advocates to be heard and acted upon:

I think, I would say that we're very highly regarded. I do feel that that's what they would say. They take us very seriously. And they like the way that we work. They see us as a strong organisation, they see people having their voice as very important, and they listen to it.

(TB1a, p.5)

Rob Beattie, a long-standing self-advocate in the organisation, was more sceptical regarding the extent to which other stakeholders were comfortable working alongside service users:

There's some people who like working with Talkback, but there are some people, I'm not sure still.

(TB3, p.4)

Simon Evans also acknowledged that whilst Talkback's work in equipping people with skills, knowledge and confidence was important in facilitating the empowerment of

people with learning difficulties, a significant element of their remit was to convince others to 'buy-in' to the principles behind self-advocacy:

Talkback needs to work with those third party organisations and to work with individuals to ensure that when they're being given choices, they have the knowledge and understanding, and can make those choices in a real way – rather than in a tokenistic way...

(TB5, p.6)

Participation in service structures

The data suggested that since its establishment, Talkback has become increasingly involved in different aspects of the planning and development of learning disability services. Aside from the LDPB (discussed in more depth below), Talkback has undertaken a number of participative activities. This has included interviewing individuals for statutory roles (for example, executive managers of the learning disability services), and taking part in the commissioning process to choose which organisations will provide local services.

Talkback has also been involved in numerous consultation and evaluation exercises.

The first significant piece of consultative work was the Day Service Evaluation project entitled '*What we do like, don't like and would like*'. This piece of work was commissioned by the council in light of the modernisation of day services that began in the late 1990s. Service users were asked to contribute their perspectives about what kind of day service provision they would like. Talkback's report opens by commenting:

If you don't know what your options or choices are, how can you say what you want? We decided to learn how to look. We talked about how hard it is to say how you would like to spend your day when all you know about is your own life experience. So some of us decided to go and see what services in other areas were like and develop our understanding of what people did. This would help us decide what we wanted.

(Talkback, no date, p.1)

Self-advocates from Talkback interviewed staff, managers and service users at a number of day centres in Buckinghamshire and Milton Keynes, in order to compare and contrast what different local authorities were offering to people with learning difficulties.

Talkback also developed 'side by side' observation work, in order to access people who did not use speech, or who were uncomfortable about being interviewed. The group took a number of photographs, and explored themes of access, local amenities and transport. The report highlighted elements of good practice, but also put forward a number of recommendations on how to give people with learning difficulties more control over the setting of timetables and activities. Jean believed that the undertaking of this report was a crucial activity in putting Talkback 'on the map'. It was also an opportunity to put the Talkback principle of 'learning how to look' (see chapter 5) into practice:

...it was a good way of learning, a good way of finding out, a good way of developing self-advocacy...self-advocacy was on other people's agendas. And it heightened the profile, not only the profile of people with learning disabilities, but also it sent out a very clear message: We can do this, yeah we need support, but we can do this by ourselves. We can make our own choices. All of those really, really key

messages...we're still asked for those reports, and the work of people with learning disabilities, has, in that respect, fed into so many different strategies and pieces of work.

(TB1a, p.4)

Talkback was revisiting this project in 2004-2005, in order to find out whether any of their recommendations had been implemented:

Liz: What do you do with the Finding Out Group at the moment?

Rob: The Day Options Book. We're going into the services what we done before, see if they've changed.

Liz: So you're revisiting that project?

Rob: Yeah, see if they've changed or not.

(TB3, p. 5)

Talkback has also been involved in the 'Abode' project, which arose as a result of the re-provision of Buckinghamshire's 'Small Health Homes'. Members of the group spent time in people's homes, finding out which issues were important to them, and the kinds of support service users felt they needed. Talkback was also invited to join Buckinghamshire's person centred planning (PCP) steering group:

Liz: What do you do in that group?

Steve: It's all to do with person centred planning.

Jean: Which is good, but we've just got a bit frustrated with it.

Steve: Yeah, because the last one we went to, there wasn't anything to do with person centred planning at all. It was all about something completely different. And Jean went green, and I (pauses)

Jean: Yeah, I mean it's separate to this really but, what has happened is that the last couple of meetings of that group, they've followed on from another meeting where a number of the people from the PCP focus group had been at this earlier meeting, so they had to do a rain-check of what had been discussed at this other meeting, which was all very staff focused, and Steve and I got a bit frustrated.

Steve: Yeah, we did.

(TB4, p.3-4)

As this anecdote indicates, despite many positive examples, sometimes such participative work presented challenges for members of the group who felt that meetings were not particularly accessible for service users, raising issues about the depth of their involvement.

Strategies for participation

Jean: I think they (the statutory authorities) respect the way that we have that (collective user) voice...people say 'you make some really, really important messages come across and stick, but you don't do it with aggression. You tend to do it more with humour. You find ways of making points that people remember, that people take away, and as a result, do something about'.

(TB1b, p.9, Jean's emphasis)

The findings of Baggott et al suggested that health consumer groups were more likely to gain real influence in the development of policy and practice by becoming 'insiders' and learning 'the rules of the game' (2004: 329). Some self-advocates would eschew

this, arguing that getting too 'close' to service providers and commissioners can lead to a neutralising of self-advocacy's objectives (Aspis, 1997, 2002).

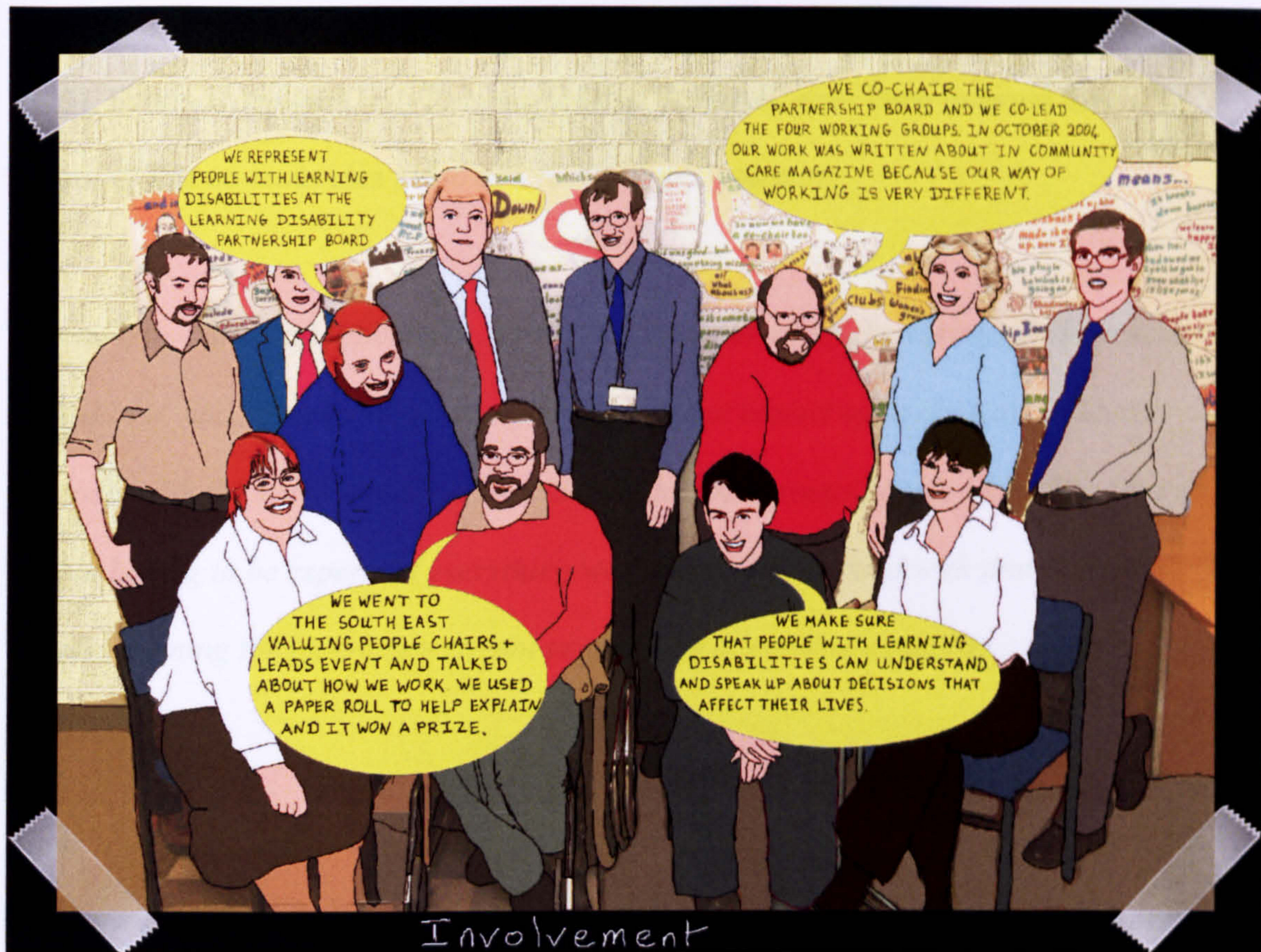
The data indicated that Talkback had developed strategies to resist traditional institutional power dynamics in which statutory officials were dominant. These strategies included developing a particular partnership 'style' which favoured negotiation and the use of humour over and above a more adversarial approach. It also involved taking practical steps to ensure that the likelihood of service users being used in tokenistic ways was mitigated.

Co-leads and the Learning Disability Partnership Board

The Buckinghamshire Learning Disability Partnership Board has developed innovative ways of involving service users in the development of policy. A small team of service managers and people with learning disabilities have been taking on an increasingly influential role in steering the work of the Board through the creation of a 'co-leads' group. Each service user is paired with a manager to oversee an aspect of the Board's work. The initiative came to national attention and was featured in the 'good practice' section of *Community Care* magazine recently.

(Buckinghamshire County Council, 2004, Report of the Cabinet Member for Adult Social Care (E), 25/11/04)

Figure 6: A Talkback image of the co-leads, with members of the Talkback staff team



The Buckinghamshire LDPB developed the idea of ‘co-leads’ in conjunction with Talkback, following on from an independent consultation about how elements of the *Valuing People* strategy could be implemented. The LDPB’s agenda was divided into four main categories (planning for our lives; support for everyday living; life outside the home; cross-cutting themes), into which 17 subgroups would feed. Senior managers were nominated to chair each category. Members of Talkback were then invited to look at the new proposals for the Partnership Board. Simon Evans explained how self-advocates at Talkback liked the idea of the board’s agenda being split into four, as this would help service users to manage the wide range of areas that had to be covered. However, Simon argued that within those arrangements, people with learning

difficulties were being invited to join the decision-making process when decisions had already been made. Research has shown the ways in which service users have been drafted in to 'legitimate' actions already taken (Buchanan and Walmsley, 2006; Hodge, 2005). Simon Evans and Jean Rein argued that Talkback were keen to avoid this situation. The co-leads idea arose as a result of this concern:

Simon: When the draft report was starting to come out, all of the various Talkbackers looked at it, had thoughts about how that would then impact upon the way Talkback interacts with the service systems. The idea of the four groups people liked. The idea of people having to be experts at everything was going to be tackled with that...(But) people planning the planning were not people with a learning disability.

(TB5, p.5-6)

Jean: ...we came to that conclusion as a way forward, to try and make sure that people were involved right from the start. And that they weren't in a position where they are responding to consultation, so they were involved right from the beginning, and people with a learning disability are increasingly in a position where they can initiate discussion, and areas of interest, as well as sometimes responding to it. Which has been very, very powerful.

(TB1a, p.11)

Alongside the idea of co-leads, the Buckinghamshire LDPB also invited a self-advocate from Talkback to co-chair the board with Peter Loose. Fred Charman had taken this role, and explained his position on the board:

Liz: And how do you find doing the Partnership Board meetings?

Fred: Oh, quite interesting actually, although I've been doing that for over two years now. And I've actually been co-chairing it for a year and a half. So I was involved in that in a very small way to start with, and the co-leads didn't actually get going until about a year and a half ago at the Partnership Board... And I co-chair the meetings with the head of Adult Social Care, Peter Loose.

(TB8, p. 2)

The article that appeared in *Community Care* argued that the co-lead system at Talkback had prevented the LDPB becoming an exercise in tick-boxing, with Graham Hopkins contending that 'this kind of cynicism is refreshingly absent' in Buckinghamshire (2004: 46). I attended one of the co-leads meetings in order to observe how this system worked in practice. Co-leads gathered prior to each LDPB meeting, in order to discuss issues on the agenda, and to give each set of co-leads an opportunity to discuss their particular branch of work (see table 4, on page 370).

The co-lead meeting was preceded (on the day) by a meeting at Talkback. Here, the co-leads were supported by the team to prepare for their meeting with the managers. At the meeting I attended, the group focused on the two items which would dominate the morning workshop sessions of the LDPB meeting. These were education for people with learning difficulties, and person centred planning. My field notes indicate that the service users were very vocal in this 'pre co-leads meeting', with everyone contributing comments, arguments and anecdotes in equal measure:

- Steven was particularly vocal when education was being discussed. He talked about his frustration that so many people he knew were 'stuck' doing courses

that they were not interested in. He suggested more people should be doing 'mainstream' courses.

- Lyn explained that people did not have to be in day centres to attend college. Rob said that he had never realised this, and wondered how many other people with learning difficulties were also lacking such information.
- Fred said there seemed to be a lack of communication between key workers and people with learning difficulties about choices over which courses people attend. This led to a discussion about how people with learning difficulties manage to 'ask the right questions'. Peter thought this was a very important point, and then discussed some of his personal experiences.
- When the group discussed PCPs, Fred asked 'how many people actually have one in place?' Steven then said 'And how good are the PCPs that are in place?'
- The service users were really involved in these discussions. Lyn, Simon and Jean let the meeting develop in a very free way, with people often diverging and telling anecdotes about personal experiences. Lyn managed to link most of these points back to the broader issues being discussed.

(Field notes, pre co-leads meeting, 22/02/05)

Shortly afterwards, the managers arrived for the co-leads meeting. My field notes suggest that this meeting was less inclusive than it was intended to be:

- In the first half hour the co-leads split into the four pairs, to discuss Partnership Board issues relating to their subject areas. Simon, Lyn and Jean were intermittently supporting different pairs. However, it seemed that much of the interaction was between the managers and the supporters.

- In the second half of the meeting, the four pairs and Lyn, Jean and Simon came back together. I assumed that this would be to summarise the content of the next LDPB meeting. However, most of the time was spent on logistics – planning future meetings. The Partnership Board schedule for 2005 is very tight, because the January meeting was cancelled at the last minute. This means that most of this year’s meetings will be held every 4-5 weeks, rather than every 6 weeks, which has made it quite difficult to organise when the co-leads will all get together. Jean led this part of the meeting, and the four service users said very little.

(Field notes, co-leads meeting, 22/02/05)

When I attended the meeting in February 2005, these meetings were in the early stages and as they were a Bucks innovation, they were not following any pre-existing models. However, much of the meeting was spent putting dates in the diary and was dominated by interaction between managers and the Talkback staff. The lack of involvement by service users was highlighted by the way this meeting contrasted with the ‘in-house’ session that preceded it.

Humour

Some statutory officials emphasised that Talkback had ‘won around’ stakeholders initially hostile to service user involvement through their use of humour. Peter Loose added that this also enabled Talkback to raise serious points that challenged services in a manner which avoided confrontation:

The other strength I see with Talkback is they have a reasonably artistic, dramatic approach, and they are able to convey messages in an entertaining, humorous and non-threatening way. At last week's partnership board they had a stint they did jointly with carers on care management. And it took the form of a discussion between a few people who were trying to work out what the care manager is. 'Oh, I think I'd like to have one of those – I wonder what they might do?'. And actually, there was quite a sharp point to it, and it certainly gave me the opportunity at the end to sort of throw my hands up in self-defence and say 'can't argue with that!' (laughs)

(BCC2, p.6)

I observed two Talkback Annual General Meetings (in 2005 and 2006), in which managers, staff and carers were in attendance. At both meetings Talkback presented their annual reports 'dramatically', using role-play, sketches, and playing pre-prepared 'films' that 'starred' Talkback members. The presentations included a number of jokes and the gentle teasing of professionals, whilst making serious points such as the need for sustained funding for self-advocacy. Peter Loose recounted another example during which Talkback drew upon this method of presenting their material. The event was a conference about the future of day services, and Talkback undertook a sketch about risk assessment:

And they did a simple sketch which was based on Steven watching television at home in the evening. And they constructed a big television screen which was eight foot square, so that they could then act behind it. And they did things like 'I'm a service user: get me out of here!'. And in one of them, the scene was a day centre, and the service users were talking about what they'd like to do, and they said 'I'd like to go down to the town'. 'That's a good idea! But just before we go, we've got to do our risk assessment', and

there's this great big roll of paper (laughs). But the message was very clear. They hadn't threatened the staff, they hadn't moaned at the staff, they'd simply made the point that risk assessments seem to be the reason for not doing something!

(BCC2, p.6)

Talkback and negotiation: influence or compliance?

Some members of Talkback emphasised how their particular style of self-advocacy had helped to ensure that relations with the statutory authority had developed in a way which maximised, rather than minimised, the level of partnership working between service users and officials:

Jean: whereas historically there's always been fear of advocacy, and self-advocacy, because we're around and about, and people see so much more of the way that we work, and what we do, they don't see us as threatening, even though they see us as quite a strength, if that makes sense.

(TB1b, p.2)

Simon contended that the preparation undertaken by Talkback self-advocates had been an important element in enabling them to gain credibility in the eyes of others:

There's lots of time spent supporting the co-leads for the Partnership Board, to make sure that they're prepared, to ensure that they understand the situation that they're going into...The senior managers hopefully very much respect the views of the Talkbackers that attend Partnership Board meetings. They work hard at listening, and

try to be very positive – and I'm sure that a lot of that comes down to the fact that Talkbackers are perceived as knowledgeable, prepared, and well-supported individuals who are able to represent others, which makes Talkback essentially a powerful force...

(TB5, p.2-3)

This point was endorsed by Jenny Harris, who added that another strength she perceived about Talkback's approach was the group's ability to be 'reasonable' and reflective:

And I think this is one of the real skills that Talkback offers to people, because they do a lot of preparation work before anything happens, and before they get into a conversation outside of themselves, and then they do a lot of reflection, and one of the things they have learnt is actually to present arguments in a way that people like us have no argument back! (Laughs). And they're always terribly reasonable, and terribly understanding...Talkback have it (the skills for negotiation) in spades, they're really very good at it. And they're very reasoned about it – they'll go back and think about things, things that have challenged.

(BCC1, p.14, Jenny's emphasis)

Jenny added that Talkback's approach stood in contrast with her experiences of other self-advocacy organisations, some of whom had adopted more confrontational methods. This corresponds with Buchanan and Walmsley's (2006) observation that managers of social services sometimes struggle to accept the demands placed upon them by consultative exercises that embrace the diversity of people with learning difficulties:

And my experience with a lot of advocacy organisations is that they support people to be angry... and there's a place to be angry – but it's the how. You know, I've seen so

many people with learning disabilities marginalised because they haven't got the techniques to use to confront things in well-reasoned arguments. And so they get marginalised and dismissed because they're just being a nuisance.

(BCC1, p.14)

Some interviewees also suggested that Talkback's ability to negotiate with stakeholders by working alongside them had helped to improve relations with carers, described by Jean as initially 'rocky'. In the passage below, Fred Charman discusses how tensions have eased between users and carers in recent years:

Fred: Like tomorrow when we go to meet the family carers. We do actually try to work alongside them.

Liz: And how is that going?

Fred: To be honest the family carers didn't like us being at the Partnership Board.

Liz: Really?

Fred: Not when it first started, no.

Liz: And did they tell you that?

Fred: Not in so many words. But it was their attitude more or less told us that they didn't really want us there.

Liz: But do you think that things are starting to improve with the carers?

Fred: Yeah, yeah.

Liz: So what is this meeting you've got with them tomorrow? What will you be talking about in that?

Fred: Everything about how things are going on their side. Getting some feedback on how things are actually working out alongside their sort of system now.

(TB8, p.3-4)

Jean emphasised the role played by people with learning difficulties in diffusing the concerns held by carers about the ability and rights of service users to be involved in the planning and development of services:

People have been their own ambassadors, there's no doubt about it, and they've changed lots of people's views. And they've created an environment where they state very clearly 'there's room for everybody here'. Yes, carers are really, really important, and they must have a voice, but it mustn't be to the exclusion of people with learning disabilities. And we do have now, a much better working relationship with carers' groups than we did have.

(TB1a, p.7-8)

Partnerships in action: observation of Buckinghamshire's LDPB meetings

The Partnership Board demonstrates real joint working between people with a learning disability, carers and service providers.

(Talkback Annual Report, 2005-2006, p.10)

I attended two Learning Disability Partnership Board meetings in order to assess whether the comments made in people's interviews, and the vision articulated in Buckinghamshire County Council's written documents was borne out in practice. The first Buckinghamshire LDPB meeting occurred in the summer of 2003, and the meetings I observed took place in March and November, 2005. By this time, the board had established a format for the meeting, outlined in table 4:

Table 4: The Buckinghamshire Learning Disability Partnership Board meetings

LDPB meetings in Buckinghamshire run from approximately 10am-3pm. The morning is dominated by the workshop sessions. Two workshops are held simultaneously in order to cover two 'subgroup' categories (of which there are 17 in total), and the group reconvene before lunch in order to discuss the issues raised.

The afternoon begins with the 'co-leads' reports. At each meeting, one set of co-leads gives an extended presentation to the group, in order to update the board about that particular category (of which there are four in total). The three other co-lead pairs then present a short summary of their area of work. The longer presentations are rotated at each meeting. The LDPB ends with a business report from the co-chairs.

The structure of the Buckinghamshire LDPBs – particularly the co-lead sessions in the afternoon - provided a formal, designated opportunity for service users to speak and raise issues. There was only one service user present who was not affiliated to Talkback, and this individual attended the meeting with her carer. The user 'voice' was in essence, (re)presented by Talkback.

Most of the day's 'discussion' took place during the workshop sessions and in response to the co-chair business reports. Service users were much less vocal at these points in the meetings. I observed that professionals and carers dominated these sessions. Simon Evans from Talkback also acknowledged this point, although he believed that when service users did speak, they were carefully listened to:

And, it would have remained very much a carer-dominated forum, which at times it can feel that way, but it could also be said that people with a learning disability don't just bang on about the same thing every time, and so when they raise a point, it is generally a valid point, and it is listened to very clearly.

(TB5, p.4-5)

At times the Talkback support team raised issues in front of the board following on from quiet conversations that were taking place between themselves and the self-advocates. My field notes demonstrated that occasionally service users raised points after being prompted by the support team to do so:

- In a discussion about access to specialised equipment for people with learning difficulties living in residential accommodation, Peter Loose asked the group: 'does anyone have any questions? Do any service users want to add anything?'
- Initially, all the service users shook their heads in response. Then Jean Rein prompted one of the self-advocates to ask a question about his personal situation, and whether somebody in his position would be entitled to an electric wheelchair.
- Peter replied that this would be unlikely, due to eligibility criteria. He suggested having a future session on access to electric wheelchairs. The meeting then moved on.

(Field notes, LDPB meeting, 18/11/05)

There were only a couple of instances in which service users interjected in the discussion without any prompting from support staff. In a general discussion about evaluating services in Buckinghamshire, Steven made an important point:

- Steven asked the board: ‘don’t you think services should also be measured by the people who use the service?’
- Peter tried to reassure Steven that this did happen, although he did not linger upon this point, or invite further discussion about it.

(Field notes, LDPB meeting, 18/11/05)

Hodge’s research into user participation forums found that whilst service users were permitted to raise points and voice their perspectives, ultimately there were ‘boundaries around the forum’s discourse’ restricting what topics could be discussed in depth (2005: 167). She argued that interjections from service users that presented ‘fundamental normative challenges to mental health services’ were sidelined in order to ‘action’ decisions that had already been made (170). The Buckinghamshire LDPB did provide the Talkback service users with opportunities to raise issues, but this occurred predominantly via the (pre-prepared) co-lead sessions in the afternoon. Other sessions throughout the board’s meeting during which more free-flowing discussion took place, did seem restricted by the ‘boundaries of discourse’ set by Peter Loose. This discourse was dominated by efforts to secure ‘actions’ and certainly minimised the opportunities to raise the ‘epistemological challenges’ to learning disability services that Hodge (2005) considers. Carers were effective at resisting these boundaries, and seemed unafraid of raising contentious - and at times uncomfortable - issues. The service users, however, appeared to be less confident in speaking unprompted. This was quite surprising given how vocal self-advocates were during ‘in-house’ Talkback meetings that I observed. In my field notes (written up immediately after the event) I surmised why this may have been the case:

- Perhaps the service users did not find the discussion particularly interesting or relevant?
- Perhaps they were worried about raising points? Although the atmosphere was friendly, the meeting was large, packed with professionals, and arguably quite intimidating.
- The meeting progressed quite quickly, and a number of complex issues were raised. Was the meeting accessible enough?
- Do the Talkback self-advocates assume that their supporters will speak on their behalf during these meetings?

(Field notes, LDPB meeting, 18/11/05)

As partnership boards were being established across the country, Fyson and Simons (2003) considered whether people with learning difficulties' involvement would be 'active and meaningful' or 'passive and tokenistic' (2003: 156). My observations demonstrated that whilst service users did not seem to be used in a tokenistic fashion, their participation in these meetings was restricted by 'boundaries of discourse' and conditions which precluded the level of involvement suggested by the rhetoric surrounding the board.

However, participation at the board did result in some positive outcomes for people with learning difficulties, as in the bullying example outlined in chapter 6.

4. Commissioning advocacy

The strategy indicates statutory organisation priorities for funding advocacy services...The best use of resources will be achieved by clearer service specifications, demonstrating value for money by developing unit costing, measuring service volume consistently, and reducing any duplication across organisations.

(Buckinghamshire County Council, Advocacy Strategy, 2003-2005, p.1)

This section focuses upon the commissioning and funding of advocacy. It assesses the accounts given by members of advocacy organisations regarding how their work is commissioned, and compares and contrasts these views with the perspectives of statutory officials. This section demonstrates that People's Voices and Talkback were primarily funded through statutory bodies, with members from both organisations acknowledging that this raised important questions regarding the independence and ownership of advocacy. Funding levels were perceived by organisational members as being unstable and insufficient, and left both groups feeling vulnerable to future changes in statutory agendas. Another key finding was that the advocacy organisations felt pressurised to measure their work in quantitative terms, although the groups had shown some resistance to this situation, and were working with the relevant agencies to promote greater utilisation of 'soft' measurements. The data suggests that the commissioning of advocacy appears to have become increasingly specified in recent years. This is evidenced in the recent use of tendering as a procurement method for self-advocacy in Milton Keynes.

4.1 Funding advocacy: different perspectives

How the groups are funded

People's Voices and Talkback are funded by a range of sources, although most of these sources are linked to government bodies. This mirrors the findings on advocacy organisations in Buchanan's (2004) recent study.

People's Voices is funded almost solely through government streams, including Buckinghamshire Adult Social Care, the Partnership Development Fund and the Department of Health (administered by the British Institute of Learning Disabilities). The Independent Advocacy Project in South Bucks was the first project to receive funding, as the original advocacy work undertaken by the South Bucks Advocacy Association. This project received a grant in 1994 from what was then called Joint Funding – resources pooled between health and social services. It has since gone on to receive continued funding of £20,000 per annum from Bucks Social Services (referred to as Adult Social Care, from 2001), in the form of Service Level Agreements (SLAs). Because of the length of time the service has been operating, it is funded on a rolling process basis – which is reviewed annually.

Barbara outlined some of the challenges to People's Voices' independence as a result of their reliance upon government funding. Whilst explicit cases of funders intervening in particular advocacy cases was unusual, Barbara suggested that commissioners had not *increased* the organisation's funding, leading her to surmise that they may approach People's Voices' work with a degree of ambivalence, if not caution:

...because of the purchaser / provider split, we've had three cases, all to do with learning difficulties, where the provider of services has complained to the commissioning body, without complaining to us about a particular advocate. And on one occasion, myself and the then chair of the management committee at the time, well, we were told that our funding would be under threat if we continued to use this advocate. But we did, and they didn't cut the funding. Or perhaps over the years they have down-marked us! (laughs) But that was the only case where it was explicit – that if we continued to use this advocate...I can only say that I know that didn't affect what we did, because it didn't affect what we did – but I can never prove it. So, that's one of the reasons I feel uneasy about the fact our main funding comes from there – but it's difficult to find it anywhere else.

(PV1, p. 9, Barbara's emphasis)

Despite being the cornerstone of People's Voices, the Independent Advocacy Project's funding has never increased from the £20,000 mark set in 1995. Like many other voluntary organisations caught in a similar situation, the established nature of the scheme means it is not eligible for other funding awards from other bodies. Every year People's Voices has attempted to encourage Adult Social Care to increase the funding for this project, at least in line with inflation, and to cover the scheme's core costs:

Barbara: And you've probably heard other people saying that the funding is always for new projects, and never for core funding for existing projects. So, that part of the project is actually badly under-funded, we just try every time, to try and get additional funding.

(PV1, p. 8)

Jean Rein suggested that the challenges faced by People's Voices also reflected Talkback's experiences. Talkback endeavoured to ensure their independence by widening their funding streams, although the organisation was primarily funded through statutory bodies (such as Buckinghamshire County Council, the Department of Health, local PCTs and monies made available through *Valuing People*):

And it's quite difficult from the point that you don't know year on year how much you're going to get, and it doesn't increase (laughs). And we all get asked to do more things. In fairness, the Bucks county council have always accepted they need to fund us. For us, we want to know that we've got funding coming from a number of different sources, to maintain our independence...So, we have a number of different projects, and the training that we do, we use to sort of top-up our self-advocacy pot to give us the independence, and also to enable us to do the level of work that we want.

(TB1a, p.6, Jean's emphasis)

Jean was concerned that the complexity and fragility of funding for advocacy created serious organisational difficulties for a group such as Talkback:

Because for a lot of voluntary organisations there's a small team of people doing a lot of work, and a lot of work has to be done to secure funding. So, if you're not very careful, you end up spending the time finding the money to keep the organisation going and not actually keeping the organisation going. You know, it can become a bit of a vicious circle. You have to learn to wear lots of different hats.

(TB1a, p.6-7)

Core funding

The issue of core funding was raised repeatedly within interviews among some members of People's Voices and Talkback. The perceived lack of funding to cover basic overheads such as office space, and to protect the organisation in the cross-over periods between specifically funded projects, caused significant concern for both groups. Interestingly, the commissioner for advocacy in Buckinghamshire believed that Adult Social Care funding *did* cover the basic 'existence' needs of the two organisations:

Chris: The core funding tends to be in that money that comes from Adult Social Care, although on top of that we have then sometimes also funded specific projects. But yes, I would say that their basic funding if you like, for them to exist, comes from Adult Social Care.

(BCC3, p.4)

This contrasts with the views of the People's Voices' chair:

Anita: We've never had funding for the core business of the organisation.

(PV2, p. 4)

Approximately 9% of each contract contributes to core organisational costs at People's Voices. This figure does not cover some of the most basic facets involved in running an organisation on a day-to-day basis:

Elizabeth: We need core funding for office space and this sort of thing.

Liz: So historically you've managed without the core funding?

Anita: Yes we have. By just taking a little from each project.

Elizabeth: I mean, it's all accounted for but it's a very unsatisfactory way of progressing...Many of the staff work in their own home offices...It would be better if we had a more viable office where we could have meetings and things.

Anita: Yes, and up until now of course, Barbara has worked as a consultant, rather than as an employee.

(PV2, p.10)

Jean Rein also suggested that Talkback had to create their own pot of core funding from specific projects. Jean argued that this was a complex and time-consuming exercise, which may also have implications regarding the extent to which service users are able to be involved in managing the budget:

No one will take responsibility for core funding. So, obviously, from each of our projects we have a slice, it has to make a contribution to all of our overheads and management costs. Which also makes it very complex. For a small organisation you've got a variety of pieces of work – projects – and so it's quite a complex thing that everything has to be broken down for each one. And because they're project-based, you always have to think 'well, the health project is funded for three years – blimey, we're now in year three! If we lose that funding, then what do we bring in to replace that contribution?'

(TB1b, p.7)

A particular anxiety arising from this is how the organisation maintains its staff 'mix' as specific projects come to an end:

Jean: It also has implications when you think about your staff team. Because, everyone's got to pay their mortgage...And I think you know, Social Care for example, don't always take that on board, because they're on their permanent contracts, and things like that. And it also has implications when money is delayed coming through. Because, as a small organisation, you don't have big reserves. We work hard to build the reserves that we need to have, but whatever funding you apply for, it's tight.

(TB1b, p.7)

Bearing in mind the challenges posed by an over-reliance on statutory funding, and the difficulties resulting from a lack of monies to cover 'core' costs, I inquired whether the organisations had attempted to seek funding from elsewhere. Talkback said they were looking into developing a Social Firm, as a means of generating their own income (see chapter 6). People's Voices had attempted to draw in resources from fund-raising, but this proved to be too time-consuming for a small organisation:

Barbara: I mean, people have done sort of, little events for us, and they're all sorts of little pots of money, but frankly I've got tired of having to account for all that... It's not worthwhile me spending time producing financial reports and activity reports for anything under £20,000.

(PV1, p. 9)

The experience around core funding of the two groups mirrors the findings of Baggott et al, 2004, on health consumer groups, who argued that 'this (lack of core funding) discouraged long-term planning, and restricted their service and policy activities' (2004: 320). However, commissioners in Buckinghamshire were acknowledging the

difficulties faced by advocacy groups on this matter, and suggested that they were trying to encourage the groups to be more candid about the finances they required to cover their core costs:

Chris: As is being encouraged for all voluntary organisations, I do encourage them now to go down a full-cost recovery approach when they're putting in any funding bids, because that's perhaps not traditionally been the way that some of the organisations would have done it...They're a lot better at that. It's great for us to get what seems a cheap service, but actually, in a way you're just building up a problem for further on, when they start to struggle financially, because they can't sustain it. Also, I think it gives people a false impression of the cost of the service, and that's not helpful either in the longer term.

(BCC3, p.4)

4.2 Specifying advocacy

There is...legitimate concern that without a strategy grounded in an understanding of advocacy requirements contracting could favour a service or throughput measurement model of success, as opposed to one based on success in supporting people in their lives (Buchanan, 2004: 10, drawing upon Henderson and Pochin, 2001).

A number of researchers have recently begun to question the implications of a commissioning process that 'contracts' advocacy services. Concerns have been voiced about the attempts made to 'measure' advocacy in terms of tangible outcomes, which may not be robust enough to comprise elements such as support and inclusion

(Henderson and Pochin, 2001). Discussing the move in recent years by commissioners to fund advocacy schemes through service level agreements (SLAs) as opposed to the traditional 'grant', Jackson argues:

It sets up the purchase-supplier dynamic, where the advocacy scheme is expected to see itself as delivering a service on behalf of the commissioners, not in response to the people who need advocacy. This compromises an agency's independence (2005: 23).

Jackson lists a number of problematic issues raised by the increasing trend towards service specifications by commissioners of advocacy. He contends that this development may:

- Present a direct challenge to the integrity of advocacy schemes.
- Lead to subtle or blatant pressures on advocacy schemes to disclose confidential information.
- Accentuate the bureaucratisation of the service provided.
- Permit the funder to retain control and place a check on the process of client empowerment.

(2005: 24)

Members of People's Voices and Talkback suggested that the commissioning process had indeed raised a number of these challenges for the organisations. Jean Rein was particularly concerned about moves to develop unit costing for advocacy:

We've talked a lot about this whole thing of unit costing which to me seems a really dangerous game. So if they say they're going to fund you 'x' amounts of units, but because of what's happening you have actually used those units by month 9, what do you do for the rest of the year? I think there are real issues.

(TB1b, p.8)

The recent attempts to design performance indicators (an integral element of the Best Value system – see Chapter 1) were also proving to be very problematic for Talkback. Jean was anxious that commissioners were pressurising advocacy organisations to measure their work in quantitative terms. Jean argued that this type of framework for evaluation tended to overlook the 'soft' work undertaken around issues such as inclusion, and the *quality* of advocacy undertaken:

And one of our real arguments around performance indicators is how you measure those things, because you can't measure things purely by numbers...I think one of the difficulties that we have is that we're not conventional in the way that we work. Because we're so creative, for example, because of the way we record things within the group, they belong to the group. And yes, that information gets fed through because of the co-leads and into the Partnership Board, and as a result, into the planning and development, but we don't count it. But I don't know – I suppose if you looked at where we were involved, then you'd see the impact of our work.

(TB1b, p.8)

However, Jean did acknowledge that commissioners were beginning to accept some of the arguments put forward by the group:

The whole thing around performance indicators, I find quite difficult. But people are getting better at accepting the soft indicators, which is great. ...I fully support that we should be very clear that money is being spent effectively – I don't have a problem with that at all. But what I do have a problem with, is that as a small organisation, a fast-moving team, we don't spend most of our time collecting data about what we're doing, instead of actually doing it.

(TB1b, p.8)

Buckinghamshire's commissioner for advocacy, Chris Flahey, explained that the moves towards increased specifications had come about as a result of trying to ensure greater accountability by advocacy groups:

What we're trying to do – and we've moved quite a way towards it – is just to get better accountability. Quite a few of the advocacy schemes have just grown up with small amounts of grant funding in the early days, and they then just supplemented that with funding they could get from elsewhere. And we didn't even have particularly formal contracts with them in those early days. In latter times, we've had agreements with the funding that we give them, and we've laid down a few more 'conditions' if you like, around the funding. (BCC3, p.1)

When I enquired further about these 'conditions', Chris explained that they were primarily focused upon outcome standards, and increasingly, around *monitoring* those standards:

What we haven't done of course, particularly well, even since we've had the standards, is monitor against them. But that we've now improved, i.e. we've started to specify the

services a bit more closely, linking into the standards so that monitoring links into that, so all the right questions are asked hopefully in a review, to pick up whether the organisation is delivering to those outcomes. But that's quite a recent thing.

(BCC3, p.2)

Accountability

Chris Flahey emphasised that the approach towards greater specification of advocacy services by commissioners could be justified in light of the department's restricted budget, and the desire to balance resources against need:

Unfortunately, as you're probably aware from the discussions you've had with others, we're not flushed with money within Adult Social Care, so we do have to be particularly targeted... we really have to say that the priority is for people we feel are really needing that support – i.e. people that are going through the care planning process, community care assessments, those are the people we wish to see prioritised. Whereas under the old grants system, then they may not have necessarily prioritised those people, they would have probably left it to the advocacy organisations to decide what was appropriate... You know, we don't want to be making referrals to them with our care management, and then find that those people can't be supported because they've got too many other commitments.

(BCC3, p.5-6)

Chris reported that the moves towards more specific contractual agreements with advocacy organisations had come about within the context of New Labour's Best Value initiative. She also argued that within Buckinghamshire, there had been a long-standing

scepticism regarding the value of advocacy among elected councillors, which had created a momentum for more precise specification documents:

... it has properly come about since then (the Best Value directives), and also because there was a sort of view around that we were spending quite a lot of money on advocacy, and people weren't really sure quite what we were getting for the money.

(BCC3, p.3)

Jean Rein also linked the development of contractual funding agreements to councillors' desire to assess whether a service was providing 'value for money'.

Well, that's something that's happening now. The members, the county councillors, are very keen on performance indicators, and are talking about the unit costing, and 'what are we getting for our money?' those sorts of things. And we have six-monthly reviews with the county council on the various projects. And we do look at numbers.

(TB1b, p.8)

Whilst Barbara Poole from People's Voices appreciated that accountability was a key issue for commissioners, she argued that advocacy organisations were also entitled to assert when they were unhappy with the outcomes specified by funders. She recounted when the standards for advocacy were being drawn up, a time in which she defended the right of advocacy groups to challenge some of the suggestions put forward by commissioners:

At that time, I was certainly very vocal to say that if you're looking at what you expected from an advocacy organisation, then fair enough, you know, the

commissioners had every right to say what they expected if they were funding us. We had the equal right to say yes or no, and whether we were happy to work to those requirements or not.

(PV1, p.11)

However, Barbara also acknowledged the pressures facing commissioners in the context of the wider council:

...when talking to Chris Flahey, I think she's under some pressure to prove that it's worth funding, because, we're a very conservative council. And we know the pressure on funding is going more and more towards service delivery, and less and less towards advocacy and campaigning and lobbying organisations. And more and more services are being transferred to the voluntary sector. I don't think, to be fair, there's any lack of recognition of the work in the officers, I think they can see the benefits of advocacy, it's the councillors and the committees... They would be happy if they could see a pound for pound saving, but of course, they can't. It's about quality of life.

(PV1, p.12-13)

Barbara highlighted a recent development, in which government has called for an increased contribution towards service provision by the voluntary sector (Kelly, 2006). Beresford has argued that 'concerns have been widely expressed that, as voluntary organisations have become more involved in providing services in a contract culture, they are less able to offer the advocacy that has historically been key to their independent role' (2006: 20). Barbara's quote acknowledges this very point, helping to explain the discursive reconstituting of advocacy as a 'service' in recent years. This will be explored further in chapter 8.

Benefits to advocacy organisations

It seemed that the development of greater specifying and monitoring of advocacy also revealed elements of the organisations' work that had previously gone unrecognised.

Chris Flahey commented that in undertaking 'base-line' research into advocacy in Buckinghamshire, commissioners had been able to 'evidence' the work performed by the advocacy groups, and demonstrate how they often operate on a 'shoe-string':

I think when people start to see what the money is spent on, and they can see the breakdown of the training, management support, support for volunteers, they can see the numbers of volunteers that are recruited, the numbers of people they're supporting, the numbers of hours that they're providing, it makes it all seem more real...So we now have a bit more evidence around that.

(BCC3, p.3)

Jean Rein also acknowledged that the increasingly contractual arrangements between commissioning and advocacy provided Talkback with opportunities to demonstrate the extent of the work they undertake, which she suggested increased self-advocacy's credibility and legitimacy in the eyes of elected members:

A lot of it is around the quality – in fairness – as well as the quantity. And in that performance...not only do they talk to us, but they go out and talk to people in the day services, and to the members of staff, so that it's clear that we are doing what we say we're doing.

(TB1b, p.8)

4.3 The impact of alternative funding streams on the local commissioning process

Maintaining advocacy services that had been established via alternative funding sources was highlighted by Chris Flahey as being a particular challenge facing the commissioners of advocacy. Advocacy can be funded through a range of schemes such as the Learning Disability Development Fund; the Partnership Development Fund (joint money); the British Institute of Learning Disabilities; and the Big Lottery Fund. Chris argued that these bodies sometimes hold different agendas and priorities to Buckinghamshire County Council, which presented difficulties when that funding came to an end:

One of the complications which we find here, which is probably true in lots of areas, is that funding comes from so many different sources, and some of those can have conditions attached that are separate from, say, the way we monitor, or approach things coming from Adult Social Care... They establish something that's really good, and perhaps identify something that's really needed, and then we as an organisation have got to think 'well actually, can we find the money now to help that to continue?' which has created quite a few problems.

(BCC3, p.3)

In terms of self-advocacy, Jean Rein suggested that although Talkback was established via Lottery funding, the organisation had worked hard to make itself 'indispensable' to Buckinghamshire County Council:

By that stage (end of the Lottery funding period), we had quite a high profile in the county, and a lot of the work we had been doing with Bucks County Council, meant we

had a very good working relationship with them. And they believed that they needed to support the advocacy and self-advocacy organisations.

(TB1a, p.6)

This was confirmed by Chris Flahey:

Talkback was one of the organisations that started with lottery funding, and they had three years of that, but we also then topped it up with some money so that they then expanded into a much bigger service.

(BCC3, p.3)

In the case of Talkback, it appeared that the lottery funding had enabled self-advocacy to take root in Buckinghamshire – perhaps before commissioners identified it as a ‘priority’ area, which was a remarkable and unusual success. However, the council were seemingly satisfied with the progress of the group, and recognised its contribution to the overall learning disability strategy when the lottery funding came to an end in 2000.

4.4 Tendering

The introduction of tendering for advocacy is a recent development in the commissioning process (Buchanan and Tilley, 2005). Buckinghamshire had not used this form of procurement for learning disability advocacy, but had tendered for the provision of advocacy for mental health service users. Chris explained the rationale behind this development:

Partly because, the ones I've described that grew up from grants, they were learning disability advocacy largely, whereas we haven't had those services just develop from the roots up in mental health. So once we decided that we wanted to see some more advocacy around for people with mental health problems, we actually did tender.

(BCC3, p.6)

Chris described what she perceived to be the strengths in using tendering as a procurement method:

I think there're obviously some strengths in doing that because you get that element of competition, and then you have the opportunity to choose perhaps what you consider is the most appropriate organisation, best value – those things.

(BCC3, p.6)

However, Chris also acknowledged some of the tensions produced in her experience in using tendering to secure advocacy services:

One of the downsides to it though was that it did set these organisations against one another, and given that we don't have that many, that wasn't that helpful. Because, as it is, working with them all as individual organisations, but also working together is quite a strength, because they can share quite a lot of expertise and knowledge, whereas when they were in this competitive situation there tended to be an element of secrecy between the organisations, protecting their own – understandably because they were competing. I think those things need to be carefully thought about: what is the value of the tendering process?

(BCC3, p.6)

Towards the end of my fieldwork, Talkback tendered for, and secured, a contract to 'provide' self-advocacy in Milton Keynes. Unlike the situation Chris Flahey described in Buckinghamshire, Milton Keynes Council was already funding an existing People First self-advocacy group. In 2005, the current advocacy 'provider' was asked to compete alongside other organisations (including Talkback) for the new self-advocacy contract, which included specifications on issues such as principles and values; service delivery; and management. The tendering process experienced a number of difficulties and 'false starts' which seemed to engender a sense of confusion and distress amongst the groups involved (Buchanan and Tilley, 2005). The challenges that arose throughout the tendering process appeared to be the result of a process 'drift' rather than any cynical attempts to exclude one particular group from undertaking advocacy in the area (Buchanan and Tilley, 2005). Nevertheless, the use of tendering in this way raised a number of important issues around power and control among different agencies in the development of advocacy, and suggested the need for further research in this area.

Conclusion

This chapter has demonstrated that relationships with external stakeholders have had a significant - albeit complex – impact on advocacy. In particular, the local authority maintains an influential presence in the development of advocacy organisations in Buckinghamshire, primarily through the growth of increasingly contractual commissioning arrangements. As evidenced here, statutory bodies are themselves facing a number of pressures from national directives and local priorities, some of which have directly affected their relationships with advocacy organisations. More often, these

competing agendas impact upon advocacy in more subtle ways, for example, by influencing how advocacy is perceived and 'valued' by a number of key stakeholders.

Through self-advocacy, people with learning difficulties have significantly increased their level of participation in the planning and provision of services in Buckinghamshire. The data suggested that Talkback has taken a less radical and assertive stand than that of some other self-advocacy organisations within this process. Talkback's strategy appears to have been effective in managing external relationships and maximising opportunities for involvement. However, this chapter also highlighted that boundaries existed to confine such participation. It seemed that the production of such boundaries was the result of a complex mix of factors which included both structural limitations (such as the format of partnership meetings and embedded perceptions of service users' capacity for involvement) as well as a lack of confidence among some self-advocates to speak up and challenge other (seemingly powerful) stakeholders. These are important issues for Talkback to address if it is to continue in its attempts to influence the development of learning disability policy and practice in Buckinghamshire.

The implications of these issues for the future of advocacy will be assessed in the final chapter.

Chapter 8: Conclusion

This chapter brings together the main thesis findings and draws some conclusions from the research. The first section will do this in relation to the four research questions posited at the outset of the thesis. The second section will use the findings from People's Voices and Talkback to discuss issues that I believe have wider applicability for other advocacy organisations. Finally, I identify the issues that appear to warrant further research.

Personal reflections

This research has taken me on a personal journey which has required constant self-reflection and self-evaluation. Many previous assumptions were shaken by an engagement with the literature, which raised challenging epistemological questions, and highlighted the ways in which my own values might affect the collection and interpretation of the data. Perhaps more significantly, my contact with the respondents in this thesis provided an ongoing source of stimulation. These interactions offered insights not only into advocacy, but also into the ways in which I as a researcher learned to steer through some of the challenges presented by such an in-depth, qualitative study. On reflection, I realise that periods in the research which felt particularly testing were as important to the development of this thesis as moments of clarity. I believe that working through such challenges as honestly as possible – whether alone, with my supervisors, or with the respondents – enriched the research and strengthens the conclusions presented here.

1. The research questions

In this section I review the findings presented throughout the thesis that shed light upon the questions raised in chapter 1.

1. What factors influence the development of advocacy in a local context?

This thesis has argued that more in-depth local studies of advocacy organisations are required, and has shown that it is possible to capture the history and socio-political context of such groups using a multi-method approach.

The emergence of advocacy in Buckinghamshire was tied closely to local deinstitutionalisation policies of the late 1980s, and the development of a mixed economy of care. Local events such as the Longcare scandal provided additional impetus for the funding of advocacy schemes. Threats to services for people with learning difficulties occurred as self-advocacy was emerging and significantly shaped the type of group that developed. It also set the scene for the direction of self-advocacy in Buckinghamshire and the nature of Talkback's external relationships, which distinguish the group from other organisations described in the literature.

In contrast to the dominant historical narrative charting the growth of advocacy, the findings revealed that advocacy in Buckinghamshire emerged through partnership working between the statutory and voluntary sector. The data also demonstrated the key role played by non-disabled supporters in facilitating the establishment and expansion of People's Voices and Talkback. The pressure to respond quickly and effectively to outside factors meant that Talkback needed to develop organisational processes which

enabled the involvement of as many service users as possible. This may help to explain why non-disabled members with prior experience of management took the lead in specific governance roles at an early stage in Talkback's development. However, this also raises questions regarding whether people's ability to establish their own group was constrained by lack of opportunity, attitudinal prejudice, or the nature of their intellectual impairment (Walmlsey, 1997).

Finally, an exploration of the local context in which advocacy has developed demonstrates the important role played by Talkback in helping to drive forward a more inclusive approach within the statutory sector. Although national directives were a key factor in prompting greater service user involvement in the planning of services, Talkback's early approach was significant in helping people with learning difficulties to gain a 'place at the table' (Simons, 1999).

2. What is advocacy in practice?

The introduction and literature review highlighted the ambiguity which often surrounds advocacy. One aim of this thesis was to find out how members of advocacy organisations understand and narrate the work they do, and to assess how this linked to practice. In particular the thesis paid close attention to the articulation of values, principles and theories among members, to see what light this could shed upon the advocacy concept.

The data revealed that People's Voices and Talkback were both driven by goals to improve the quality of life of people with learning difficulties and to enable them to have a voice. These goals matched the espoused aims of writers on advocacy described

in the literature. However, both groups diverged from other advocacy organisations highlighted in existing studies in various ways. This finding emerged through a close examination of the groups' values and principles, in other words, ideas about *how* advocacy could achieve its aims.

The dominant discourse at People's Voices framed one-to-one advocacy as a neutral facilitator; an instrument with which service users could resolve difficult issues, or pursue specific objectives – no matter how radical (as long as they were within the law). Unlike the citizen advocacy model, organisational rhetoric at People's Voices stressed that the path to empowerment was not reliant upon the development of expressive, emotional, and socially involved relationships. It was argued that these kinds of advocacy partnerships posed risks of increased dependency, and thus compromised the objective of user control. However, one of the advocates suggested that this framing of advocacy was somewhat at odds with her experience on the ground. In the context of certain partnerships, it was clear that in order to become a means through which service users could be enabled to take more control, the advocate felt that some befriending was an important, and indeed, necessary part of the process. This highlighted one notable tension within the practice of one-to-one advocacy.

A second notable tension was the articulation of one-to-one advocacy within 'helping' discourses. The advocates (and some members of the board) described advocacy in terms such as 'doing good', and 'supporting the vulnerable'. These narratives shifted advocacy away from the language of empowerment expressed in the 'official' organisation rhetoric, and refocused it upon the altruistic motivations of the advocates. Page has argued that 'well intentioned selflessness may, in certain circumstances, only serve to induce feelings of stigma amongst those in receipt of such help' (1996: 13).

Whilst Barbara Poole endeavoured to frame one-to-one advocacy in a way that refuted images of charity (thus attempting to minimise the potential for dependency and stigma), this line was not consistently adopted throughout the organisation. Arguably, as voluntary one-to-one advocacy schemes do – in the main - rely on volunteers from the local community, it may be difficult for organisations to suppress such alternative narrations of advocacy.

Members of Talkback expressed their understandings of what advocacy is, or ought to be, in different ways. For example, the staff team placed an emphasis on self-advocacy's educational and political aims – such as developing the skills of 'emotional literacy', and participating in the planning and development of services. Whilst people with learning difficulties also spoke about self-advocacy in these terms, they placed a significant emphasis on the group's role in facilitating social events, friendships and opportunities to be involved in new ventures and activities. Whilst the two approaches are not mutually exclusive, they do suggest that self-advocacy might be valued for different reasons by disabled and non-disabled people.

Unlike other self-advocacy organisations, members of Talkback rarely referred to a 'rights' agenda (the only exception being one self-advocate). Indeed, Jean Rein explicitly stated that whilst Talkback clearly supported people's rights, she felt that a discursive emphasis on rights could be unhelpful when negotiating new spaces in which people with learning difficulties could participate. This approach may have arisen as a means of distinguishing Talkback from other self-advocacy organisations – notably People First groups. Alternatively, it may be a remnant of past events, which required Talkback to develop a particular style in order to gain access to decision-making structures within learning disability services. What was notable (and arguably quite

unique) about Talkback's approach, was the emphasis on 'learning to look'. This was explicitly stated by the staff team only, although it did appear implicitly in the narratives of people with learning difficulties. The idiom was used metaphorically to describe the process of becoming more questioning, and thus more informed – viewed by Talkback staff as a central tenet of effective self-advocacy.

Whilst members of both organisations drew implicitly upon elements of the social model of disability and social role valorisation, explicit references were uncommon. However, the data reflected Clark's (1991) assertion that members of organisations in the health and social care field often draw subconsciously upon substantive social scientific knowledge. Whilst the advocates at People's Voices were keen to distance themselves from 'theory', preferring to rationalise their responses within advocacy partnerships in terms of intuition and personal experience, examples arose which contradicted their assertions. Views about the barriers faced by service users in day-to-day life indicated that the advocates were often drawing upon social model conjectures, although the advocates also identified limitations posed by people's intellectual impairments.

At Talkback, staff members drew implicitly upon both the social model and social role valorisation. Talkback's policy of training service staff, professionals and other members of the local community to communicate effectively with people with learning difficulties was one clear example of how the group drew upon elements of the social model. Likewise, on a number of occasions, staff emphasised the valued social roles held by people with learning difficulties both within and beyond the organisation, even though at times this stood in tension with what the self-advocates themselves were articulating. Whilst the self-advocates did not appear to be drawing on sociological

theory either implicitly or explicitly when describing the activities and purpose of Talkback, their conversations with non-disabled workers often revealed conflicting perceptions on the nature of intellectual impairment. Whilst the staff sometimes drew attention to a service user's 'learning disability' in order to emphasise a particular achievement, or an example in which they held a valued social role, self-advocates rarely acknowledged impairment as the principal identifier of other individuals. At times this produced tensions in the narratives which highlighted the contested assumptions upon which people acquire the label of 'learning disability'.

In summary, the data showed that advocacy was perceived in various ways by different organisational members. Whilst advocacy is undoubtedly driven by a well-developed values-base and strong principles, at times these values and principles stood in tension – occasionally becoming contradictory. Advocacy was viewed by both organisations as the means through which objectives such as user control and a better quality of life could be achieved. However the specific processes that might enable such outcomes proved to be sites of contestation.

3. What are the tensions and challenges that arise in the practice of advocacy?

Notable gaps in the advocacy literature included in-depth explorations of the tensions and challenges that arise within advocacy, and how organisations negotiate such difficulties in the face of wider pressures. In particular, the literature was ambiguous on the subject of who actually runs advocacy groups – arguably an uncomfortable question for organisations driven by agendas of service user autonomy and control.

The thesis has shown that the boundaries between user control and user participation in the governance arrangements of advocacy organisations were frequently blurred. As one might expect, people with learning difficulties had a greater participatory role in the organisational maintenance of Talkback, although Barbara Poole did allude to the lack of involvement of service users in the running of People's Voices, and the tensions that this produced. At Talkback, it appeared that service users were highly involved in some – although not all – of the systems which were shaping the organisation's growth. In both groups, members produced a variety of accounts with regard to how their respective organisations were led and managed, suggesting that the language of 'user control' and notions of the 'team' were ambiguous and may have disguised as well as shed light upon certain organisational processes. In particular, the roles of influential individuals in advocacy were contested by different organisational members. There were certainly occasions in which non-disabled members of staff appeared to be narrating themselves out of their roles. This may be a result of organisational values which emphasised equality and user control. The very notion of 'leaders' – particularly if they do not have learning difficulties – may be seen by some members to eschew such principles. The staff team at Talkback stressed the role played by *all* members in the running of Talkback, and in this way can be seen to adhere to Block's (1993) notion of a collection of 'stewards' guiding and shaping the group's future. However, the accounts by people with learning difficulties and the Talkback chair suggested that staff members – and more specifically the chief executive - were perceived as being leading figures within the organisation.

Members of People's Voices were particularly concerned about the risks posed to the long-term sustainability of the group by an over-reliance on one or two key individuals. This issue was raised only in passing by one Talkback member, although the data

suggested that the group's smooth operation relied mainly on the small staff team – in particular Jean Rein. Indeed, an implicit concern about Talkback's future - in light of precarious funding streams and the increasingly competitive environment in which self-advocacy operates - may help to explain how Jean and the other staff members came to adopt such influential roles within the group's management.

The data suggested that Talkback appeared to be at the second stage of Bylov's 'generation' model of self-advocacy, in which the organisation is run *with* people with learning difficulties. Talkback's move to the third stage - in which it would be run *by* people with learning difficulties - seemed reliant upon Jean Rein being able to impart her knowledge and expertise to self-advocates. The discussion about converting the organisation into a social firm demonstrated that some members envisaged the increasing involvement of people with learning difficulties in the administrative and managerial structures of Talkback. However, the fast pace of Talkback's expansion, coupled with growing pressures from the external environment may mean that the governance systems at Talkback at the time of writing, remain in place for the foreseeable future.

The thesis has shown that an organisation's value-system may need to be compromised in order to secure an efficient organisation with an assured future. What is the impact of this upon organisational members? Whilst the 'team' rhetoric may be appealing, does it produce effective strategies for an organisation in times of crisis? Drawing upon Block's (1993) work – can 'partners in charge' be accountable without being controlling? The findings have demonstrated the vulnerability of organisations whose history is bound up with a very small number of individuals. Whilst these individuals may be responsible for building the organisation into a successful entity, they may also

be accountable for its collapse should the group neglect to develop effective succession plans.

The findings also demonstrated variation in organisational members' perceptions on the nature of intellectual impairment. Whilst self-advocates rarely identified themselves or others as having 'learning difficulties', non-disabled staff at Talkback - and advocates at People's Voices - frequently highlighted people's impairments, if only to draw attention to their achievements as somebody holding such a label. Some writers have questioned whether the social model is sufficient to account for the experiences of people with learning difficulties, and in the context of self-advocacy Clement (2003) suggested that some people's intellectual impairment might simply be too great to permit them a real involvement in running a group. Certainly at People's Voices it was clear that efforts had not been made to involve people with learning difficulties as members of the board. Talkback had made great efforts to include service users – although clearly not through actions such as official organisational titles (as in People First groups). Were self-advocates at Talkback therefore less involved than those in other self-advocacy organisations? Clement's (2003) research would suggest that Talkback had perhaps found more innovative and democratic ways of including people, particularly through the 'About Us Voice' and User Parliament structure, which seemed to go some way in reconciling the individual / collective tension facing many self-advocacy groups.

However, it also appeared that self-advocates had become reliant upon the role undertaken by non-disabled staff to perform certain organisational tasks. Was this a result of the 'real' limitations of people's impairment which meant it was more organisationally efficient for the staff to undertake specific activities? Perhaps it was a consequence of underlying assumptions among staff about people's capabilities which

restricted their opportunities for involvement? Or had the self-advocates actively chosen to confer responsibility to staff for tasks that did not interest them? Further research (with a more ethnographic emphasis) might help to elucidate such ambiguities.

4. How do relationships with external stakeholders impact upon organisations that practise advocacy?

A central tenet of this thesis has been to examine the ways in which outside forces shape the development of advocacy. In particular it focused upon the relationships that advocacy groups have developed with statutory bodies.

The research found that whilst advocacy was accepted as an important component in community and residential living for people with learning difficulties in Buckinghamshire, there remained some confusion among professionals, carers and statutory officials regarding the remits and philosophies of different types of advocacy organisations. Whilst Talkback made notable attempts to reduce the misunderstandings surrounding advocacy, other organisations have been less 'visible' within the county, and less proactive in developing external relationships. It appeared that People's Voices was reluctant to become too 'close' to statutory officials, preferring to undertake their work away from the spotlight of public forums. On the one hand, this may have assisted the organisation in its aim to remain as independent as possible from statutory authorities. On the other, it may have contributed to the perpetuation of what Stuart Mitchelmore described as 'myths' about the purpose and roles of advocacy organisations (field notes, 18/11/05). In the light of data which demonstrated how managers and commissioners in Buckinghamshire narrated 'boundaries' around what constituted appropriate and inappropriate remits for advocacy, a lack of dialogue

between one-to-one advocacy organisations and statutory officials raised issues about the group's capacity to control how its future development is shaped.

Recent years have witnessed the increasing involvement of people with learning difficulties in the planning and provision of local services in Buckinghamshire. The thesis outlined some of the ways in which this involvement has occurred, and emphasised the central role played by advocacy groups in helping to facilitate this development. Joint working between Talkback and a range of statutory and voluntary bodies enabled the growth of some innovative practices in partnership arrangements, such as the development of the co-lead system at the Learning Disability Partnership Board. The thesis argued that Talkback drew upon a number of 'strategies' which helped to smooth relations between service users and other stakeholders. This has enabled people with learning difficulties to secure a more equal footing within current partnership developments. However, the data also indicated that whilst the participation of people with learning difficulties was becoming increasingly 'institutionalised' within Buckinghamshire's learning disability service structures, service users continued to face challenges regarding the *extent* of their involvement. The language of 'partnership' sometimes appeared to be employed as a means of masking processes which continued to exclude people with learning difficulties from 'challenging normative frameworks' (Hodge, 2005) and from contributing meaningfully to important decision-making discussions. Talkback's approach has so far been one of 'negotiation' in its relationships with outside bodies, which has been appealing to statutory officials. One challenge facing the organisation as it continues to expand is how its proximity to statutory stakeholders can be straddled alongside its desire to be an influential and independent player. Talkback's approach also raises questions about the extent to which professionals, managers, commissioners and carers in Buckinghamshire are prepared to

accept service users in all their diversity, or whether they are implicitly stipulating that people with learning difficulties are trained to behave in 'appropriate'- and perhaps uncontentious – ways.

The question of *who* or *what* is shaping the development of advocacy, is thrown into sharp relief most clearly with the issue of commissioning. The thesis has shown that People's Voices and Talkback relied heavily upon financial support from Buckinghamshire council. However, this support was tied to specifications set by bodies with a range of priorities – some of which came into direct conflict with the principles and espoused aims of the advocacy organisations. Although the data showed that commissioners were aware of these tensions, the current commissioning process (which looks likely to draw more frequently upon tendering as a procurement option in the future), raises some worrying issues around power and control for advocacy organisations. The data suggested that advocacy organisations were resisting shifts in the way that advocacy was funded, and influencing the mechanisms by which advocacy is 'measured'. The research has also shown that advocacy organisations – in particular Talkback – worked hard to make themselves appear 'indispensable' to the development of policy and practice within learning disability services. However, whether advocacy can continue to wield such influence should the initial impetus and enthusiasm behind *Valuing People* lose pace, remains a pertinent issue. In this way, ownership of the advocacy agenda continues to be a site of contestation in Buckinghamshire.

2. The wider application of this research

Advocacy is clearly a dynamic and diverse phenomenon. If, as I have argued, the growth of People's Voices and Talkback was dependent upon local factors, can any common threads be extrapolated which have relevance for advocacy organisations beyond these two case studies? I suggest that on a number of counts, this research can be used as a lens through which to examine wider issues facing advocacy for people with learning difficulties, and other small voluntary organisations in the health and social care field in England.

Advocacy, voluntary organisations and the state

People's Voices and Talkback were both framed as 'services' by people in the statutory sector, and occasionally by organisational members. Whilst this is unsurprising given the current commissioning and funding arrangements, it does raise important issues about the ownership and control of advocacy organisations, and prompts an analysis of who is driving the advocacy agenda.

Whilst the government's renewed emphasis on the heightened participation of voluntary organisations in the provision of health and social care services has generally been welcomed by the third sector (Kelly, 2006), concerns have been raised that small, bottom-up voluntary groups with an advocacy focus, are being overshadowed by large, service-orientated organisations chasing substantial government contracts (Beresford, 2006). Recent research by the National Council of Voluntary Organisations has highlighted that 55% of voluntary organisations had not had their funding agreed for this financial year and 41% had not been paid on time (Kelly, 2006) – a potentially

devastating scenario for small groups with few reserves. Indeed, this issue was emphasised by People's Voices and Talkback, and had been a source of anxiety for members of both groups. Although the organisations had attempted to diversify their funding streams in reasonable ways, both continued to rely upon government to sustain their activities.

Whilst advocacy has been given a prominent role in recent policy initiatives, respondents highlighted their concerns for a future when advocacy may no longer be so fashionable. Talkback made significant progress in augmenting its remit and expanded considerably throughout the course of the research. However, as one respondent indicated, this was tied closely to the vision and proficiency of its chief executive. Would the group have developed to the same extent without such a 'star' (Rolph, 2002)? And to what extent was Talkback's success in securing contracts dependent upon the key role played by non-disabled staff? These questions, though not wholly resolved here, have implications for other advocacy organisations.

The research has shown that both groups relied heavily upon a small number of leading figures. Whilst the personal commitment of such individuals had enabled the groups to grow, their role also raised questions about organisational sustainability. Small voluntary groups such as the two advocacy organisations researched here, are vulnerable in the face of key individuals leaving the group. This sense of fragility is heightened in the wider context of insecure funding, and commissioning practices which at times appear to emanate from the priorities of statutory bodies, rather than advocacy groups themselves. Within this environment, it may become more difficult for people with learning difficulties to position themselves in roles that shape the advocacy groups of which they are a part.

3. Future research

Whilst this study has shed light upon a number of issues relevant to organisations that practise advocacy, it has also revealed areas for future research:

Relationships with other advocacy organisations

One omission in this thesis has been an analysis of the relationships that advocacy organisations conduct with other advocacy groups. Whilst space precluded an in-depth discussion of this theme, more importantly, I became aware that the organisations were uncomfortable with such analyses in a piece of research that was not anonymised. This is not to suggest that the groups' relationships with one another were necessarily difficult or problematic. Rather, within a context in which funding between groups had become increasingly competitive, members did not feel it appropriate to comment upon the activities of other organisations. However, advocacy has been viewed as a fragmented phenomenon characterised by significant philosophical divides (Henderson and Pochin, 2001), although it has been argued that the current policy environment requires advocacy groups to present a united front (Peter, 2002). Thus an exploration of how such organisations perceive one another would be timely, although such research may necessitate an anonymised approach.

The role of future procurement practices in the commissioning of advocacy

The government's Third Sector Public Service Delivery Action Plan was due to be published in Autumn, 2006, as this thesis was completed. It was anticipated that this document will highlight best practice in the procurement and commissioning of

voluntary sector services. It is interesting to consider what such 'best practice' will look like, and how it might affect advocacy. In the light of one local authority's recent use of tendering to secure advocacy for people with learning difficulties (outlined in chapter 7), I would argue that future procurement practices need to be monitored closely by researchers. Throughout the course of this research I became aware that there were very few forums in which good practice among advocacy groups could be shared. Arguably the use of tendering would further inhibit the development of such dialogues.

Conclusion

This thesis has provided an in-depth analysis into the development of advocacy for people with learning difficulties through the window of two organisations. There is a necessity for other kinds of studies – including more local analyses - to be undertaken in order to capture the achievements and challenges faced by such groups, and also to reveal the complexities inherent in their work. In this way, researchers, commissioners, and of course, those at the centre of advocacy organisations will gain a deeper understanding of the claims made about advocacy, and how these translate into practice.

APPENDIX 1: Information sheet

Liz Tilley
PhD Project

Advocacy Organisations for People with Learning Difficulties in Buckinghamshire

Can you help?

In my PhD thesis I will be exploring advocacy organisations for people with learning difficulties in Buckinghamshire. The research will focus on the experiences of:

self-advocacy groups and user-controlled groups
other types of advocacy organisations

Buckinghamshire has a very rich history of voluntary organisations for people with learning difficulties, and I very much hope that you would like to help me put together the exciting story of these groups.

Capturing the experiences of advocacy organisations for people with learning difficulties is a fascinating project. These groups have played an important role in:

- Shaping developments in **attitudes** and **policy** within the learning disability field.



- Providing much needed **support, advice** and **friendship** for people with learning difficulties and their families.



To do my research, I would like to talk to different people about their memories of the organisation with which they have been involved. For example:

- your memories about the early days of the organisation
- the kind of work the organisation has done
- what it's been like to be part of the organisation

If you would like to take part, you decide:

When to meet me

How many times we can meet

How much information you would like to talk about

When you would like to the interview to end

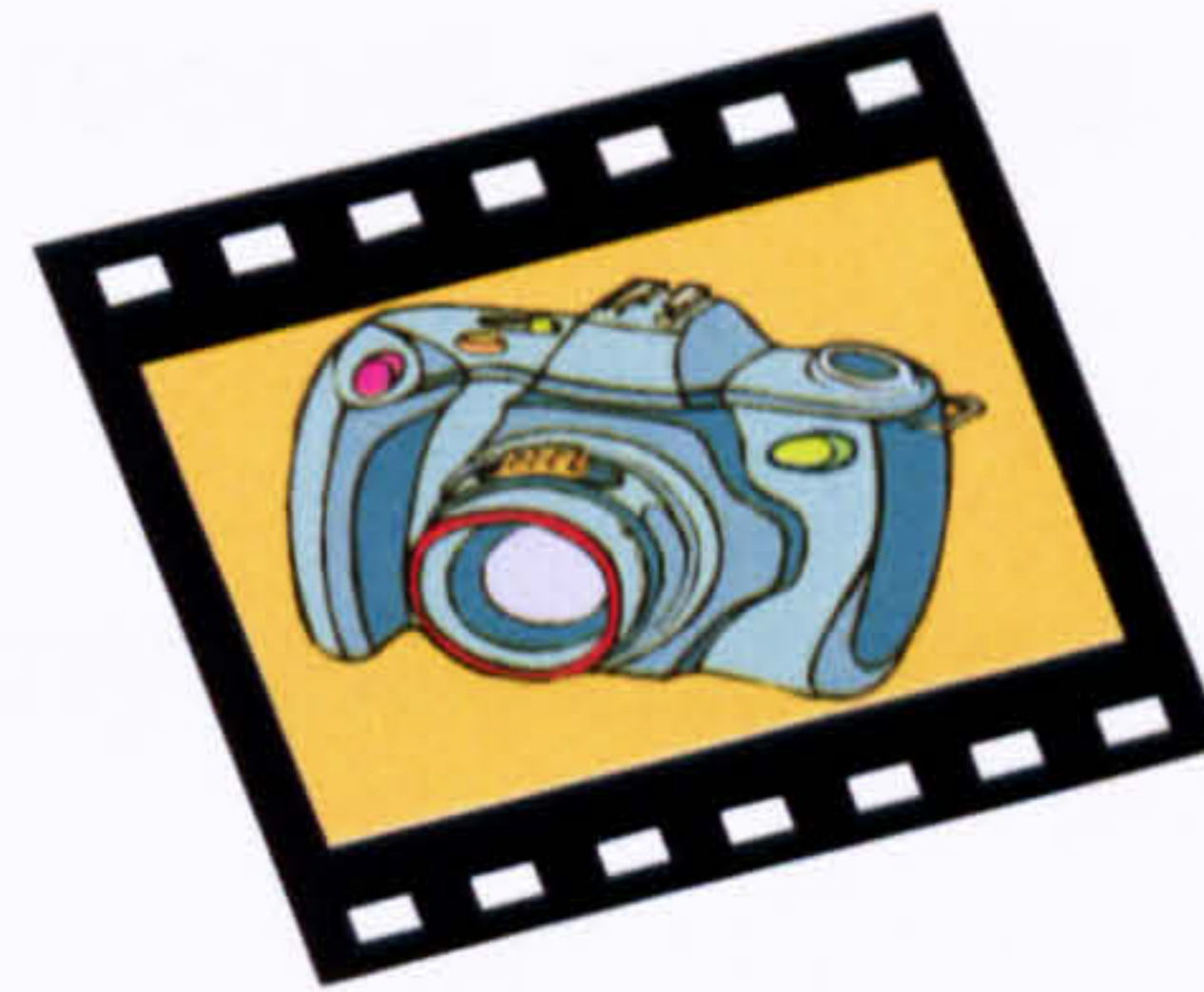
If and when you would like to meet again

If you want to use your real name.



It would also be interesting to look at some of the written documents belonging to the organisation, which may have been kept over the years. This could include back-dated **magazines** or **newsletters**, **minutes of meetings**, or

perhaps **campaign material and publicity literature**. It might also include looking at personal items, such as **photographs**, if you were happy to show them to me.



I believe that it is very important to base my research around people's own memories and experiences, as it gives people an opportunity to be involved in reconstructing their own history. If you think that your organisation would like to become involved in this project, please contact me at:

e.k.tilley@open.ac.uk

01908 655891 (office)
020 8368 8939 (home)
07980 919 462 (mobile)

The School of Health and Social Welfare
The Open University
Milton Keynes
MK7 6AA

Thank you
Liz Tilley

APPENDIX 2: Consent Form

- I agree to meet Liz Tilley to talk about
..... (your organisation)
- I agree that she can tape record or write down our discussion
- I agree that she may use my comments in her PhD thesis
- I agree that she may use my comments in publications such as journal articles, or in conference papers
- I understand that I will decide when we can meet
- I understand that I will decide how many times we can meet
- I understand that I will decide how much to talk about
- I understand that I will decide when to bring the discussion to a close
- I understand that I will have the opportunity to restart the interview
- I understand that I will decide whether or not to use my real name

Signed:

Date:

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